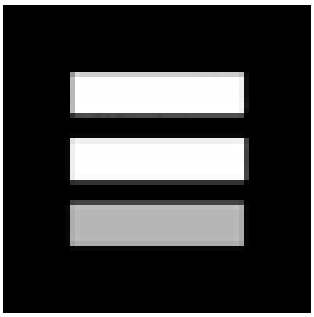

NKDEP Survey of African-American Adults' Knowledge, Attitudes and Behaviors Related to Kidney Disease

Report from the Follow-Up Survey

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Prepared for: National Institute of Diabetes and Digestive and Kidney Diseases

Submitted by: Equals Three Communications, Inc.

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Introduction to the Project

The National Kidney Disease Education Program (NKDEP) is a pioneering program designed to reduce the economic, social and human burden of chronic kidney disease (CKD) and kidney failure by encouraging prevention, early detection and treatment of CKD among high-risk individuals and early CKD patients. Prior to launching a national health education campaign, NKDEP conducted pilot-site interventions in four locations to refine and test campaign strategy. The program, begun in May 2003, targets (1) African Americans at risk for kidney disease, specifically those who have diabetes, hypertension and/or a family history of kidney failure and (2) primary care providers (PCPs), specifically family practitioners, general internists, nurse practitioners and physician assistants. Four pilot sites—Atlanta, Baltimore, Cleveland and Jackson—were selected based on the large population of African Americans in each location and the existing availability of partnership networks and resources. A composite control site comprises the Memphis, St. Louis and New Orleans metropolitan areas.

In the pilot sites, community-based communication programs were implemented to educate African American adults (age 30 and older) to assess their risk status, to persuade those who are at risk to get tested regularly for CKD and take steps to prevent CKD and to motivate those who have CKD to take steps to slow its progression. The pilot programs were also intended to educate primary care providers in these communities to monitor at-risk patients more effectively, to communicate better with patients regarding CKD and to combat early-stage CKD more aggressively through tighter glycemic and blood pressure control and appropriate medication use.

In Spring 2003, prior to launching the pilot-site program, a survey was conducted to serve as a baseline measurement of African-American adults' knowledge, attitudes and behaviors related to kidney disease. This report presents the findings from follow-up data collected in May 2004 to assess program effects among African Americans. The baseline and follow-up findings will be used to validate NKDEP's model of program effects and assess pilot program effectiveness as well as to implement changes to improve the effectiveness of the national program.

Methodology

Data Collection

A telephone survey of adult African-American residents age 30 and older was conducted between May 1 and June 15, 2004, in the NKDEP pilot and control-site locations using a questionnaire formatted and programmed into the Ci3 WinCati Computer-Assisted Telephone Interviewing system.

The study design matched that of the baseline survey. Approximately 400 interviews in each pilot-site location and 133 in each control city were conducted, for a total of 2,000 completed interviews. The procedures used were intended to ensure that all adult African-American residents age 30 and older in each study city had an equal (or near equal) chance of being selected for inclusion in the sample. The provision of equal opportunity of selection is a necessary requirement if a probability sample is to be obtained. This process also minimizes bias, and allows inferences about the target group to be made from the results obtained. A random digit dialing (RDD) race-targeting procedure was used to increase the likelihood that an African-American household was encountered. Under this procedure, census tracts with 30% or more density of African-American residents were selected to draw the RDD sample in each city.

Assuming the sampling procedures outlined above produced a random sample of the population of interest, the estimated theoretical standard error associated with the sample estimates obtained (n = 2,039) across the overall sample when the population proportion (P) is 50 percent (i.e., a "worst case scenario") is .011. [1] In addition, the theoretical standard error decreases as the proportion (P) approaches 0 or 100. Thus, if 85% of the sample provides a given response, the standard error is .0078.

Sampling error for estimates obtained in the study across the overall sample is no greater than +/- 2.2%, with a 95% level of confidence. [2] That is, if 50% of the sample gave a certain response to a question, we can be 95% certain that between 47.8 and 52.2% of the population as a whole would give that same response. This expected error decreases as the sample proportion approaches 0 or 100. Sampling error within each individual city, and across all three control cities (n = 400) is no greater than +/- 4.9% at the 95% confidence interval. No respondent selection method was used to select the individual interviewed within the household, rather, any African American age 30 or older was eligible to complete the interview. However, the study design did aim for a minimum of 30% males in the final sample to match gender ratios obtained in the baseline survey.

In addition to sample size, the quality of a sample is determined by cooperation rate; that is, the proportion of members of the original sample who provide a completed survey. Table 1 details results of the telephone procedures for the combined sample. In Table 1, we see that the cooperation rate[3] for the study was 47.3 percent. Of the 8,274 eligible households contacted, 2,039 yielded complete interviews. Importantly, of those households determined to be eligible for participation in the study, the refusal rate was only 25.4%.

Once a respondent was located and cooperation obtained, quality-control procedures ensured that high-quality data were produced. Interviewing occurred during both day and night-time hours, and each record in the sample was attempted a minimum of 10 times before a telephone number was retired. Supervisors were assigned to monitor interviewers in progress using both audio and visual monitoring techniques.

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[1] The standard errors are derived from the mathematical formula: Square Root (P x Q)/n
where: P = the proportion of the population exhibiting a characteristic (i.e., knew what kidney disease was); Q = (1-P), the proportion not exhibiting the characteristic; n = size of the sample.

[2] The standard error is used to estimate the sampling margin of error of the estimates (i.e., the probable difference in results between interviewing the entire population of African Americans 30 and older in the target cities versus taking a scientific sample of the population) that extend 1.96 standard error units around that value (i.e., the 95% confidence level). The standard error is calculated according to the following formula:

P +/- 1.96 * (standard error)

[3] Cooperation rate is computed using the American Association for Public Opinion Research (AAPOR) guidelines for reporting results of survey. The rate computed here is AAPOR Cooperation Rate 3 (COOP3). COOP3 = Interviews/(Interviews + Partials + Refusals).

Table 1: Final Disposition of Telephone Procedures, Overall Sample

	N	%
Interview		
Complete	2,039	92.3
Partial	169	7.7
Total	2,208	100.0
Eligible, Non-Interview		
Final Refusal	2,103	34.7
Resp. Never Available	64	1.0
Ans. Machine	3,185	52.5
Other		
Physically/Mentally Unable	176	2.9
Language Unable	171	2.8
Miscellaneous Unable	8	0.1
Callback, Respondent Not Selected	196	3.2
Callback, Respondent Selected	163	2.7
Total	6,066	100.0
Unknown Eligibility: Non-Interview		
Unknown if Household		
Busy	641	8.8
No Answer	5,701	78.3
Technical Phone Problems	435	5.9
Unknown: Other	508	7.0
Total	7,285	100.0
Not Eligible		
Out of Sample	3	0.1
Fax/Data Line	2,011	7.9
Non-Working Number	1,331	5.3
Disconnected Number	6,491	25.7
Technological Circumstances		
Number Changed	232	0.9
Cell Phone	142	0.6
Call Forwarding	315	1.2
Not a Household		
Business/Government/Other	2,772	11.0
Institution	36	0.1
Group Quarters	19	0.1
No Eligible Respondent	11,848	47.0
Quota Filled	20	0.1
Total	25,200	100.0
Cooperation Rate		47.3

Sample Characteristics

Gender
There were 1,450 women and 580 men represented in the sample population (71% and 29%, respectively).

Age
The sample was fairly evenly distributed among different age categories with the majority of individuals (52%) falling between the ages of 35 and 54. Individuals ages 30 to 34 comprised 13% of the sample population, 26% were ages 35 to 44, 26% were ages 45 to 54, 17% were ages 55 to 64 and 16% were ages 65 or older.

Income
Fifteen percent of the sample population (298 respondents) did not report their income level. As such, all the income-related descriptive figures are computed based on the 1,741 respondents who did report their income level.

Of these respondents, 28% reported having an income of less than $20K. A larger percentage of respondents in the control sites (37%) reported having an income of less than $20K than did those in the pilot sites (26%).

About half of the sample for which income was reported (46%) was in the low- to middle-income range, reporting annual household income between $20K and $60K per year, 25% of which earned between $20K and $39K. While slightly less than one-quarter of the respondents in the pilot sites (24%) reported having an income of $20K to $39K, a larger percentage of individuals in the control sites (30%) claimed the same level of earnings.

More than one-tenth (12%) of those who reported their income had an income of $60K to $79K. Thirteen percent of respondents in the pilot sites reported having this income, while 9% of those in the control sites did. Six percent of the valid sample had an income of $80K to $99K, and another 8% earned $100K or more. More respondents in the pilot sites reported these two levels of income than in the control site (7% of pilot site respondents whose income is $80K to $99K versus 3% of control site, and 9% of pilot site respondents whose income is more than $100K compared to 4% of the control site.)

Education.
Close to a quarter (23%) of the sample population had a high school education and 9% had less than a high school education. Less than a third (28%) of the total sample population had some college education, 7% had graduated from community college (AA degree), 19% were college graduates, 3% had some graduate school education and 11% held a graduate degree. A slightly lower percentage of respondents in the control sites (28%) reported having some college education than did respondents in the pilot sites (30%).

Table 2 below depicts the breakdown of the total sample by demographic subgroups and compares each factor to the relevant U.S. population estimates for African Americans.[4]

Table 2: Comparison of the Sample Demographic to the National Estimates for the African-American US Population

	Sample (Percentage of respondents)	Population (Percentage of total)
Gender		
Male	29	49
Female	71	51
Age		
30-34	13	7
35-44	26	15
45-54	26	12
55-64	17	7
65 or older	16	8
Income		
Less than $20K	28	26
$20K-$39.9K	25	13
$40K-$59.9K	21	25
$60K-$79.9K	12	21
$80K-$99.9K	6	11
$100K or more	8	4
Education		
Less than High School	9	16
High School Graduate	23	32
Some College	28	25
AA degree	7	--
College Graduate	19	18
Some Graduate School	3	--
Graduate Degree	11	9

Data Analysis and Reporting

This report presents the overall sample descriptive statistics and variation by specific demographic and medical subgroups. The information has been grouped into 10 topic areas, and the sequence of reporting does not follow the sequence of questions on the survey instrument. The survey instrument is attached for reference (see Appendix). An index of questions follows the table of contents (see page 3).

As Table 2 documents, the sample for this study does not demographically match national statistics for the African-American adult population. No attempt was made to represent national demographics; this report presents unweighted data. Variation in response across demographic subgroups is reported when it was statistically significant.

[4] U.S. Census Bureau: The Black Population in the United States; March 2002 (pp l-164). Accessed on July 15th, 2003, at http://www.census.gov/population/www.socdemo/race/ppl-164.html.

Respondents were also categorized into several relevant medical classifications.

The variable *Risk Status* identifies those respondents who indicated they had at least one of the three key risk factors: diabetes, hypertension/high blood pressure, or a family history of kidney failure. *Patients with Diabetes* were identified based on Q5 of the survey that asked patients if they had ever been diagnosed with diabetes. A similar question (Q8) was used to identify *Patients with Hypertension*. The variable *Family History of Kidney Failure* identifies those respondents who reported that a close blood relative (parents, child, sibling or grandparent) had kidney failure (using responses to Q31, 31a and 31b).

Test Status separated respondents based on whether or not they had ever been tested for kidney disease (Q16).

Knowledge of CKD Definition is based on respondents open-ended descriptions of kidney disease (Q13). Respondents who described kidney disease as a stoppage or reduction of kidney function were categorized as "Understands CKD" and those who did not were identified as "Does not understand CKD."

The sample breakdown with respect to these computed variables is shown below in Table 3.

