



National  
Kidney  
Foundation®

HYPERKALEMIA:  
SURVEY OF AWARENESS AND EXPERIENCE  
AMONG ADULTS WITH CKD

A Report of Findings

March 6, 2017

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## READING OPTIONS: 5-in-1 Drill-down Report

### 1. ONE HOUR (OR MORE) TO DIGEST IN FULL

- **HOW:** Read the highlighted sentence of each numbered paragraph and learn about the key global finding. Read the non-highlighted text in the numbered paragraphs for important supporting information, such as specific numbers and perspective. Read the bullet points to find out how these global findings change and differ for key sub-groups. Compare the findings to other information you may have available from other sources. Consider following along with the questionnaire or tables, using the reference provided at the end of each global finding.
- **Short on time? Start with the “Summary: Findings & Suggested Actions”** sections and the highlighted text throughout the report.

### 2. HALF HOUR SELECTIVE FOCUS

- **HOW:** Read the highlighted sentences throughout the report. When you get to the area of immediate interest, read the supporting detail about the global findings in the numbered paragraph(s) and the significant sub-group differences in the bullet points that follow.
- **Short on time?** Skip the bullet points, saving for another time all the insight they offer into what is going on at the sub-group level.

### 3. 10-MINUTE LOOK AT ALL THE TOPICS COVERED

- **HOW:** Read the highlighted sentences throughout the report.
- **Short on time? Read the “Summary: Findings & Suggested Actions”** in full.

### 4. 2-MINUTE OVERVIEW

- **HOW: Go straight to the “Summary: Findings & Suggested Actions”**
- **Short on time?** Read the highlighted sentences.

### 5. FLIP THROUGH THE GRAPHS (SIMULATED POWERPOINT)

- **HOW:** Use the list of charts in the Table of Contents to jump from graph to graph.

## ACKNOWLEDGEMENTS

Many people helped make this study possible. We gratefully acknowledge all their efforts and extend special thanks to:

- The patients who shared their experiences and opinions.
- The sponsor, for providing an educational grant to conduct this study.

## PURPOSE OF STUDY

This nationwide online survey was conducted among 488 adults with chronic kidney disease (CKD). It focused on exploring their awareness and experience related to hyperkalemia.

People who have CKD are at increased risk for experiencing a sudden rise in blood potassium levels (hyperkalemia). While treatable once it is diagnosed, hyperkalemia is not always immediately recognizable to patients and physicians. If left untreated, hyperkalemia can impair the heart's ability to function and may be life-threatening. This risk may not be particularly well-known among patients in the early stages of CKD.

NKF plans to have a special focus on this risk on World Kidney Day (March 9, 2017) and then continue to prepare patients with kidney disease to be better partners in minimizing the impact of hyperkalemia.

In support of these two initiatives, the study addresses these *key issues*:

1. What patients, particularly those in the early stages of CKD, know—or think they know—about hyperkalemia,
2. The personal experience of these patients with hyperkalemia, and
3. What steps they have taken, if any, to minimize this risk.

## SUMMARY: Findings & Suggested Actions

Based on the perceptions and experiences of 488 CKD patients nationwide.

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### Finding #1: Hyperkalemia is a top health concern

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**Half of all CKD patients say hyperkalemia is “very important” to them personally (50%), or about the same as for heart disease (47%) and anemia (47%). Only hypertension is seen as more important (62% rate high blood pressure as “very important”). A few patients (4%-5%) say that each of these health concerns is “not at all important” to them personally. More see hyperkalemia as “very important” personally than either diabetes (39%) or high cholesterol (34%).**

At least two-thirds have experienced high potassium (hyperkalemia) at some point (66%) and the total may be as high as 73%. While the incidence is lower among those in the three earliest stages of CKD, 47% of them have still experienced hyperkalemia. One in five CKD patients reports having a potassium level that is currently high (19%). Most who recall their diagnosis say it was made by a nephrologist (74%).

One in five who have experienced hyperkalemia have been living with it for more than five years (18%). Half have lived with it for at least a year (50%). Yet 37% see hyperkalemia as a short-term issue like anemia (44%). It is particularly likely to be seen as short-term by those who have experienced it (41% vs. 29% among those never diagnosed with high potassium levels).