Table 3: Total Sample (Percentage)

Patients with Diabetes		**Family History of CKD**	
Has diabetes	15	Has family history	84
Does not have diabetes	85	Does not have family history	16
Patients with Hypertension		**Knowledge of CKD Definition**	
Has hypertension	41	Does not understand CKD	54
Does not have hypertension	59	Understands CKD	46
Test Status		**Risk Status**	
Tested	42	At-risk	63
Not tested	51	Not at-risk	37

Summary of Findings

Overview

Each table gives the percentage of the total sample size. When a subset of the total sample was used, the sample size is given. All percentages are rounded off to the nearest tenth. "0" indicates answers less than 0.5% and "-" indicates no response.

For questions that have multiple responses, the top three answers in order of frequency are given. Chronic kidney disease (CKD), diabetes and hypertension are included. When these conditions do not appear as one of the top three answers, these terms are italicized. "Don't know" is also included when relevant. (See Table 4).

Table 4: Respondent Sample Size

Total	Pilot	Control	Atlanta	Cleveland	Baltimore	Jackson
2039	1625	414	399	413	416	397

Awareness of CKD

When asked to name the top three health concerns facing African Americans, respondents named diabetes (61%), hypertension (54%) and heart disease (45%) most frequently (*Question 2*). A substantial proportion of respondents also mentioned cancer (34%) and HIV/AIDS (30%). Only 4% mentioned CKD or kidney failure (See Table 5).

Table 5: Three Most Serious Health Problems Facing African Americans
(Percentage of Total Sample)

	Total	Pilot	Control	Atlanta	Cleveland	Baltimore	Jackson
Diabetes	61	61	59	61	63	59	61
Hypertension	54	55	51	57	53	58	52
Heart Disease	45	46	44	42	45	47	49
CKD	*4*	*4*	*3*	*2*	*4*	*3*	*6*

- Younger respondents were more likely to mention HIV/AIDS (47%) and drug/alcohol abuse (9%) than those in other age groups. Mention of diabetes was highest among those 35 to 44 (67%), while mention of hypertension was highest among the middle age groups (61% for those ages 45 to 54 and 63% for those ages 55 to 64). Mention of heart disease was significantly higher among older respondents, with this aspect being mentioned by 50% of those 65 and older.

- AIDS, diabetes, hypertension and obesity were health concerns mentioned more frequently by those with higher incomes. Specifically, 41% of those with household incomes of $80,000 to $99,000 mentioned AIDS as a major health concern, 67% of respondents with incomes of $60,000 to $79,000 said diabetes was a major concern, about 6 in 10 with incomes between $60,000 and $99,000 reported hypertension as a major concern (59% for $60,000 to $79,999 bracket and 62% for $80,000 to $99,999 bracket) and 14% of those with incomes over $100,00 said obesity was a major concern.

- Those with higher education levels mentioned diabetes as a health concern more frequently. Specifically, it was mentioned by 72% of those with some postgraduate studies. Additionally, those with some postgraduate studies also mentioned AIDS (41%) and obesity (16%) more frequently than those at other education levels. Those in the lowest education categories (40% of those who had a high school education or less) tended to mention cancer more frequently as a major health concern than those with higher education attainments.

Awareness of CKD was also assessed in the context of negative health effects of diabetes. When asked to list the negative health consequences of untreated diabetes, only 16% mentioned CKD (*Question 3*) as seen in Table 6. Even fewer (9%) mentioned CKD as a negative health outcome of hypertension (*Question 6*) as seen in Table 7. While respondents who had diabetes and hypertension were more likely to mention CKD as an outcome of these illnesses, these proportions were also relatively small; only 26% of patients with diabetes mentioned CKD as an outcome of diabetes and 13% of patients with hypertension mentioned it as a consequence of leaving hypertension untreated.

Table 6: Negative Health Effects of Unmanaged Diabetes
(Percentage of Total Sample)

	Total	Pilot	Control	Atlanta	Cleveland	Baltimore	Jackson
Amputation	31	31	29	33	29	40	22
Blindness	30	31	28	32	29	38	24
Premature death	24	25	21	28	27	25	18
CKD	*16*	*16*	*15*	*17*	*15*	*15*	*19*

Table 7: Negative Health Effects of Unmanaged Hypertension
(Percentage of Total Sample)

	Total	Pilot	Control	Atlanta	Cleveland	Baltimore	Jackson
Stroke	59	60	58	57	59	63	60
Heart attack	40	41	33	42	38	41	44
Premature death	19	20	17	19	21	24	14
CKD	*9*	*9*	*11*	*10*	*8*	*7*	*10*

As seen in Table 8, when specifically asked whether they are aware of an illness called CKD, virtually all (88%) respondents said yes (*Question 12*).

Table 8: Awareness of CKD
(Percentage of Total Sample)

	Total	Pilot	Control	Atlanta	Cleveland	Baltimore	Jackson
Yes	88	88	87	88	88	91	85
No	12	11	13	11	11	9	15
Not sure	*1*	*1*	*1*	*1*	*1*	*0*	*0*

- Those with a family history of kidney disease were more likely to say they were aware of CKD (93%), but awareness was not higher for those with hypertension (87%) or diabetes (90%).

As seen in Table 9, most respondents thought CKD is *very* (43%) or *somewhat* (39%) common (*Question 33*). This number was fairly consistent across all subgroups with minor variations in the proportion of people who regarded CKD as *very common*. Respondents over 65 were almost twice as likely to report *don't know* than those under 34 (16% vs. 9%). Those in the control site were twice as likely to believe CKD is *very rare* than those in the pilot site (6% vs. 3%).

Table 9: Commonality of CKD
(Percentage of Total Sample)

	Total	Pilot	Control	Atlanta	Cleveland	Baltimore	Jackson
Very common	43	43	43	43	39	43	48
Somewhat common	39	39	38	37	43	40	35
Not common	4	5	3	5	4	5	4
Very rare	4	3	6	3	3	2	3
Don't know	*10*	*11*	*10*	*12*	*11*	*9*	*10*

Knowledge of CKD

When asked to define CKD, about half (46%) correctly identified it as a stoppage or reduction in kidney function (*Question 13*). Another 30% gave vague or incorrect responses, such as general disease or ailment of the kidneys (22%) or an infection of the kidneys (9%). More than a fifth (23%) answered *don't know* (See Table 10).

Table 10: Definition of CKD
(Percentage of Total Sample)

	Total	Pilot	Control	Atlanta	Cleveland	Baltimore	Jackson
Don't know	*23*	*23*	*22*	*22*	*23*	*17*	*29*
Stoppage	22	21	26	22	21	25	17
General disease	22	22	21	22	21	25	19
Unspecific reduction	19	19	18	24	17	20	15
Diabetes causes	*6*	*6*	*6*	*3*	*8*	*5*	*8*
Hypertension causes	*5*	*4*	*5*	*4*	*4*	*4*	*6*

- Younger respondents and those with more education and income were more likely to correctly define CKD. Specifically, 53% of those 35 to 44 correctly defined CKD compared to 30% of those 65 and older. Fifty-two percent of those with a household income of $100,000 and over correctly defined CKD compared to 34% of those earning less than $20,000, and 57% of respondents with a college degree correctly defined CKD compared to only 23% of those who had not graduated high school.

When asked whether there is anything that would let a person know that they had CKD, about two-thirds of respondents (62%) incorrectly indicated that the disease has symptoms (*Question 19*). Only 15% definitively indicated that the disease has no symptoms, while 23% said they were not sure (See Table 11).

Table 11: Signs of CKD
(Percentage of Total Sample)

	Total	Pilot	Control	Atlanta	Cleveland	Baltimore	Jackson
Yes	62	63	54	67	61	64	61
No	15	14	19	14	16	12	15
Don't know	*23*	*22*	*27*	*19*	*23*	*24*	*24*

- Those in the lowest education and income categories were *less* likely to say that there are signs or symptoms that would let a person know they had CKD (23% who had not completed high school compared to 13% of those with a postgraduate degree; 18% of those with an income of less than $20,000 compared to 12% of those with an income of over $100,000). Those who were tested for CKD (67%), aware of a family history of kidney failure (66%) or able to give an accurate definition of the disease (69%) were *more* likely to say that there are signs or symptoms that would let a person know they had CKD.

- Those in the pilot sites were more likely to say that CKD has symptoms than those in the control site (63% vs. 54%).

When asked what would let a person know they had CKD, the most common responses were symptoms such as difficulty urinating (22%), general pain (17%) and frequent urination (17%) (*Question 19a*) as seen in Table 12. Significantly more females (24%) mentioned difficulty urinating than males (19%). Less then one percent of all respondents mentioned getting tested for CKD or being told by a doctor that they had CKD.

Table 12: Symptoms of CKD
(Percentage of Respondents Who Answered 'Yes' to Knowing CKD Symptoms)

	Total	Pilot	Control	Atlanta	Cleveland	Baltimore	Jackson
Difficulty urinating	36	36	36	35	35	40	34
General pain	28	27	33	30	27	27	22
Frequent urination	27	29	18	29	26	32	30
Don't know	*8*	*9*	*7*	*8*	*7*	*11*	*9*

n = 1,253

- More respondents in the pilot sites named frequent urination as a symptom than those in the control site (29% vs. 18%). Pilot-site respondents were less likely to mention "Other" than control-site respondents (19% vs. 25%).

- Women were more likely than men to mention difficulty urinating (38% vs. 31%) and swelling (13% vs. 5%). Men, however, were more than women to mention other changes in urine (17% vs. 11%) and jaundice (13% vs. 6%).

- Younger respondents were more likely than older respondents to mention "Other" (27% of those 30 to 34 vs. 16% of those 65 and over).

As seen in Table 13, nearly half of the sample (46%) was unable to name *any* causes of CKD when asked to do so in an open-ended way (*Question 20*). Only 18% named diabetes, 16% named hypertension and 3% mentioned genetics or family risk. Other common responses were drinking too little water (14%) and consumption of soda or pop (6%). While there was some subgroup variation in these responses, the overall awareness of the causes of CKD was low in all segments of the sample.

Table 13: Reported Causes of CKD
(Percentage of Total Sample)

	Total	Pilot	Control	Atlanta	Cleveland	Baltimore	Jackson
Don't know	*46*	*45*	*49*	*46*	*46*	*43*	*47*
Diabetes	18	19	13	18	20	18	21
Hypertension	16	17	13	14	17	18	19
Too little water	14	13	16	15	13	16	10

- Patients with diabetes and/or hypertension were somewhat more likely to associate CKD with these two conditions and were less likely to give incorrect or inaccurate causes of CKD. However, roughly one-third of patients with diabetes (34%) named diabetes and 20% of patients with hypertension identified hypertension as a cause of CKD.

Respondents were also asked whether they are aware that diabetes and hypertension are leading causes of CKD (*Question 21 & 22*, respectively). About half (57%) of respondents said that they are aware that diabetes causes CKD (See Table 14) and 42% said hypertension causes CKD (See Table 15).

Table 14: Awareness of Diabetes as Cause of CKD
(Percentage of Total Sample)

	Total	Pilot	Control	Atlanta	Cleveland	Baltimore	Jackson
Yes	57	57	58	53	56	57	64
No	40	40	39	45	41	42	33
Don't know	*3*	*2*	*3*	*2*	*2*	*2*	*4*

Table 15: Awareness of Hypertension as Cause of CKD
(Percentage of Total Sample)

	Total	Pilot	Control	Atlanta	Cleveland	Baltimore	Jackson
Yes	42	41	43	39	40	41	44
No	56	56	54	59	57	58	52
Don't know	*2*	*2*	*2*	*2*	*3*	*1*	*3*

- Awareness of diabetes as a cause of CKD was impacted by respondent age, test status and risk status, and having diabetes or hypertension. Older respondents were significantly more aware that diabetes can lead to CKD. Specifically, 67% those 55 to 64 and 65% of those 65 and older reported hearing that diabetes can lead to CKD. Sixty-nine percent of those who had been tested for CKD, 64% of those at risk, 78% of those with diabetes and 66% of those with hypertension were aware that diabetes can lead to CKD.

- About half of respondents 55 to 64 (49%) were aware that hypertension can lead to CKD. Education also affected awareness of hypertension as leading to CKD, with about half of those with some postgraduate studies (52%) or a postgraduate degree (51%) aware that hypertension can cause CKD.

As with diabetes, those who had been tested (54%), those who were at risk (48%), those with diabetes (50%) and those with hypertension (52%) were all aware that hypertension can cause CKD.

Respondents were also asked who they believed to be at higher risk for CKD (*Question 18*). About a fifth (23%) mentioned that African Americans are at higher risk; 15% mentioned persons with diabetes; and 11% mentioned persons with hypertension (See Table 16). Fourteen percent of respondents said people who consume certain beverages are at higher risk, 7% said men, 4% women, 5% older people and 14% mentioned some other (unlisted) factor. The most frequent answer, *Don't Know* accounted for a quarter (25%) of the responses.

Table 16: High-Risk Individuals for CKD
(Percentage of Total Sample)

	Total	Pilot	Control	Atlanta	Cleveland	Baltimore	Jackson
Don't know	*25*	*25*	*26*	*24*	*25*	*25*	*25*
African Americans	23	24	21	23	20	25	27
With diabetes	15	15	14	13	15	14	19
Other	14	14	14	16	18	17	7
Certain beverages	14	13	16	*16*	*15*	*12*	*9*
With hypertension	*11*	*12*	*9*	*12*	*12*	*10*	*14*
Family with CKD	*2*	*3*	*2*	*3*	*1*	*2*	*4*

- Women were more likely than men to identify persons with diabetes (17% vs. 10%) and hypertension (12% vs. 8%) as at higher risk. Identification of these two risk factors dropped as age increased. While 23% of those 55 to 64 said persons with diabetes, 12% of those over 65 did so. Similarly, 18% of those aged 55 to 64 said persons with hypertension compared to 8% of those over age 65.

- Those who had been tested for CKD, were at risk, had diabetes or had hypertension all reported that those with diabetes or those with hypertension were more likely to get CKD.

    - Specifically, 18% of those tested for CKD compared to 14% of those not tested, 19% of those at risk compared to 9% of those not at risk, 33% of those with diabetes compared to 12% of those without diabetes and 19% of those with hypertension compared to 13% of those without hypertension all reported that those with diabetes are more likely to get CKD.

    - Similarly, 14% of those tested compared to 10% of those not tested, 13% of those at risk compared to 8% of those not at risk, 17% with diabetes compared to 10% of those without diabetes and 15% of those with hypertension compared to 8% of those without hypertension all said that persons with hypertension are more likely to get CKD.

- Those who had a family history of kidney failure were also more likely to mention African-American race as a factor (29%).

Prevalence of Risk Factors

Fifteen percent of respondents said they had diabetes and 41% had hypertension (*Question 5 & 8,* respectively) as seen in Table 17 and 18.

Table 17: Self-Reported Diabetes
(Percentage of Total Sample)

	Total	Pilot	Control	Atlanta	Cleveland	Baltimore	Jackson
Yes	15	15	16	9	20	11	19
No	85	85	84	91	79	89	81
Don't know	*0*	*0*	*0*	*0*	*0*	-	-

Table 18: Self-Reported Hypertension
(Percentage of Total Sample)

	Total	Pilot	Control	Atlanta	Cleveland	Baltimore	Jackson
Yes	41	41	43	32	40	36	55
No	59	59	57	68	59	64	45
Don't know	*0*	*0*	-	*0*	-	*1*	*0*

- The prevalence of diabetes was slightly higher among men (17%) than women (14%). Those in the lowest income bracket of less than $20,000 were almost twice as likely to have diabetes than those in the next income bracket of $20,000 to $39,000 (25% vs. 14%), and more than five times as likely as those in the $80,000 to $99,999 range (5%). Those with the least education were more than three times as likely to report diabetes (27%) compared to those with a postgraduate degree (8%).

- The prevalence of hypertension was also related to the income and education levels of respondents. Specifically, 59% of those with a household income of less than $20,000 reported having hypertension compared to 27% of those in the $100,000 and over category.

- There was significant overlap in these two conditions. Two-thirds of adults with diabetes also had hypertension and about a quarter of adults with hypertension had diabetes.

Family history of kidney failure was ascertained through a series of questions asking respondents if they knew anyone with kidney failure, whether this person was a friend/co-worker or relative, and (if they mentioned a relative) what relationship they had with the person who had kidney failure (*Questions 31, 31a & 31b,* respectively). Seventy percent of the sample said they knew someone with kidney failure (See Table 19). About half of those who knew someone said this person was a relative (see Table 20) , and about a fifth of that population mentioned a close relative such as a parent, sibling, grandparent or child (see Table 21). Overall, 11% of the sample was identified as having a close blood relative with kidney failure.

Table 19: Personal Knowledge of Someone with Kidney Failure
(Percentage of Total Sample)

	Total	Pilot	Control	Atlanta	Cleveland	Baltimore	Jackson
Yes	70	70	71	67	68	72	74
No	29	29	28	32	31	28	26
Don't know	*1*	*1*	*1*	*1*	*1*	*0*	*0*

- Of those who said they knew someone with kidney failure, 48% reported knowing a friend or co-worker and 47% a relative (See Tables 20 and 21).

Table 20: Relationship to Person with Kidney Failure
(Percentage of Respondents Who Answered 'Yes' to Knowing Someone with Kidney Failure)*

	Total	Pilot	Control	Atlanta	Cleveland	Baltimore	Jackson
Friend/coworker	48	48	51	51	44	47	44
Relative	47	48	44	45	45	50	49
Close relative	20	20	22	18	21	20	20
Other relative	27	28	22	27	24	30	29
Other	11	11	9	8	14	12	9
Don't know	-	-	*1*	-	-	-	*1*

n = 1,434
* Some percentages do not total to 100 because respondents gave more than one answer

Table 21: Relationship to Relative with Kidney Failure
(Percentage of Respondents Who Answered 'Yes' to Knowing Relative with Kidney Failure)*

	Total	Pilot	Control	Atlanta	Cleveland	Baltimore	Jackson
Close relative	43	42	50	42	46	42	39
Parent	20	18	26	17	21	17	19
Sibling	15	15	17	11	16	19	14
Grandparent	6	7	4	12	6	7	5
Child	2	2	3	2	2	0	2
Other relative	11	58	49	60	50	62	54
Aunt/uncle	21	21	20	24	19	25	15
Cousin	18	18	15	15	14	19	24
Non-blood relative	18	19	15	21	17	18	18
Don't know	*1*	*1*	*1*	-	-	*1*	*2*

n = 680
* Some percentages do not total to 100 because respondents gave more than one answer

About a third (31%) of respondents said that having a relative with kidney failure *somewhat* increases a person's risk for CKD (See Table 22). Another third (32%) believe that this factor has *little* to *no influence at all*. Only one-fifth (21%) said that this factor increases a person's risk *a great deal* (*Question 32*).

Table 22: Risk of CKD if Relative Has the Condition
(Percentage of Total Sample)

	Total	Pilot	Control	Atlanta	Cleveland	Baltimore	Jackson
A great deal	21	21	18	20	17	26	22
Somewhat	31	31	29	31	34	32	27
A little	15	15	15	17	14	13	17
Not at all	17	17	18	18	18	17	14
Don't know	*17*	*16*	*19*	*15*	*17*	*13*	*19*

- Respondents over 55 were twice as likely (29% of those 65 and older and 22% of those 55 to 64) to say they did not know the impact of having a relative with kidney failure than younger respondents (12% of those 30 to 34).

- Respondents with higher income and education levels more often said that family history increases a person's risk *a great deal* than those at lower levels. Specifically, 26% of those with some postgraduate education compared to 16% of those without high school degrees believed that the risk increases *a great deal*. Similarly, 31% of those with incomes of $80,000 to $99,999 believed it increases *a great deal* compared to 21% of those with incomes less than $20,000.

Experience with Diabetes

When asked to name negative health consequences of uncontrolled diabetes (see Table 23), respondents mentioned amputation (31%) and blindness (30%) most often (*Question 3*). Only 16% named CKD. About 21% said they did not know of any negative health consequences.

Table 23: Negative Health Effects of Unmanaged Diabetes
(Percentage of Total Sample)

	Total	Pilot	Control	Atlanta	Cleveland	Baltimore	Jackson
Amputation	31	31	29	33	29	40	22
Blindness	30	31	28	32	29	38	24
Premature death	24	25	21	28	27	25	18
CKD	*16*	*16*	*15*	*17*	*15*	*15*	*19*
Heart attack	13	13	10	12	12	13	15
Stroke	11	11	13	11	10	10	11
Coma	10	10	11	11	9	9	11
Must take insulin	2	2	3	3	2	2	2
Other effects	16	16	17	17	17	17	12

- More women than men named blindness (32% vs. 27%), CKD (17% vs. 13%) and comas (11% vs. 7%) as negative consequences. Men were more likely than women to say they did not know any negative consequences of uncontrolled diabetes (25% vs. 19%).

- Respondents with higher income and education levels named CKD more often than those with lower income levels. While 23% of those with incomes over $100,000 named the disease as a negative consequence, only 15% of those with incomes under $20,000 did so. Those with postgraduate degrees were more than three times as likely as those without high school degrees to name CKD (24% vs. 8%).

- Income and education also affected whether respondents named other negative consequences. Those with an income of more than $100,000 were almost twice as likely to mention amputation than those with incomes under $20,000 (42% vs. 22%). Those with a postgraduate degree were more than three times as likely to mention amputation than those without a high school degree (44% vs. 14%). Thirty-seven percent of those with incomes of more than $100,000 mentioned blindness compared to 23% of those with incomes under $20,000. Thirty-nine percent of those with postgraduate degrees mentioned this risk, while only 16% of those without high school degrees did.

When asked what kinds of tests persons with diabetes should have regularly, 58% mentioned daily blood glucose testing and almost a quarter mentioned general blood tests (23%). Four percent named a general urine test (See Table 24). Less than three percent of respondents mentioned other tests that someone with diabetes should have regularly, such as hemoglobin A1C (3%), an eye exam (2%) and a foot exam (1%).

Specific tests, such as proteinuria and microalbuminuria were suggested less than 0.5% of the time. Almost a quarter of respondents responded *don't know* (24%). (*Question 4*).

Table 24: Tests for Persons with Diabetes
(Percentage of Total Sample)

	Total	Pilot	Control	Atlanta	Cleveland	Baltimore	Jackson
Blood glucose	58	59	57	57	64	58	56
Don't know	*24*	*24*	*26*	*30*	*18*	*25*	*24*
General blood test	23	23	23	21	22	24	25
General urine test	4	4	5	3	5	6	3

- Women (61% of women vs. 52% of men), those with more income (68% of those with incomes of more than $100,000 vs. 49% of those with incomes under $20,000), those with more education (64% of those with a postgraduate degree vs. 44% of those without a high school degree), those with diabetes (68% of those with diabetes vs. 57% of those without diabetes) and those who knew what CKD is (65%), were more likely to mention daily blood glucose monitoring.

Diabetic respondents (n = 305) were asked what steps they have taken to manage their diabetes (*Question 5a*). Seventy percent mentioned lifestyle changes, including diet changes (60%), exercise (28%) and weight loss (5%) More than half (52%) mentioned medication, including prescription medication (52%) or insulin (23%). Only 2% said they were doing nothing at all to manage their diabetes (See Table 25).