Just over one-third of the CKD patients diagnosed with hyperkalemia have needed emergency care to address it (38%). The incidence rises to 51% among those who have been living with hyperkalemia for more than five years.

Nearly all who have experienced hyperkalemia are concerned about their potassium levels **and 44% are “very concerned.”** Even more see hyperkalemia as **“very important” to them personally (59%).**

They are turning their concern into action, not only complying with doctor recommendations but also taking the initiative to make lifestyle and other changes beyond what their doctor recommended in an effort to control their potassium levels. At least one in ten CKD patients who have been diagnosed with high potassium elected on their own without a specific doctor recommendation to drink more water (16% of them have done so on their own), visit a dietitian (15%), schedule more frequent lab tests (13%), and exercise more (11%).

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## Finding #2: There are gaps in CKD patient awareness and knowledge about hyperkalemia

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Despite generally being tested at least twice a year, CKD patients are not necessarily aware of their potassium levels. At least 15% of those whose potassium levels are currently high **don't think to report that** diagnosis without additional prompting. The reporting gap jumps to 41% among those whose potassium levels were high in the past but are now normal or low. Another 7% are unsure about their potassium levels and whether they have ever been high.

**Altogether hyperkalemia does not really seem to fully “be on the radar” of at least 27% of CKD patients, most if not all of whom have experienced hyperkalemia.**

There is less agreement on whether high potassium is a short-term health concern than there is about anemia, bone disease/fractures, high cholesterol, diabetes, heart disease, and hypertension. Certain groups are more likely than others to see hyperkalemia as short-term: those who have experienced it, particularly when newly diagnosed; those under the age of 55; those with Stage 5 CKD; those who have undergone a kidney transplant or dialysis; and those who are **“very aware” of the heart risk associated with high potassium.**

One in ten CKD patients admit to having no idea about the serious heart risks associated with high potassium levels (10%), rising to 20% when they are in the three earliest stages of CKD. **Still, most CKD patients claim to be “very aware” of this risk (73%),** including 83% of those diagnosed with hyperkalemia.

One-third has **never heard of the term “hyperkalemia”** (30%) and a total of 53% have no idea what it means. Even among those who have experienced hyperkalemia, just 51% are familiar with the term.

Patients often turn to multiple sources when they decide to seek health information, most notably their doctor (63%) and the Internet (46%); 22% specifically say they use both of these sources. A total of 25% say they get information from some other medical source such as a nurse, center, or clinic. Just 8% mention using some other source such as a patient support group or journal.

Nephrologists play a big role. Three-quarters of those who have experienced hyperkalemia say it was first diagnosed by their nephrologist (75%). A total of 17% of all CKD patients specify that they turn to their nephrologist for health information. Nephrologists appear to be doing a good job educating patients who ask about hyperkalemia. **CKD patients who are “very aware” of the heart risk of high potassium and those who are most familiar with the term “hyperkalemia” are twice as likely to turn to their nephrologist when they face a health challenge.**

One in ten with CKD in Stages 1-3 who have experienced high potassium say they received no recommendations for actions to address it (9%). This is rarer in the later stages of CKD (1%-4%).



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### Finding #3: Diet is the main focus of doctor hyperkalemia recommendations, patient actions, and patient challenges

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Seven out of every eight patients who have experienced high potassium recall their doctor or nurse practitioner recommending they change their diet to address their potassium levels (85%) and 27% recommended that they visit a dietitian. At least one in five were also told to drink more water (22%) and become more active (20%). Only a few (2%) recall being told to decrease their alcohol or recreational drug use. Most of these other lifestyle-related suggestions were in addition to diet change; only 5% say their doctor recommended one or more of them without also mentioning diet change.

More than twice as many received diet change recommendations as recommendations for more frequent lab tests (34%) or a new prescription drug (37%). Even fewer report receiving a recommendation to stop or change a prescription drug (13%). A total of 48% say they received some sort of recommendation involving prescription drugs or over-the-counter remedies.

Nine out of ten complied with the recommendation to change their diet (89%) and 77% made the recommended visit to a dietitian. Patient diet-related compliance rates are comparable to those of drinking more water (86%), stopping or changing a prescription drug (81%), taking a new prescription drug (77%), and lab testing frequency (76%). Fewer patients report complying with doctor recommendations related to over-the-counter remedies (42% for stopping, 58% for taking), decreasing alcohol and recreational drug use (57%), and exercise (64%).