Table 25: Ways to Manage Diabetes
(Percentage of Respondents Who Answered 'Yes' to Having Diabetes)

	Total	Pilot	Control	Atlanta	Cleveland	Baltimore	Jackson
Dietary changes	60	59	64	68	60	54	58
Medication	52	51	55	50	54	61	44
Exercise	28	29	24	35	22	35	31
Don't know	-	-	-	-	-	-	-

n = 305

- In general, younger respondents were more likely than older respondents ((79% of those 30 to 34 vs. 56% of those 65 and older) to mention lifestyle changes. Those with higher incomes, those with more education and those who had been tested for CKD were more likely to mention both medication and lifestyle changes. Specifically, medication was mentioned by 80% of respondents with a household income of $80,000 to $99,000 vs. 52% of those with a household income of less that $20,000. Lifestyle changes were mentioned by 85% of those with some graduate studies compared to 52% of those who had not graduated high school. However, lower income respondents were more likely to adopt a lifestyle change. For example, 73% of those with a household income of $20,000 to $39,000 mentioned a lifestyle change compared to 40% of those with an income of $80,000 to $99,000.

The majority of patients with diabetes reported seeing their doctor at least once every three to four months (*Question 5b*). (See Table 26).

Table 26: Frequency of Doctor Visits for Diabetes
(Percentage of Respondents Who Answered 'Yes' to Having Diabetes)

	Total	Pilot	Control	Atlanta	Cleveland	Baltimore	Jackson
Once every 3-4 months	89	89	88	91	89	91	88
Once every 6 months	8	7	11	3	9	4	8
About once every year	2	3	-	3	3	2	3
About once every 2 years or less	0	-	2	-	-	-	-
Don't Know	1	1	-	3	-	2	1

n = 298

When asked to rate their compliance with their health-care provider's recommendations for managing diabetes on a 10-point scale, with "10" being *"Do everything provider recommends,"* the patients with diabetes in this sample gave themselves a mean rating of 7.8 (*Question 5c*) as seen in Table 27.

Table 27: Rate of Following Doctor's Advice for Diabetes
(Percentage of Respondents Who Answered 'Yes' to Having Diabetes)
10 = Do everything provider recommends; 1 = Do not follow at all

	Total	Pilot	Control	Atlanta	Cleveland	Baltimore	Jackson
9-10	38	37	42	49	40	33	33
7-8	42	42	39	42	43	44	40
5-6	16	16	15	9	14	18	20
3-4	1	-	5	-	-	-	-
1-2	3	4	-	-	4	4	7
Mean	7.8	7.8	8	8.3	7.9	7.6	7.6

n = 301

Experience with Hypertension

The most frequently mentioned negative consequences of uncontrolled hypertension (see Table 28) were stroke (59%) and heart attack (40%). Premature death (19%), CKD (9%) and amputation/limb loss (1%) were also mentioned (*Question 6*). About 1 in 10 respondents (12%) could not identify any negative consequences of uncontrolled hypertension.

Table 28: Negative Health Effects of Unmanaged Hypertension
(Percentage of Total Sample)

	Total	Pilot	Control	Atlanta	Cleveland	Baltimore	Jackson
Stroke	59	60	58	57	59	63	60
Heart attack	40	41	33	42	38	41	44
Premature death	19	20	17	19	21	24	14
CKD	*9*	*9*	*11*	*10*	*8*	*7*	*10*
Amputation	1	1	2	1	1	1	2

- Those with higher education levels named more negative consequences. Specifically, 71% of those with postgraduate degrees mentioned stroke, while only 41% of those without a high school degree did so. Similarly, those with at least some postgraduate education were twice more likely than those without a high school diploma to name heart attack as a possible consequence (53% vs. 26%).

- Respondents who had hypertension were also more likely to mention CKD than those who did not (13% vs. 7%).

- Those who had been tested for CKD named it as a negative consequence (12%) more often than those not tested (7%).

- Respondents in the pilot site reported heart attack as a possible consequence more frequently than those in the control site (41% vs. 33%).

When asked what tests a person with hypertension should have regularly, about three-quarters (73%) mentioned blood pressure testing, and about 10% mentioned a general blood test (*Question 7*). Only 1% mentioned urine tests with very few respondents mentioning any specific tests for CKD. More than a fifth (22%) said they did not know of any tests (See Table 29).

Table 29: Tests for Persons with Hypertension
(Percentage of Total Sample)

	Total	Pilot	Control	Atlanta	Cleveland	Baltimore	Jackson
Blood pressure test	73	73	70	73	73	76	72
Don't know	*22*	*21*	*23*	*23*	*22*	*19*	*21*
General blood test	10	10	13	9	9	10	11
General urine test	1	1	1	2	1	1	2

- Following the general pattern seen before, women (75% of women vs. 69% of men), those with more income (79% of those with incomes more than $100,000 vs. 68% of those with incomes under $20,000) and those with more education (81% of those with a postgraduate degree vs. 55% of those without a high school degree) were more likely to mention regular blood pressure tests. These groups

were also less likely to say they did not know of any tests that patients with hypertension should have regularly (20% of women vs. 25% of men, 18% in the highest income bracket vs. 25% in the lowest, 13% of those with the highest education attainment vs. 35% of those with the lowest).

- Knowledge of tests was also related to having hypertension, being at risk or having been tested for CKD. Specifically, 82% of those with hypertension were more likely to mention blood pressure tests than those without (66%). Seventy-seven percent of those at risk also named this test compared to 66% of those not at risk. Similarly, 76% of those tested suggested blood pressure vs. 70% of those who have not been tested. These groups were also less likely to answer: *Don't Know* (28% with hypertension vs. 12% without, 17% at risk vs. 29% not at risk, 19% tested vs. 24% not tested).

Respondents with hypertension (n = 837) were asked what steps they have taken to manage this condition (*Question 8a*). More than three-quarters mentioned medication (76%) and/or regular monitoring (6%) and about two thirds (69%) mentioned lifestyle changes including dietary changes (43%), exercise (19%) and weight loss (5%) (See Table 30). One percent said that they were doing nothing to control their hypertension.

Table 30: Ways to Manage Hypertension
(Percentage of Respondents Who Answered 'Yes' to Having Hypertension)

	Total	Pilot	Control	Atlanta	Cleveland	Baltimore	Jackson
Medication	76	75	77	77	73	81	72
Dietary changes	43	45	35	45	35	44	52
Exercise	19	19	17	25	14	25	16
Don't know	-	-	*1*	-	-	-	*1*

n = 837

- As among those who had diabetes, older patients with hypertension were more likely to mention medication (57% of those over the age of 65) while younger respondents were more likely to mention lifestyle changes (56% of those 35 to 44 vs. 40% of those over 65). Lifestyle changes were also more commonly reported among those with higher income and those with higher education. In particular, 66% of those with an income of $80,000 to $99,000 reported making a lifestyle change compared to 48% of those earning less than $20,000. The pattern was similar for educations levels, with 79% of respondents with some postgraduate studies reporting lifestyle changes compared to 38% of those who had not graduated high school.

- Patients with hypertension who also had diabetes were *less* likely to report that they exercise regularly to control their hypertension than those without diabetes (13% vs. 19%).

The majority of patients with hypertension reported seeing their doctor at least once every three to four months *Question 8b*). (See Table 31).

Table 31: Frequency of Doctor Visits for Diabetes
(Percentage of Respondents Who Answered 'Yes' to Having Hypertension)

	Total	Pilot	Control	Atlanta	Cleveland	Baltimore	Jackson
Once every 3-4 months	73	72	76	70	76	74	69
Once every 6 months	17	18	14	20	17	17	20
About once every year	7	8	7	8	6	7	8
About once every 2 years or less	1	1	2	1	1	1	-
Don't Know	1	1	1	1	1	1	3

n = 825

In rating compliance with their health-care provider's recommendations for managing hypertension, those respondents with high blood pressure had a mean rating of 8.2 on a 10-point scale, with a rating of 1 being *"Do not follow at all"* and 10 being *"Do everything provider recommends"* (*Question 8c*) (See Table 32).

Table 32: Rate of Following Doctor's Advice for Hypertension
(Percentage of Respondents Who Answered 'Yes' to Having Hypertension)
10 = Do everything provider recommends; 1 = Do not follow at all

	Total	Pilot	Control	Atlanta	Cleveland	Baltimore	Jackson
9-10	54	54	54	53	55	54	52
7-8	29	28	33	29	27	26	29
5-6	11	13	5	13	13	15	11
3-4	2	1	5	1	2	1	1
1-2	4	3	5	2	3	1	2
Mean	8.2	8.3	8.2	8.3	8.2	8.3	8.2

n = 831

Routine Care for Diabetes or Hypertension

As seen in Table 33, more than a quarter of respondents (26%) with diabetes or hypertension reported that they limit routine care for their condition because of difficulty in paying for this care (*Question 9*).

Table 33: Self-Reported Limiting of Routine Care
(Percentage of Respondents Who Answered 'Yes' to Having Diabetes or Hypertension)

	Total	Pilot	Control	Atlanta	Cleveland	Baltimore	Jackson
Yes	26	26	28	28	27	15	32
No	72	72	72	71	71	83	65
Not sure	2	2	-	1	2	1	4

n = 918

- Reports of limiting routine care due to cost increased as income and education level decreased. While more than one-third (40%) of those with incomes under $20,000 said they have limited their routine care due to cost, only 8% of those with incomes of more than $100,000 reported such difficulties. Similarly, those with less than a high school degree were more than twice as likely as those with a postgraduate degree to report difficulties (35% vs. 14%)

- Of those respondents who said they had diabetes, the majority (63%) reported they have not had to limit their routine care.

More than three-quarters (78%) of respondents with diabetes or hypertension said they have not discussed with their physician different ways to pay for routine care (See Table 34). Only 20% of respondents said they had such discussions (*Question 10*).

Table 34: Discussion with Physician About Paying for Routine Care
(Percentage of Respondents Who Answered 'Yes' to Having Diabetes or Hypertension)

	Total	Pilot	Control	Atlanta	Cleveland	Baltimore	Jackson
Yes	20	19	26	20	20	15	20
No	78	80	72	79	78	83	79
Not sure	2	2	2	1	2	3	1

n = 913

- Patients with lower incomes were more likely to have discussed payment options with their physician than those with higher incomes. Specifically, 26% of those with incomes under $20,000 reported having such a discussion compared to 10% of those with incomes of more than $100,000.

- Respondents who have not been tested for CKD were more likely to report not having such a discussion compared to those who have been tested (83% vs. 74%).

As seen in Table 35, when asked what sources of information they turn to about managing their diabetes or hypertension, the most frequent responses were their physician (86%) (*Question 11*). The table does not add up to 100% because respondents were allowed two responses.

Table 35: Source of Information to Manage Diabetes or Hypertension
(Percentage of Respondents Who Answered 'Yes' to Having Diabetes or Hypertension)

	Total	Pilot	Control	Atlanta	Cleveland	Baltimore	Jackson
Physician	86	84	90	83	83	87	85
Other	24	25	21	39	26	30	13
Nurse/PA	13	12	17	12	11	5	19
Don't know	*5*	*5*	*2*	*4*	*6*	*6*	*2*

n = 927

- Patients with higher incomes were more likely to report *Other* than those with lower incomes. Forty-three percent of those with incomes of more than $100,000 gave this response compared to 17% of those with incomes under $20,000. Similarly, those with higher education levels gave this answer more often than those with lower levels (31% of those with postgraduate degrees compared to 10% of those with less than a high school degree).

Perception of Personal Risk for CKD

When asked to rate their own risk for CKD, 17% of respondents rated their risk as higher than average, 34% said it was lower than average and 41% thought it was average (*Question 23*). About 8% said they did not know their risk level (See Table 36).

Table 36: Perceived Risk of Getting CKD
(Percentage of Total Sample)

	Total	Pilot	Control	Atlanta	Cleveland	Baltimore	Jackson
Higher than average	17	18	14	15	18	18	20
Lower than average	34	34	33	43	32	38	22
Average	41	41	44	35	43	40	45
Don't know	*8*	*7*	*9*	*6*	*6*	*4*	*13*

- Younger people were more likely to regard themselves at lower risk. Specifically, 45% of respondents 30 to 34 rated their risk as lower than average compared to 18% of those 65 and older.