One-third of those experiencing hyperkalemia have visited a dietitian (36%), half as many as have changed their diet (83%), but more than the 22% whose doctor recommended they visit a dietitian. About as many have tried more frequent lab tests (39%), drinking more water (35%), and taking a new prescription drug (33%). The only other actions that at least one in ten have taken is exercising more (24%) and stopping or changing a prescription drug (16%).

Two-thirds mention diet when listing their biggest challenge in dealing with high potassium (69%), including 74% of those who have changed their diet and 76% who have visited a dietitian. They most often mention food constraints (31%), with 12% naming one or more specific foods that are particularly challenging for them. Others mention the challenge of eating the right foods (18%), figuring out the right foods (10%), and tracking what they eat (12%).

Only 7% mention medications when naming their biggest challenge in dealing with high potassium, about the same proportion as mention dialysis (6%) and the struggle to keep it under control (7%). Even more (10%) cite a lack of information such as lack of potassium labeling and reliable sources of information.

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## Suggested Actions

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While these actions are not new to NKF, they may help guide it in prioritizing efforts.

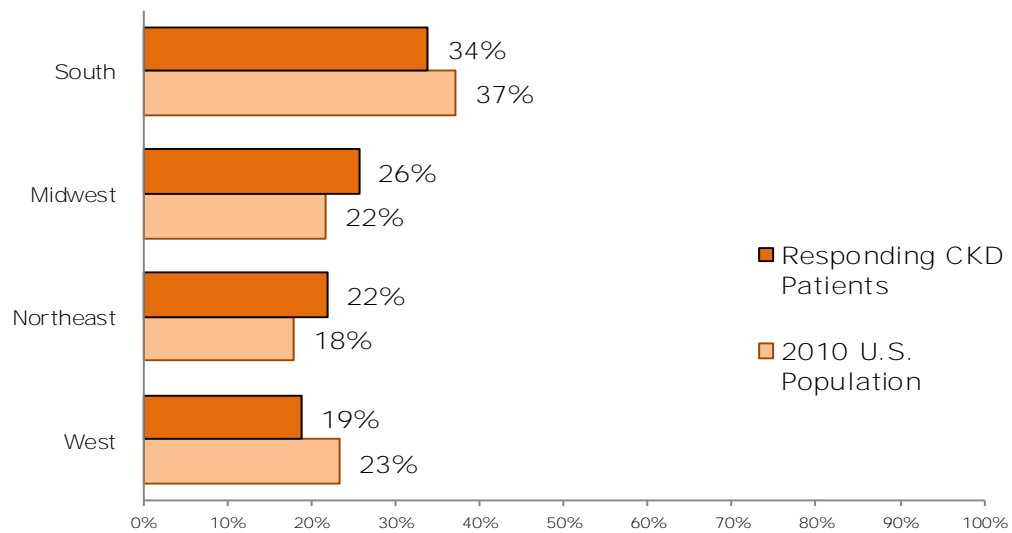
1. Help prepare patients to talk with their doctors and other medical providers about hyperkalemia so that they will think to initiate a conversation and know the right questions to ask. This can be in the form of lists or other educational tools on the internet. It can also include steps they can take to minimize the risks or occurrence of high potassium.
2. Encourage doctors, particularly nephrologists, to proactively talk to their patients about high potassium, reminding them that patients **don't always think of it or fully understand it enough to ask questions**. Doctors may need materials to help facilitate this conversation and to share with their patients.
3. Provide continuing diet education, such as new recipes, menus, and approaches to identifying and incorporating the right food combinations at home and on the go.
4. Work with food manufacturers and others to better label potassium on their packaging and on the web.
5. Ensure that internet searches take you to hyperkalemia-related information using alternate terms since patients may not think to use that term.

## DETAILED FINDINGS

### *Who is Included*

1. This report includes the views of adults with CKD from across the United States. Comparable to the U.S. population as a whole, a total of 34% live in the South, 26% in the Midwest, 22% in the Northeast, and 19% in the West. – *Table 31, Question 23—Your state?*

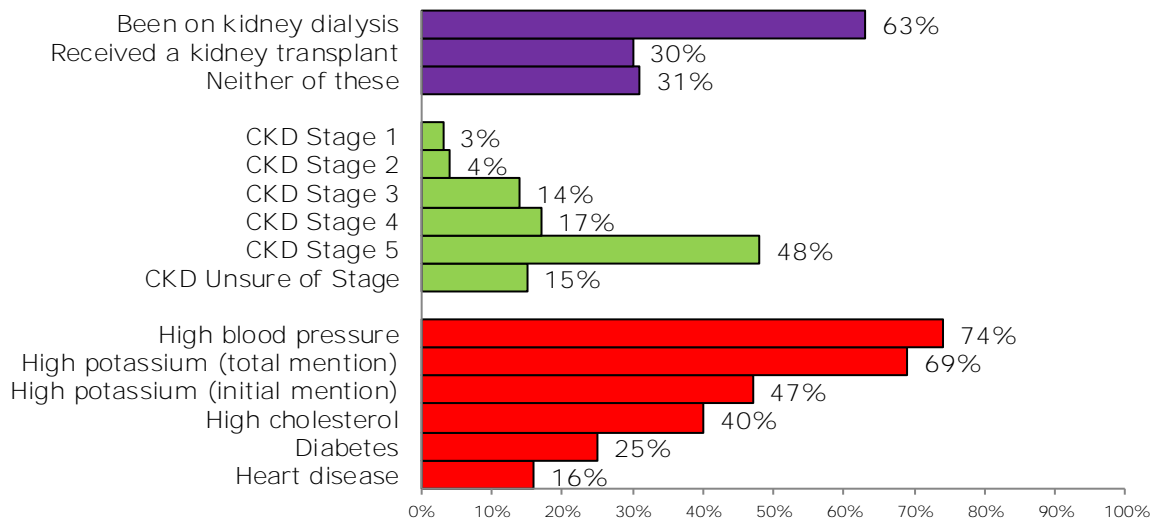
Chart 1: Region of Respondents vs. U.S. Population



- More than a third of the minorities live in the South (40% vs. 28% of the whites). They are less likely than whites to live in the Midwest (13% vs. 29%) or Northeast (14% vs. 23%).
  - Those who have been living with high potassium for more than five years are more likely to live in the Northeast (32% vs. 17%-25% who have been living with it for less time), making it their top region.
2. Many have experienced other health challenges in addition to the treatments they have undergone related to their CKD. This includes 47% who initially say their doctor has told them at some point that their potassium levels are high, second only to high blood pressure (74%). Almost as many have been diagnosed with high cholesterol (40%). Fewer indicate they have either heart disease (16%) or diabetes (25%). After further questioning about high potassium, a total of 69% indicate they have experienced it at some point. (See page 21 for more details about the hyperkalemia diagnosis.) Half are currently at CKD Stage 5 (48%), although the proportion could be higher as 15% are unsure of the stage of their CKD. Two-thirds (69%) have undergone kidney dialysis (63%), a kidney transplant (30%), or both (26%). Respondent

personal demographic characteristics are outlined on page 37. – *Tables 1-3 & 16-17, Question 1—To make sure we ask you the right questions, has your doctor ever told you that you have one of the following?, Question 2—What stage is your kidney disease?, Question 3—Have you ever experienced either of these?, Question 9—Are your potassium levels currently:, Question 10—Has your doctor ever told you that your potassium level is too high?*

Chart 2: Respondent Characteristics



*Kidney Dialysis/Transplantation*

- More report having been on kidney dialysis who:
  - Have experienced hyperkalemia (71% vs. 43% who do not recall ever being diagnosed with high potassium).
  - Have been recently diagnosed with hyperkalemia (76% vs. 65%-68% who have been living with it for at least a year).
  - Have required emergency care for high potassium (77% vs. 68% who have not required such care despite being diagnosed with it).
  - Are “very aware” of the heart risk associated with high potassium (70% vs. 42% no more than somewhat aware of the heart risk).
  - View hyperkalemia as a short-term issue (71% vs. 57% who do not list it as short-term).
  - Identify as a racial or ethnic minority (75% vs. 58% of whites).
  - Have Stage 5 CKD (83% vs. 22% in Stages 1-3 and 37% in Stage 4) or unsure of the Stage (82%).
  - Have received a kidney transplant (78% vs. 63% of all CKD patients).