- Respondents' self-ratings were related to their actual risk status. About a quarter of those at risk for CKD (23%) rated themselves at high risk, compared to 7% of those who were not at risk. Nearly half (46%) of not-at-risk respondents rated their risk as lower than average, while 26% of high-risk respondents did so.

- Among high-risk people, those with diabetes were most likely to place themselves in either the average or the high-risk category. Two-fifths of those with diabetes (40%) identified themselves as having higher-than-average risk compared to a quarter of patients with hypertension and 29% of those with a family history of kidney failure.

Respondents were asked to give reasons for their personal risk ratings (*Question 24*). The three most common categories of responses were those related to general lifestyle or weight-management issues (31%), those related to the respondent's disease status and/or disease management (23%) and those related to their family's health (16%).[5] A tenth (13%) of respondents gave reasons related to consumption of water or soda; 6% mentioned presence or absence of symptoms; and 3% mentioned taking their medications. About a fifth (20%) gave some other (unlisted) reason and 14% said they did not know why they had assigned themselves to a particular risk category (See Table 37).

Table 37: Reasons for Risk of Getting CKD
(Percentage of Total Sample)

	Total	Pilot	Control	Atlanta	Cleveland	Baltimore	Jackson
Other	20	20	21	26	20	21	13
Healthy diet	17	18	16	22	16	21	12
Don't know	*14*	*13*	*19*	*11*	*12*	*13*	*17*
Hypertension	10	11	7	9	10	12	14
Diabetes	*8*	*8*	*7*	*4*	*10*	*7*	*10*
Manage hypertension	*6*	*6*	*3*	*5*	*7*	*7*	*5*
Manage diabetes	*2*	*2*	*1*	*2*	*3*	*1*	*2*

- Respondents in the pilot sites were more likely to mention hypertension as a factor affecting risk than those in the control site (11% vs. 7%). They were also more likely to answer *don't know* than those in the control sites (13% vs. 19%).

- Respondents 65 and older were more likely than those 30 to 34 to name hypertension (12% vs. 3%), diabetes (9% vs. 5%) and age (4% vs. 0.4%), but less likely to base their risk rating on their family's good health (3% vs. 11%).

- Those with diabetes and hypertension were several times more likely than those who did not have these illnesses to mention disease-related factors. For example, 45% of those with diabetes attributed their risk for CKD to diabetes, but only 1% of those without diabetes did so. Similarly, 24% of those with hypertension attributed their risk for CKD to it, but only 1% of those without hypertension did so.

- Those who understood what CKD is and those who had been tested for it were more likely to name CKD risk factors. Sixteen percent of at-risk respondents named hypertension compared to 1% of not-at-risk respondents. Eleven percent of at-risk respondents named diabetes as a factor, but only 1% of not-at-risk respondents did.

- Those who said their risk for CKD is higher than average (n = 345) most often named hypertension (36%) and/or diabetes (30%). About a fifth (18%) of those who gave themselves a higher-than-average rating mentioned family history of CKD as a factor affecting their risk, and 14% mentioned the fact that they are African American.

- In general, younger people tended to name family history as a reason more often while older people tended to mention diabetes or hypertension. Specifically, 9% age 35 to 44 named family history compared to 2% of those 65 and older, whereas of those 65 and older, 9% named diabetes and 12% hypertension compared to 5% and 3% respectively, of those 30 to 34.

[5] General health or presence or absence of specific conditions.

- Those who said their risk for CKD is lower than average (n = 685) most often gave general lifestyle reasons such as the fact that they have a healthy diet (35%), exercise regularly (19%) and drink lots of water (18%). About a tenth of this group said they did not have a family history of CKD (8%) or that they have a generally healthy family (12%). Fewer gave disease-related reasons, i.e., that their hypertension or diabetes is controlled (6% and 3% respectively). More than a quarter (26%) gave some other (unlisted) reason, and 4% said they thought they are at low risk because they had no reason to think they are at high risk.

    - Younger respondents and those in the higher educational categories were more likely to attribute their low risk to exercise (14% of those 30 to 34 compared to 5% of those 65 and older and 14% of those with a college degree compared to 2% of those who had not completed high school) or diet (25% of those 30 to 34 compared to 9% of those 65 and older and 22% of those with a college degree compared 10% of those who had not finished high school).

- Those who had risk factors for CKD were more likely to attribute lower risk to well-controlled hypertension (8% vs. 2%), well-controlled diabetes (9% vs. 3%) or to the fact that they take their medication regularly (4% vs. 0.4%).

- About half the sample (n = 845) said their risk is average. More than a third (37%) gave reasons related to weight or lifestyle factors, about a quarter (25%) gave some disease-related response, a similar proportion (18%) said they did not know why their risk is average and 15% mentioned their family's health (or lack of health) in this regard.

    - Respondents at the pilot sites were more likely than those at the control sites to give a disease-related response on this question (27% vs. 14%).

    - Those at risk for CKD were more likely to give disease-related reasons than those not at risk (38% versus 6%).

Screening and Prevention of CKD

More than two-fifths of respondents (42%) reported that they had been tested for CKD (*Question 16*) (See Table 38).

Table 38: Self-Reported Testing for CKD
(Percentage of Total Sample)

	Total	Pilot	Control	Atlanta	Cleveland	Baltimore	Jackson
Yes	42	41	45	38	45	42	40
No	51	52	50	56	48	49	54
Don't know	*7*	*7*	*5*	*6*	*8*	*9*	*6*

- Men were significantly more likely than women to say they had been tested (49% vs. 39%), as were older respondents (52% of those 65 and older compared to 31% of those 30 to 34).

- People with diabetes (61%) and hypertension (51%) were more likely to say they have been tested, as were people at risk for CKD (49%). However, those with a family history of kidney failure were no more likely than others to say they have been tested (17%).

Of those respondents who said they had been tested for CKD, almost half (46%) reported that their last test was less than six months ago (See Table 39). One-fifth (22%) reported that the test was one to two years ago (*Question 17).*

Table 39: Occurrence of Test for CKD
(Percentage of Respondents Who Answered 'Yes' to Being Tested for CKD)

	Total	Pilot	Control	Atlanta	Cleveland	Baltimore	Jackson
Less than 6 months	46	47	45	39	52	47	47
6-12 months ago	17	19	12	23	16	18	18
1-2 years ago	22	22	22	22	21	20	24
More than 2 years	11	18	13	15	8	14	9
Don't know	*2*	*4*	*2*	*1*	*4*	*1*	*2*

n = 853

- Older respondents were more likely to report a CKD test within the last six months. Specifically, 51% of those over 65 reported this compared to only 34% of those 30 to 34.

- Education levels also affected when people reported being tested for CKD. Those with postgraduate degrees were twice as likely to report being tested 6 to 12 months ago compared to those without a high school degree (30% vs. 15%). On the other hand, those without a high school degree were more likely to report being tested more than two years ago than those with a postgraduate degree (15% vs. 9%).

When asked what tests can be used to detect CKD, 56% of respondents answered *don't know* or gave no response (*Question 25*) (See Table 40). Most of those who answered gave relatively vague responses, such as "blood test" (25%) and "urine test" (24%). Men (28%) were more likely than women (24%) to mention blood tests, whereas women (25%) were more likely than men (20%) to mention urine tests. Four percent mentioned a blood pressure test.

Table 40: Tests for CKD
(Percentage of Total Sample)

	Total	Pilot	Control	Atlanta	Cleveland	Baltimore	Jackson
Don't know	*56*	*56*	*58*	58	55	57	54
General blood test	25	26	23	28	27	27	20
General urine test	24	25	20	23	22	22	32
Other	5	5	5	6	6	5	2

Relatively few respondents could name specific ways to prevent CKD or stop its progression (*Question 26*). More than one-third (36%) of respondents could mention no ways of preventing or treating CKD (See Table 41). Only a tenth mentioned controlling diabetes and 11% controlling hypertension. The most common responses to this question were general practices such as having a healthy diet (31%) and drinking lots of water (23%), followed by exercising regularly (14%).

Table 41: Potential Advice from Doctor to Prevent CKD
(Percentage of Total Sample)

	Total	Pilot	Control	Atlanta	Cleveland	Baltimore	Jackson
Don't know	*36*	*35*	*42*	*29*	*35*	*35*	*40*
Healthy diet	31	33	25	39	31	35	29
Drink lots of water	23	23	23	25	23	24	19
Regular exercise	14	14	15	15	12	17	10
Control hypertension	*11*	*12*	*8*	*14*	*10*	*12*	*10*
Control diabetes	*10*	*11*	*5*	*13*	*10*	*9*	*12*

- Diet and exercise were mentioned most often by the youngest respondents, and their mention declined with age. For example, a third of respondents ages 30 to 34 (34%) mentioned maintaining a healthy diet compared to 20% of those 65 and over. Additionally, 18% percent of those 30 to 34 mentioned exercise compared to only 6% of those 65 and over.

- Respondents with higher income and education levels also named diet and exercise more often. Specifically, 24% of those with a household income of less than $20,000 mentioned maintaining a healthy diet compared to 42% of those with an income of $100,000, and 21% of those with less than a high school education mentioned it compared to 50% of those with a postgraduate degree. In terms of exercise, it was mentioned by 10% of those with a household income of less than $20,000 and 8% of those with less than a high school education, compared to 15% of those earning more than $100,000 and 24% of those with a postgraduate degree.

- Those in the pilot sites were more likely to mention specific disease-related advice than those in the control site. For example, 12% of respondents in the pilot sites said a doctor might advise control of hypertension compared to 8% of those in the control site. Eleven percent of those in the pilot site said controlling diabetes compared to 5% of those in the control site. Pilot site respondents also mentioned a healthy diet more frequently than control site respondents (33% vs. 25%). More respondents in the control site said *don't know* than those in the pilot sites (42% vs. 35%).

Patients with Chronic Kidney Disease

Thirty-six, or 1.8% of the sample population, indicated they had CKD (*Question 14*) (See Table 42).

Table 42: Have CKD
(Percentage of Total Sample)

	Total	Pilot	Control	Atlanta	Cleveland	Baltimore	Jackson
Yes	2	1	3	2	2	1	1
No	97	98	96	97	97	98	97
Don't know	*1*	*1*	*1*	*0*	*1*	*1*	*2*

- More than half of these respondents (58%) were in the lowest income bracket of less than $20,000 household income.

- Seventy-eight percent of the respondents with CKD had less than a college degree compared to 22% of those with at least an associate's degree.

- Those who reported having CKD were more likely to be at-risk for CKD (89%) or have hypertension (72%), yet less likely to have diabetes (33%).

Four percent of respondents reported that their doctor has ever told them that their kidneys were not functioning as well as they should or that they may suffer from CKD in the future (*Question 15*) (See Table 43).

Table 43: Told Kidneys Not Functioning at Optimal Level
(Percentage of Respondents Who Answered 'No' or 'Don't Know' to Having CKD)

	Total	Pilot	Control	Atlanta	Cleveland	Baltimore	Jackson
Yes	4	4	6	3	5	3	4
No	96	96	93	97	96	96	95
Don't know	*1*	*1*	*1*	-	-	*1*	*1*

n = 1,993

- Those who said they had been told their kidneys were not functioning at an optimal level were more likely to have been tested for CKD (7% of those tested vs. 2% of those untested) and to be at risk for CKD (6% at risk vs. 1% not at risk).

- Those who had been told their kidneys were not functioning properly were more likely to have diabetes and hypertension. Of those who had been told, 13% of those with diabetes were told compared to 3% of those without diabetes. Six percent of those with hypertension were told compared to 3% of those without hypertension.

Communicating About CKD

Less than one in five respondents (19%) reported that they have had a discussion about CKD with their doctor (*Question 27*) (See Table 44).

Table 44: Discussions with Doctor About CKD
(Percentage of Total Sample)

	Total	Pilot	Control	Atlanta	Cleveland	Baltimore	Jackson
Yes	19	19	19	15	19	21	22
No	80	80	80	85	80	78	78
Don't know	*1*	*1*	*1*	*1*	*1*	*1*	*1*

- Doctor-patient discussions occurred more often among older persons (22% of those 65 and older compared to 14% of those 30 to 34), those with higher incomes (24% with a household income of $100,000 or more vs. 17% of those earning less than $20,000) or education (28% of those with some postgraduate studies vs. 18% who had not graduated high school), those who had been tested for CKD (35% of those who had been tested compared to 12% of those who had not), those at risk for CKD (23% of those at risk vs. 12% not at risk). Respondents with diabetes or hypertension also reported more discussions with their doctor than those without either of those two conditions.

About half of the respondents (49%) mentioned that their doctor has asked them if they had a family member with CKD or kidney failure (*Question 28*). Another half reported not being asked at all (49%) (See Table 45).

Table 45: Discussion with Doctor About Family History of CKD
(Percentage of Total Sample)

	Total	Pilot	Control	Atlanta	Cleveland	Baltimore	Jackson
Yes	49	49	45	49	50	49	50
No	49	48	53	49	47	48	48
Don't know	*2*	*3*	*2*	*2*	*3*	*3*	*2*

Respondents who had discussed CKD with their doctor were asked what their doctor had told them (*Question 27a*). The most common advice/information mentioned by this sample (n = 389) was to get tested regularly (19%), to control hypertension to prevent or control CKD (14%) or to control diabetes (11%) (See Table 46). Nine percent were told that they were at risk for CKD or failure. Forty-three percent were given other advice, while only 3% mentioned being told that they have the power to prevent CKD.

Table 46: What Doctor Said About CKD
(Percentage of Respondents Who Answered 'Yes' to Discussing with Doctor)

	Total	Pilot	Control	Atlanta	Cleveland	Baltimore	Jackson
Other	43	43	46	55	47	43	31
Regular testing	19	17	25	17	15	20	16
Don't know	*14*	*14*	*15*	*17*	*11*	*14*	*14*
Control hypertension	14	16	5	16	15	17	16
Control diabetes	*11*	*13*	*5*	*5*	*18*	*13*	*14*

n = 389

- Respondents in the pilot site were almost three times as likely to be told to control diabetes as a way to prevent or control CKD than those in the control site (13% vs. 5%). This result was similar to the advice to control hypertension (16% of pilot site respondents vs. 5% of control site respondents).

Nineteen percent of respondents had talked about CKD in the past year with someone other than their doctor (See Table 47). More women (21%) than men (16%) reported having such discussions, as did those with higher education levels (31% of those with a postgraduate degree vs. 12% of those without a high school diploma), who had been tested for CKD (23% of those tested vs. 16% of those not tested) or were at risk (22% of at risk vs. 15% of not at risk) (*Questions 29 and 29a*).

Table 47: CKD Discussions with Someone Other Than Doctor
(Percentage of Total Sample)

	Total	Pilot	Control	Atlanta	Cleveland	Baltimore	Jackson
Yes	19	19	20	22	20	21	14
No	80	80	79	77	79	78	85
Don't know	*1*	*1*	*1*	*1*	*1*	*1*	*1*

- Of the respondents who mentioned that they have discussed CKD with someone (n = 395), 8% mentioned that it was with a friend or relative in general, 6% said it was with a friend or relative with CKD, and 3% said it was a friend or relative with diabetes or hypertension.

As seen in Table 48, fourteen percent of all respondents reported that they had encouraged someone else to be tested for CKD (*Question 30*).[6] Of these (n = 293), 59% said they had given this advice to a relative and 39% said they had advised a friend or co-worker and 14% mentioned someone else (*Question 30a*) (See Table 49).

Table 48: Self-Reports of Encouraging Someone to be Tested for CKD
(Percentage of Total Sample)

	Total	Pilot	Control	Atlanta	Cleveland	Baltimore	Jackson
Yes	14	14	15	15	13	14	16
No	85	85	84	85	87	85	84
Don't know	*0*	*0*	*1*	*0*	-	*1*	-

Table 49: Self-Reported Relationship to Person Encouraged
(Percentage of Respondents Who Answered 'Yes' to Encouraging Someone)

	Total	Pilot	Control	Atlanta	Cleveland	Baltimore	Jackson
Relative	59	62	49	59	62	62	66
Friend/co-worker	39	36	50	35	33	36	40
Other	14	14	14	14	15	12	13

n = 293

Of the 174 respondents that said they had encouraged a relative to get tested, 37% said it was a sibling, 26% said they gave this advice to their child, 22% said a parent and the remainder said a more distant relative or a non-blood relative (*Question 30b*) (See Table 50).

Table 50: Self-Reported Relationship to Relative Encouraged
(Percentage of Respondents Who Answered 'Yes' to Encouraging Relative)

	Total	Pilot	Control	Atlanta	Cleveland	Baltimore	Jackson
Sibling	37	39	26	27	41	44	44
Child	26	24	36	29	22	17	27
Parent	22	22	19	35	16	31	10

n = 174

- Persons who had a family history of CKD were twice as likely as those who did not to have encouraged someone to be tested (24% vs. 12%). Those who had been tested for CKD were also much more likely to encourage others (24% vs. 8%), as are those at risk (16% vs. 11%) and those with diabetes (19% vs. 14%) (*Question 30*).

[6] This figure might overestimate the true number, as some might be giving the "socially desirable" answer.

Awareness and Exposure to Information About CKD

Less than one-third (28%) of respondents recalled seeing, hearing or reading any information about CKD in the past year (*Question 34*) (See Table 51).

Table 51: Exposure to CKD Information in Past Year
(Percentage of Total Sample)

	Total	Pilot	Control	Atlanta	Cleveland	Baltimore	Jackson
Yes	28	28	29	28	26	30	29
No	70	70	68	69	73	69	69
Don't know	*2*	*2*	*3*	*2*	*1*	*1*	*1*

- Exposure to information was related to respondents' age, with a greater proportion of older people reporting exposure to information (30% of those 65 and over vs. 22% of those 30 to 34). Exposure also tended to increase with income (39% of those with incomes from $80,000 to $99,999 vs. 22% of those with incomes under $20,000) and education levels (42% of those with a postgraduate degree vs. 14% of those without a high school degree).

- Those who had been tested for CKD (39%), were at risk for CKD (31%), or had diabetes (38%) were more likely to have been exposed to information on CKD. Seventeen percent of those with a family history of CKD reported seeing, hearing or reading information about CKD in the past year.

Those who reported exposure to CKD-related information were asked to say where this occurred (*Question 34b*). A doctor's office was the most common response, with more than a third (36%) mentioning this source (See Table 52). About a quarter mentioned newspapers or magazines (24%), 15% mentioned TV, 8% the Internet and 4% a dialysis center. Other sources included community events and pharmacies. Older respondents also mentioned church, while younger respondents mentioned school. About a fifth (22%) gave a response of *other*.

Table 52: CKD Information Sources
(Percentage of Respondents Who Answered 'Yes' to Hearing Information)

	Total	Pilot	Control	Atlanta	Cleveland	Baltimore	Jackson
Doctor's office	36	36	36	27	37	38	43
Newspaper/magaz.	24	26	18	28	26	17	33
Other	*22*	*21*	*28*	*21*	*21*	*20*	*21*
TV	15	15	14	18	10	16	15
Don't know	*3*	*3*	*3*	*2*	*5*	*3*	*3*

n = 577

- Those tested for CKD were more than twice as likely to report hearing about this information from a doctor's office than those who were not tested (16% vs. 6%).

Respondents most often said they received information about CKD in a brochure, poster or flyer (44%) (*Question 34a*) (See Table 53). Those at risk (15% of at risk vs. 9% of not at risk), with diabetes (23% of those with diabetes vs. 11% of those without) or with hypertension (16% of those with hypertension vs. 10% of those without) were more likely to have seen these formats.

Table 53: CKD Information Formats
(Percentage of Respondents Who Answered 'Yes' to Hearing Information)

	Total	Pilot	Control	Atlanta	Cleveland	Baltimore	Jackson
Brochure, poster	44	45	40	40	48	41	51
Other	*22*	*21*	*28*	*20*	*20*	*24*	*21*
News story	21	21	21	25	20	20	18
Ad/announcement	13	14	12	10	14	14	16
Don't know	*4*	*4*	*4*	*4*	*3*	*4*	*4*

n = 577

- Twenty-one percent of respondents reported hearing about CKD via a news-story and 13% named an advertisement or public service announcement. Other forms included a Web site (7%), a health fair (6%), a class (4%) and church (2%).

- Those not at risk were almost twice as likely than those at risk to report hearing about CKD at a health fair or screening (2% vs. 1%).

Twenty-seven percent of those who reported seeing or hearing something about CKD in the past year said they had actively sought out this information (*Question 34c*) (See Table 54).

Table 54: CKD Information Seeking
(Percentage of Respondents Who Answered 'Yes' to Hearing Information)

	Total	Pilot	Control	Atlanta	Cleveland	Baltimore	Jackson
Actively Looking	27	27	29	24	31	27	25
Saw by chance	72	72	69	74	67	72	75
Don't know	*1*	*1*	*2*	*2*	*2*	*1*	-

n = 576

- Those who were at risk were more likely to say they had actively sought information on CKD than those who were not (31% vs. 18%).

Eight percent of respondents indicated that they had heard or read the NKDEP campaign message: *You have the power to prevent kidney disease* (*Question 34d*) (See Table 55).

Table 55: Heard NKDEP Campaign Message
(Percentage of Total Sample)

	Total	Pilot	Control	Atlanta	Cleveland	Baltimore	Jackson
Yes	8	8	9	8	6	6	13
No	18	18	17	18	19	22	14
Don't know	*2*	*2*	*3*	*2*	*1*	*2*	*2*

Appendix: Survey Instrument

Diabetes and Kidney Disease Study

Follow-Up Survey, May 2004

Hello, my name is [NAME], and I'm calling on behalf of the U.S. Department of Health and Human Services. We are calling households in your area to talk to African-American adults about some health issues.

[INTERVIEWER NOTE: IF ASKED, THE SURVEY WILL TAKE 15 – 20 MINUTES]

Q1 – Is there an African American over the age of 30 I could speak to?

1. Yes
2. No [TERMINATE INTERVIEW WITH, 'I'M SORRY, I NEED TO SPEAK TO SOMEONE OVER THE AGE OF 30 WHO IS AFRICAN AMERICAN. THANK YOU']

9. Ref/DK/NA [TERMINATE INTERVIEW WITH, 'I'M SORRY, I NEED TO SPEAK TO SOMEONE OVER THE AGE OF 30 WHO IS AFRICAN AMERICAN. THANK YOU']

[Once adult on phone] Would you have some time now to answer these questions?

S1 –

1. Yes
2. No [SET CALLBACK, TERMINATE]

Before we begin with the questions, I want you to know that the information you provide will be kept confidential and your participation is completely voluntary. At the end of our conversation I will give you some contact information in case you have any questions about this study or about the topics discussed. I also need to let you know that a supervisor may be listening for quality control purposes.

[NOTE TO INTERVIEWER: A lot of these questions are a little technical. Please try to encourage respondents to offer their opinions even if they are not certain of the answer, and ensure that they are not intimidated by the technical nature of the questions.]

Q2 – As I just mentioned, I'm calling on behalf of the National Institutes of Health and most of my questions today will focus on health issues. Here's the first question: In your opinion, what are the three most serious health problems facing African Americans today?