- More report having received a kidney transplant who:
  - Have experienced hyperkalemia (35% vs. 10% who do not recall ever being diagnosed with high potassium).
  - Have lived with hyperkalemia for more than five years (49% vs. 31%-34% diagnosed within the past five years).
  - Have required emergency care for high potassium (40% vs. 33% who have not required such care despite being diagnosed with it).
  - Are familiar with the term “hyperkalemia” and what it means (37% vs. 25% who are not familiar with the term).
  - View hyperkalemia as a short-term issue (38% vs. 26% who do not).
  - Are female (35% vs. 23% of males).
  - Are under 55 years of age (43% vs. 17% who are older).
  - Have been on kidney dialysis (38% vs. 30% of all CKD patients).
  - Are unsure of their CKD Stage (53% vs. 16%-20% in Stages 1-3 and 33% in Stage 5).

*CKD Stage*

- More are in Stage 5 who:
  - Have experienced hyperkalemia (55% vs. 33% who do not recall ever being diagnosed with high potassium). At the other extreme, a total of 15% of those diagnosed with hyperkalemia are in Stages 1-3 (vs. 34%).
  - Have experienced a kidney transplant or dialysis (64% among dialysis patients and 52% among transplant vs. 16% when neither of these). At the other extreme, a total of 8% who have undergone dialysis and 14% a kidney transplant are in Stages 1-3 (vs. 49%).
  - Are familiar with the term “hyperkalemia” and what it means (56% vs. 41% who are not familiar with the term). At the other extreme, a total of 19% (vs. 24%) familiar with the term are in Stages 1-3.
  - Are “very aware” of the heart risk associated with high potassium (56% vs. 26% no more than somewhat aware of the heart risk). At the other extreme, a total of 16% “very aware” are in Stages 1-3 (vs. 34%).
  - View hyperkalemia as a short-term issue (62% vs. 40% who do not list it as short-term). At the other extreme, a total of 12% seeing it as short-term are in Stages 1-3 (vs. 36%).

*Initial Mention of High Potassium*

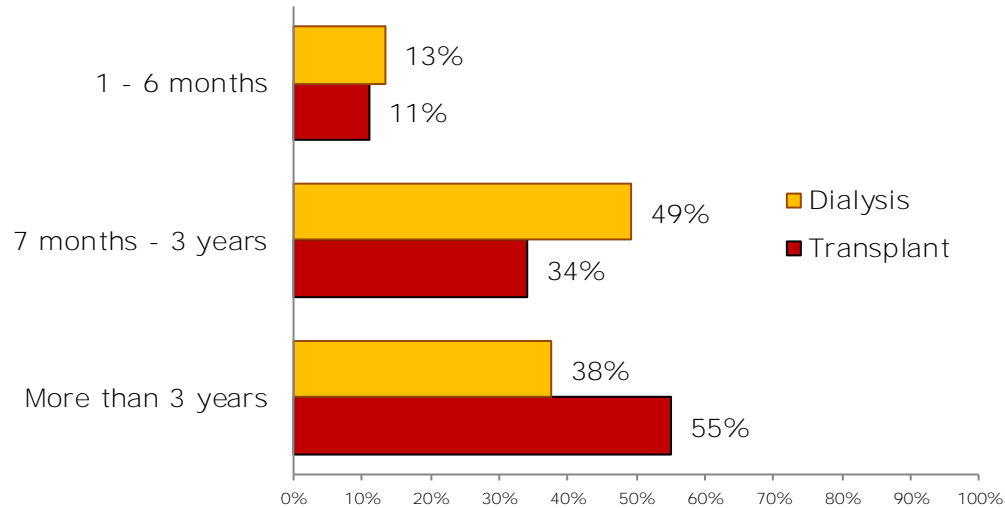
- Initial mention of high potassium is more common by those who:
  - Are **“extremely concerned” about their potassium levels** (74% vs. 47% of all CKD patients).
  - Have lived with hyperkalemia longer, rising from 57% when diagnosed within the past year, 74% when 1-5 years ago, and 81% when more than 5 years ago.
  - Have required emergency care for high potassium (77% vs. 60% who have not required such care despite being diagnosed with it).
  - Have Stage 4 or 5 CKD (48%-51% vs. 37% in an earlier stage).
  - Have experienced a kidney transplant or dialysis (51% among dialysis patients and 61% among transplant vs. 37% when neither of these).
  - Are **familiar with the term “hyperkalemia” and what it means** (54% vs. 40% who are not familiar with the term).
  - Are **“very aware” of the heart risk associated with high potassium** (53% vs. 29% no more than somewhat aware of the heart risk).
  - White (50% vs. 37% of minorities).