[INTERVIEWER NOTE: DO NOT READ RESPONSES, CHOOSE FIRST THREE MENTIONED. PUT INTO PRE-CODED CATEGORIES IF AT ALL POSSIBLE]

[PROGRAMMER NOTE: FIRST THREE RESPONSES NEED TO BE ORDERED]

1. Access to health care/insurance issues
2. AIDS/HIV
3. Cancer
4. Diabetes/Sugar/Sugar diabetes
5. Drugs or alcohol use/abuse
6. Heart disease/stroke/heart attack
7. Hypertension/high blood pressure
8. Kidney disease/Kidney Failure/End Stage Renal Disease
9. Obesity/Overweight
10. Poverty
11. Violence
12. Other [Specify] _____
13. Don't know/Don't remember
14. Ref/NA
15. Exit

[INTERVIEWER NOTE: KIDNEY STONES, CANCER OR INFECTIONS OF THE KIDNEY ARE NOT KIDNEY DISEASE]

Q3 – As you may know, many African Americans have diabetes or sugar diabetes. Do you have any idea of what the negative health effects of not looking after one's diabetes might be?

[INTERVIEWER NOTE: DO NOT READ RESPONSES, CHOOSE ALL THAT APPLY]

[PROGRAMMER NOTE: YES/NO TOGGLE]

1. Stroke
2. Amputation/limb loss
3. Premature death/Death
4. Heart attack
5. Blindness/loss of vision/retinopathy/glaucoma
6. Must take insulin
7. Kidney disease/Kidney failure/End stage renal disease/dialysis
8. Coma/pass out/sugar attack
9. Other [Specify] _____
10. Don't Know/Don't remember
11. Nothing will happen
12. Ref/NA
13. Exit

[INTERVIEWER NOTE: KIDNEY STONES, CANCER OR INFECTIONS OF THE KIDNEY ARE NOT KIDNEY DISEASE]

Q4 – Do you happen to know what kind of tests a person with diabetes should have regularly?

[INTERVIEWER NOTE: DO NOT READ RESPONSES, CHOOSE ALL THAT APPLY]

[PROGRAMMER NOTE: YES/NO TOGGLE]

1. Daily blood glucose/daily monitoring
2. Blood test (general)
3. Urine test (general)/urinalysis
4. Proteinuria/urine protein/protein in the urine
5. Hemoglobin A1c/hbA1c/A1c
6. Microalbuminuria/albumin in urine
7. Creatinine/serum creatinine/creatinine clearance
8. GFR/glomerular filtration rate
9. Foot/podiatrist exam
10. Eye/retinal/retinopathy exam/glaucoma exam/eye pressure test
11. Don't know/Don't remember
12. Ref/NA
13. Exit

Q5 – Do you have, or has a doctor or other health care provider ever said you have diabetes?

1. Yes
2. No [SKIP TO Q6]
3. Don't know/Don't remember [SKIP TO Q6]

9. Ref/NA [SKIP TO Q6]

Q5a – What are you doing to manage your diabetes or keep it under control?

[INTERVIEWER NOTE: DO NOT READ RESPONSES, CHOOSE ALL THAT APPLY]

[PROGRAMMER NOTE: YES/NO TOGGLE]

1. Nothing
2. Exercise
3. Dietary changes
4. Weight loss
5. Medication
6. Insulin injections
7. Nutritional or herbal supplements
8. Meditation/spiritual intervention
9. Alternative therapies
10. Other [Specify] _____
11. Don't know/Don't remember
12. Ref/ NA
13. Exit

Q5b – How often do you see a doctor or health care provider to check on your diabetes and help you manage it?

1. At least once every 3-4 months (or more frequently than that)
2. About once every 6 months
3. About once every year
4. About once every 2 years (or less frequently than that)
5. Don't know/Don't remember
6. Ref/ NA
7. Exit

Q5c – On a scale from 1 to 10, how well do you think you follow your doctor's or health care provider's recommendations for your diabetes? A 1 means you do not follow at all what your provider recommends and a 10 means that you do everything your provider recommends.

1. Do not follow at all
2. . . .
3. . . .
4. . . .
5. . . .
6. . . .
7. . . .
8. . . .
9. . . .
10. Do everything provider recommends
11. Does not see a provider
12. Don't know/Don't remember

99. Ref/ NA

Q6 – As you may know, many African Americans have hypertension or high blood pressure. Do you have any idea of what the negative health effects of not looking after one's high blood pressure might be?

[INTERVIEWER NOTE: DO NOT READ RESPONSES, CHOOSE ALL THAT APPLY]

[PROGRAMMER NOTE: YES/NO TOGGLE]

1. Stroke
2. Amputation/limb loss
3. Premature death/Death
4. Heart attack
5. Kidney disease/kidney failure/end stage renal disease
6. Don't know/Don't remember
7. Nothing
8. Other [Specify] _____
9. Ref/NA
10. Exit

Q7 – Do you happen to know what kind of tests a person with high blood pressure or hypertension should have regularly?

[INTERVIEWER NOTE: DO NOT READ RESPONSES, CHOOSE ALL THAT APPLY.]

[PROGRAMMER NOTE: YES/NO TOGGLE]

1. Blood pressure test
2. Blood test (general)
3. Urine test (general)/urinalysis
4. Proteinuria/urine protein/protein in the urine
5. Hemoglobin A1c/hbA1c/A1c
6. Microalbuminuria/albumin in urine
7. Creatinine/serum creatinine/creatinine clearance
8. GFR/glomerular filtration rate
9. Eye/retinal/retinopathy exam/glaucoma exam/eye pressure test
10. Don't know/Don't remember
11. Ref/NA
12. Exit

Q8 – Do you have, or has a doctor or other health care provider ever said you have high blood pressure or hypertension?

1. Yes
2. No [SKIP TO Q11]
3. Don't know/Don't remember [SKIP TO Q11]

9. Ref/DK/NA [SKIP TO Q11]

Q8a – What are you doing to keep your high blood pressure or hypertension in control?

[INTERVIEWER NOTE: DO NOT READ RESPONSES, CHOOSE ALL THAT APPLY]

[PROGRAMMER NOTE: YES/NO TOGGLE]

1. Nothing
2. Exercise
3. Dietary changes
4. Weight loss
5. Medication
6. Regular monitoring
7. Meditation/spiritual intervention
8. Nutritional/herbal supplements
9. Alternative therapies
10. Staying calm, happy
11. Other [Specify] _____
12. Don't know/Don't remember
13. Ref/ NA
14. Exit

Q8b – How often do you see a doctor or health care provider to check on your high blood pressure or hypertension and help you manage it?

1. At least once every 3-4 months (or more frequently than that)
2. About once every 6 months
3. About once every year
4. About once every 2 years (or less frequently than that)
5. Don't know/Don't remember
6. Ref/ NA
7. Exit

Q8c – On a scale from 1 to 10, how well do you think you follow your doctor's or other health care provider's recommendations for your high blood pressure or hypertension? A 1 means that you do not follow at all what your provider recommends and a 10 means that you do everything your provider recommends.

1. Do not follow at all
2. . . .
3. . . .
4. . . .
5. . . .
6. . . .
7. . . .
8. . . .
9. . . .
10. Do everything provider recommends
11. Does not see a provider
12. Don't know/Don't remember

99. Ref/ NA

IF HAVE EITHER DIABETES OR HYPERTENSION, ASK Qs 9, 10 and 11. ELSE SKIP TO Q12.

Q9 – Do you limit routine care for your diabetes or high blood pressure because it is difficult for you to pay for this care? By routine care I mean regular visits to your health care provider, tests, medications, etc.

1. Yes
2. No
3. Not sure

9. Ref/NA

Q10 - Have you and your physician or health care provider ever discussed different ways to pay for routine care for your hypertension or diabetes, such as office visits, tests, medications, etc.?

1. Yes
2. No
3. Not sure

10. Ref/NA

Q11 – When you have questions about managing your diabetes or hypertension which two sources of information do you use most often?

1. Physician
2. Nurse/PA
3. Pharmacist
4. Diabetes educator or other counselor
5. Social worker or other community worker
6. Church official
7. Friend, relative, colleague, etc. (laypersons)
8. Other - Specify _____
9. Don't know/Not sure

99. Ref/NA

Q12 – Have you ever heard of an illness called Kidney Disease?

1. Yes
2. No
3. Not sure

9. Ref/NA

Q13 – Can you tell me what you think kidney disease is?

[INTERVIEWER NOTE: DO NOT READ RESPONSES, CHOOSE ALL THAT APPLY]

[PROGRAMMER NOTE: YES/NO TOGGLE]

1. General disease or ailment of the kidneys
2. An infection of the kidneys
3. Stoppage: Kidneys stop working
4. Unspecific reduction: Functioning is reduced/Don't work as well as they should
5. Specific reduction: Inability to filter blood of waste, water and/or chemicals
6. Has no symptoms
7. Has symptoms of some kind (e.g. urinating too much, too little)
8. Immediate need for dialysis or a kidney transplant
9. Ultimately/eventually leads to kidney failure/dialysis/kidney transplant
10. If not treated leads to kidney failure/dialysis/kidney transplant
11. Treatable/chronic/preventable illness
12. Deadly illness/something that kills you
13. Diabetes causes
14. Hypertension/high blood pressure causes
15. Family members of people with kidney failure/kidney disease at risk
16. African Americans at risk/happens to African Americans
17. Other specific race (not African American) at risk/happens to other race
18. Older people at risk/happens to older people
19. Don't know/Don't remember
20. Ref/NA/Exit

Kidney disease is a reduction in kidney function. It means that your kidneys are less able to balance fluids in your body, remove waste products from your blood, and release hormones into your blood.

Q14 – Do you have kidney disease as I've just described it?

1. Yes [SKIP TO Q16]
2. No
3. Don't know/Don't remember
9. Ref/DK/NA

Q15 — Has a doctor or health care provider ever told you that your kidneys are not functioning as well as they should or that you might suffer from kidney failure in the future?

1. Yes
2. No
3. Don't know/Don't remember

9. Ref/DK/NA

Q16 – Have you ever been tested for kidney disease?

1. Yes [ASK Q17]
2. No [SKIP TO Q18]
3. Don't know/Don't remember [SKIP TO Q18]

9. Ref/NA

Q17 – How recently did you have your last test?

1. 1 – less than 6 months ago
2. 6 – less than 12 months ago
3. 1 – 2 years ago
4. More than 2 years ago
5. Don't know/Don't remember

9. Ref/NA

Q18 – Who do you think is more likely to get kidney disease or is at a higher risk for kidney disease? [INTERVIEWER NOTE: DO NOT READ RESPONSES, CHOOSE ALL THAT APPLY] [PROGRAMMER NOTE: YES/NO TOGGLE]

1. Persons with diabetes
2. Persons with hypertension/high blood pressure
3. Family members of kidney disease or kidney failure patients
4. African Americans
5. Hispanics
6. Persons of another race
7. Older age people
8. Men
9. Women
10. Overweight or obese people
11. People who eat/don't eat certain foods
12. People who drink/don't drink certain beverages
13. People who do not exercise
14. People who have/don't have faith
15. People with high cholesterol
16. People on chemotherapy/receiving cancer treatment
17. Other [Specify _____]
18. Don't know/Don't remember
19. Ref/NA
20. Exit

Q19 – Are there any signs or symptoms that would let a person know they had kidney disease?

1. Yes [ASK Q19a]
2. No [SKIP TO Q20]
3. Don't know/Don't remember [SKIP TO Q20]

9. Ref/NA [SKIP TO Q20]

Q19a– What are they?

[INTERVIEWER NOTE: DO NOT READ RESPONSES, CHOOSE ALL THAT APPLY]

[PROGRAMMER NOTE: YES/NO TOGGLE]

1. Would not know/There is no way to know
2. Get tested/only if tested
3. Pain (general)/lower back pain
4. Difficulty urinating
5. Frequent urination
6. Protein in urine
7. Other change in urine
8. Swelling/edema
9. Fatigue
10. Jaundice/yellow eyes/yellow skin
11. Other symptoms; specify: _____
12. Doctor would tell them
13. Don't know/Don't remember
14. Ref/NA
15. Exit

Q20– Do you happen to know what can cause kidney disease?

[INTERVIEWER NOTE: DO NOT READ RESPONSES, CHOOSE ALL THAT APPLY]

[PROGRAMMER NOTE: YES/NO TOGGLE]

1. Overweight/obesity
2. Diabetes/sugar diabetes/sugar
3. Hypertension/high blood pressure
4. Too little water/not drinking enough
5. Too much water/drinking too much
6. Drinking soda or pop
7. Prescription medication
8. Over-the-counter medicine
9. Genetics/family risk/family member with kidney failure
10. Poor diet
11. Lack of exercise
12. Other [Specify _____]
13. Don't know/Don't remember
14. No answer/Refused
15. Exit

Q21 – Have you ever heard that hypertension is one of the leading causes of kidney disease?

1. Yes
2. No
3. Don't know/Don't remember

9. Ref/NA

Q22 – Have you ever heard that diabetes is one of the leading causes of kidney disease?

1. Yes
2. No
3. Don't know/Don't remember

9. Ref/NA

Q23 – How would you rate your risk for getting kidney disease? Would you say it is higher than average, lower or about average?

1. Higher
2. Lower
3. Average
4. Don't know

9. Ref/NA

Q24 – Why do you think so?

[INTERVIEWER NOTE: DO NOT READ RESPONSES, CHOOSE ALL THAT APPLY]

1. Have hypertension
2. Have hypertension well controlled
3. Have diabetes
4. Have diabetes well controlled
5. Am overweight/obese
6. Am thin/not overweight
7. Have symptoms
8. Have no symptoms
9. Have no reason to think I am at risk
10. Am Black/African American
11. Am of specific race (not Black/African American)
12. My age (too old)
13. Have a healthy diet
14. Have a poor or unhealthy diet
15. Drink lots of water
16. Don't drink enough water
17. Drink too much soda or pop
18. Don't drink soda or pop
19. Family is healthy
20. One or more family members have it/runs in my family (genetic risk for)
21. Doesn't run in my family (no genetic risk for)
22. Exercise regularly
23. Take my prescription medication for hypertension and/or diabetes as directed
24. Other medication or OTC usage/non-use
25. Spiritual reason (God looks after me, etc)
26. I don't know why I think so
27. Other reason [Specify _____]
28. Ref/NA
29. Exit

Q25 – Do you know what kind of tests a person can have to test for kidney disease?

[INTERVIEWER NOTE: DO NOT READ RESPONSES, CHOOSE ALL THAT APPLY]

[PROGRAMMER NOTE: YES/NO TOGGLE]

1. Blood pressure test
2. Blood test (general)
3. Urine test (general)/urinalysis
4. Proteinuria/urine protein/protein in the urine
5. Hemoglobin A1/hbA1c/A1c
6. Microalbuminuria/albumin in urine
7. GFR/glomerular filtration rate
8. Creatinine or serum creatinine/creatinine clearance
9. Other [SPECIFY _____]
10. Don't know/Don't remember
11. Ref/NA
12. Exit

Q26 – What advice might a doctor or other health care provider give to someone so they could prevent kidney disease or stop it from getting worse?

[INTERVIEWER NOTE: DO NOT READ RESPONSES, CHOOSE ALL THAT APPLY]

[PROGRAMMER NOTE: YES/NO TOGGLE]

1. Control hypertension
2. Control diabetes
3. Have a healthy diet
4. Drink lots of water
5. Eat less protein
6. Avoid soda
7. Take prescription medicine
8. Avoid medicines
9. Get tested
10. Exercise regularly
11. Watch for protein in urine
12. Lose weight
13. Nothing
14. Don't Know/Don't remember
15. Ref/NA
16. Exit

Q27 – Have you ever discussed kidney disease with a physician or health care provider?

1. Yes [ASK Q27a]
2. No [SKIP TO Q28]
3. Don't know/Don't remember [SKIP TO Q28]

9. Ref/DK/NA [SKIP TO Q28]

Q27a – What did your health care provider tell you?

[INTERVIEWER NOTE: DO NOT READ RESPONSES, CHOOSE ALL THAT APPLY]

[PROGRAMMER NOTE: YES/NO TOGGLE]

1. Control diabetes to prevent/control kidney disease
2. Control hypertension to prevent/control kidney disease
3. Medication change needed
4. Be tested regularly
5. That I am at risk for kidney disease or kidney failure
6. That I have the power to prevent kidney disease
7. Other [Specify _____]
8. Don't know/Don't remember
9. Ref/NA
10. Exit

Q28 - Has your health care provider ever specifically asked you if any of your close family members has or had kidney disease or kidney failure?

1. Yes
2. No
3. Don't know/Don't remember

9. Ref/DK/NA

Q29 - Have you discussed kidney disease with anyone (other than your physician/health care provider) in the last year?

1. Yes [ASK Q29a]
2. No [SKIP TO Q30]
3. Don't know/Don't remember [SKIP TO Q30]]

10. Ref/DK/NA [SKIP TO Q30]

Q29a – Who did you discuss it with?

[INTERVIEWER NOTE: DO NOT READ RESPONSES, CHOOSE ALL THAT APPLY]

[PROGRAMMER NOTE: YES/NO TOGGLE]

1. Friend/relative who has diabetes or hypertension
2. Friend/relative or family member with kidney disease or kidney failure
3. Friend/relative (general)
4. Other [Specify _____]
5. Don't know/Don't remember
6. Ref/NA
7. Exit

Q30 – Have you ever encouraged anyone to get tested for kidney disease?

1. Yes [ASK Q30a and b]
2. No [SKIP TO Q31]
3. Don't know/Don't remember [SKIP TO Q31]

9. Ref/NA [SKIP TO Q31]

Q30a – Whom did you encourage?

[INTERVIEWER NOTE: DO NOT READ RESPONSES, CHOOSE ALL THAT APPLY]

[PROGRAMMER NOTE: YES/NO TOGGLE]

1. Friend/Coworker
2. Relative
3. Other
4. Don't know/Don't remember
5. Ref/NA
6. Exit

[PROGRAMMER NOTE: IF Q30a DOES NOT EQUAL 2, SKIP TO Q31]

Q30b – What relative did you encourage?

[INTERVIEWER NOTE: DO NOT READ RESPONSES, CHOOSE ALL THAT APPLY]

[PROGRAMMER NOTE: YES/NO TOGGLE]

1. Parent
2. Grandparent
3. Aunt or Uncle
4. Sibling
5. Child
6. Cousin
7. Non-blood relative (step or god-parent/child)
8. Other
9. Don't know/Don't remember
10. Ref/NA
11. Exit

Q31 – Now I want to ask you a couple questions about kidney failure. Have you ever known anyone with kidney failure? This would be someone who had dialysis or a kidney transplant.

1. Yes [ASK Qs 31a & b]
2. No [SKIP TO Q32]
3. Don't know/Don't remember [SKIP TO Q32]

9. Ref/NA [SKIP TO Q32]

Q31a – Who do/did you know with kidney failure?

[INTERVIEWER NOTE: DO NOT READ RESPONSES, CHOOSE ALL THAT APPLY]

[PROGRAMMER NOTE: YES/NO TOGGLE]

1. Friend/Coworker
2. Relative
3. Other
4. Don't know/Don't remember
5. Ref/NA
6. Exit

[PROGRAMMER NOTE: IF Q31a DOES NOT EQUAL 2, SKIP TO Q32]

Q31b – What relative had or has kidney failure?

[INTERVIEWER NOTE: DO NOT READ RESPONSES, CHOOSE ALL THAT APPLY]

[PROGRAMMER NOTE: YES/NO TOGGLE]

1. Parent
2. Grandparent
3. Aunt or Uncle
4. Sibling
5. Child
6. Cousin
7. Non-blood relative (step or god-parent)
8. Other
9. Don't know/Don't remember
10. Ref/NA
11. Exit

Q32 – Do you think having a relative with kidney failure increases a person's risk for kidney disease? Would you say it increases the risk of kidney disease . . . ?

1. Not at all
2. A little
3. Somewhat
4. A great deal
5. Don't Know

9. Ref/NA

Q33 – How common do you think kidney disease is? Would you say it is . . .?

1. Very common
2. Somewhat common
3. Not common
4. Very rare
5. Don't know

9. Ref/NA

Q34 – Have you seen, heard or read any information on kidney disease in the last year or so?

1. Yes [ASK Q34a,b, c]
2. No [SKIP TO Q35]
3. Don't know/Don't remember [SKIP TO Q35]

9. Ref/NA [SKIP TO Q35]

Q34a – What have you seen, heard or read?

[INTERVIEWER NOTE: DO NOT READ RESPONSES, CHOOSE ALL THAT APPLY]

[PROGRAMMER NOTE: YES/NO TOGGLE]

1. Advertisement, public service announcement
2. Brochure, poster or flyer
3. Education class
4. Website
5. News-story (television, radio or print)
6. Health fair, screening or other community event
7. Church sermon/activity
8. Other
9. Don't know/don't remember
10. Ref/NA
11. Exit

Q34b – Where was this information?

[INTERVIEWER NOTE: DO NOT READ RESPONSES, CHOOSE ALL THAT APPLY]

[PROGRAMMER NOTE: YES/NO TOGGLE]

1. In a newspaper or magazine
2. On TV
3. On the radio
4. Doctor's office
5. Dialysis clinic
6. Internet
7. Church
8. Pharmacy
9. School/college
10. Community event
11. Other
12. Don't know/don't remember
13. Ref/NA
14. Exit

Q34c – Were you looking for this information or did you just come upon it by chance?

1. Looking for the information
2. Found it by chance
3. Don't know/don't remember

9. Ref/DK/NA

Q34d – Have you seen, heard or read the phrase, "You have the power to prevent kidney disease" in the last year?

1. Yes
2. No
3. Don't know/don't remember

8. Ref/NA

Now I'd like to ask you a few questions about yourself.

Q35 – Which of the following best describes your age? Would it be . . .?

1. 30 – 34
2. 35 – 44
3. 45 – 54
4. 55 – 64
5. 65 or older

9. Ref/DK/NA

Q36 – Which of the following best describes your yearly household income? Would it be . . . ?

1. Less than $20,000
2. $20,000 – $39,999
3. $40,000 - $59,999
4. $60,000 - $79,999
5. $80,000 - $99,999
6. $100,000 or more

9. Ref/DK/NA

Q37 – Which of the following best describes the highest education level you have reached?

[INTERVIEWER NOTE: READ RESPONSES IN ASCENDING ORDER AND ASK INTERVIEWEE TO STOP YOU WHEN YOU REACH THE RIGHT EDUCATION BRACKET.]

1. Less than high school
2. High school graduate
3. Some college
4. Community college graduate (AA degree)
5. College graduate (BA degree)
6. Some graduate school
7. Graduate degree (JD, MD, PhD, etc)

9. Ref/DK/NA

Q38 - What is your zip code?

_____

99999 – Ref/DK/NA

[RANGE: 00000 – 99999]

Q39 – Code gender

1. Male
2. Female

9. Not ascertained

That's all the questions I have for you today. Thank you for your time and assistance. If you would like additional information about kidney disease I can provide you with some.

Public reporting burden for this survey is estimated to average 20 minutes. An agency may not conduct or sponsor, and a person is not required to respond to, a collections of information unless it displays a currently valid OMB control number. The control number for this survey is 0925-0515 and expires on January 31, 2005. If you have any comments regarding the burden estimate or other aspects of this collection of information, please let me know and I will give you an address where they can be sent.

COMMENTS CAN BE SENT TO:
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