*Mention of Other Health Issues*

- Almost twice as many CKD patients who have experienced hyperkalemia mention that they have heart disease (19% vs. 11% who say they have not been diagnosed with high potassium).
- Those who have received a transplanted kidney are less likely to mention having been told they had either heart disease or diabetes (11% mention heart disease vs. 17% who have not had a kidney transplant; 14% mention diabetes vs. 25%-27% who have not had a kidney transplant).
- More men than women say they have diabetes and heart disease (30% vs. 21% for diabetes; 21% vs. 13% for heart disease).
- More who are age 55 or older report having diabetes and heart disease (30% vs. 19% for diabetes; 22% vs. 10% for heart disease).
- Diabetes is reported most often in the South and least often in the West (32% in the South, 14% in the West, and 25% elsewhere). Even in the South, however, diabetes is reported less often than either high blood pressure (76%), high potassium (46%), or high cholesterol (41%).

3. Relatively few are new to kidney dialysis or transplantation (11%-13% of those who have experienced either). Most who have been on dialysis report it has been for at least 7 months (87%); 38% say it has been more than three years. Similarly, 89% who have received a kidney transplant received their most recent one at least 7 months ago, including the 55% who say it was more than three years ago. – Tables 4-5, Question 4—How long have you been on kidney dialysis?, Question 5—How long ago did you last receive a transplanted kidney?

Chart 3: Experience with Kidney Dialysis & Transplant  
Among those Who Have Experienced Them

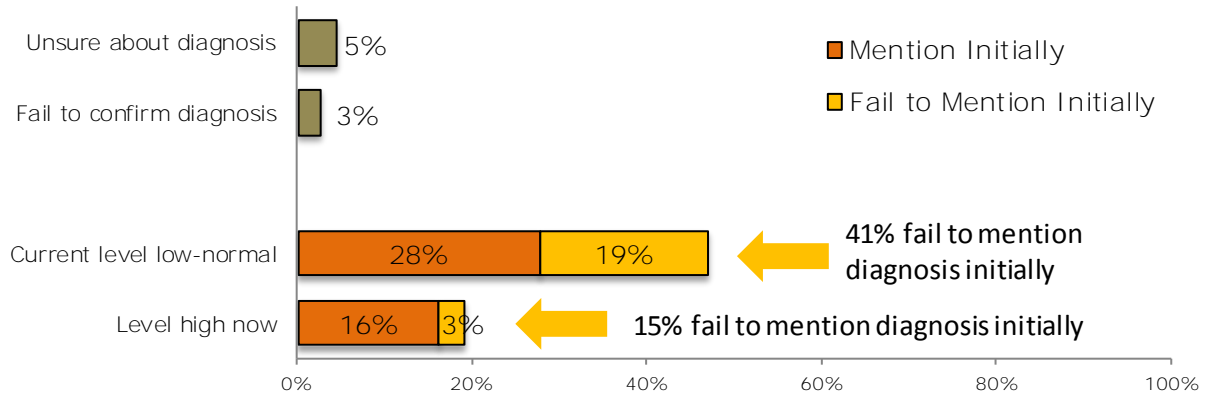


- One in six under the age of 55 who have undergone kidney dialysis have been on it for less than seven months (17% vs. 7% when older).
- More have spent longer than three years on kidney dialysis who:
  - Have Stage 5 CKD (43% vs. 23%-28% in an earlier stage).
  - Have lived with hyperkalemia for more than five years (56% vs. 33% when less than one year and 44% when 1-5 years). Just 5% (vs. 9%-15%) report their kidney dialysis began within the past six months.
  - Have never required emergency care for their high potassium (43% vs. 37% who have required such care at least once). Just 9% (vs. 15%) report their kidney dialysis began within the past six months.
  - Are familiar with the term “hyperkalemia” and what it means (43% vs. 31% who are not familiar with the term). Just 9% (vs. 17%) report their kidney dialysis began within the past six months.
  - Are “very aware” of the heart risk associated with high potassium (40% vs. 22% no more than somewhat aware of the heart risk). Just 10% (vs. 26%) report their kidney dialysis began within the past six months.

*General Awareness of Hyperkalemia*

1. High potassium is not necessarily top-of-mind, even among those who have been diagnosed with it. A total of 5%-8% of the CKD patients are unsure whether their potassium levels have ever been high. Another 22% of all CKD patients fail to recall their hyperkalemia diagnosis without additional prompting. For example, 15% of the CKD patients whose potassium levels are currently high do not think to mention their high potassium diagnosis until questioned further. Recall is even lower when potassium levels are no longer high—41% of them need additional prompting to recall having had hyperkalemia (representing 19% of all CKD patients). (More on incidence is on page 20.) – *Tables 1 & 16-17, Question 1—To make sure we ask you the right questions, has your doctor ever told you that you have one of the following?, Question 9—Are your potassium levels currently:, Question 10—Has your doctor ever told you that your potassium level is too high?*

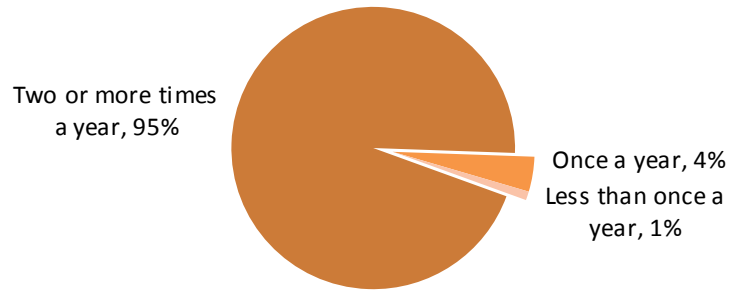
Chart 4: Recall of Hyperkalemia Diagnosis



- Two-thirds of the CKD patients who indicate at any point that they have been diagnosed with high potassium mention it when first asked (68%).
  - Nearly all unsure about their diagnosis have bloodwork done at least once a year (96%) if not more often (88% say at least twice a year).
2. Nearly all report being tested at least twice a year (95%), giving their doctor the opportunity to discover hyperkalemia. Still, 1% say their doctor typically orders bloodwork or lab tests less than annually. – *Table 26, Question 18—How often does your doctor typically order bloodwork or lab tests for you?*
    - Twice a year testing is universal among those diagnosed within the past year and those who have ever required emergency care due to high potassium as well as those who say they have tried more frequent lab tests to address their hyperkalemia (100%). Multiple lab tests a year are also essentially universal among those who are extremely concerned about high potassium (99%).

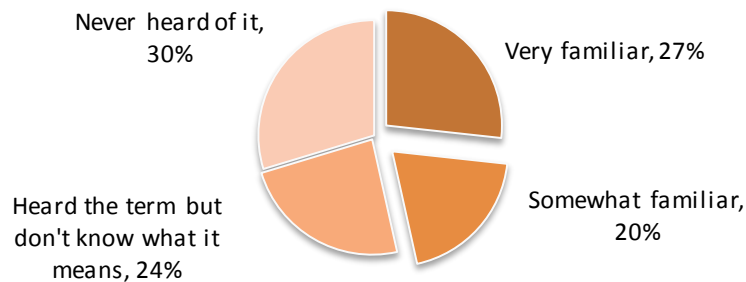


Chart 5: Lab Testing Frequency



- Testing is a little less frequent when:
    - Never experienced hyperkalemia (88% vs. 98% who have been diagnosed with it are tested two or more times a year), with 11% reporting they are tested once a year.
    - Never undergone dialysis or a transplant (91% vs. 97% who have undergone these treatments are tested two or more times a year), with 9% reporting they are tested once a year.
    - CKD is Stage 1-3 or they are unsure of the Stage (90% vs. 98% Stage 4-5 are tested two or more times a year), with 7%-9% reporting they are tested once a year.
3. Half admit they are not really familiar with the term “hyperkalemia” (53%), including 30% who say they have “never heard of it.” Just 27% claim to be “very familiar” with the term and what it means. – Table 6, Question 6—How familiar are you with the term “Hyperkalemia” and what it means?

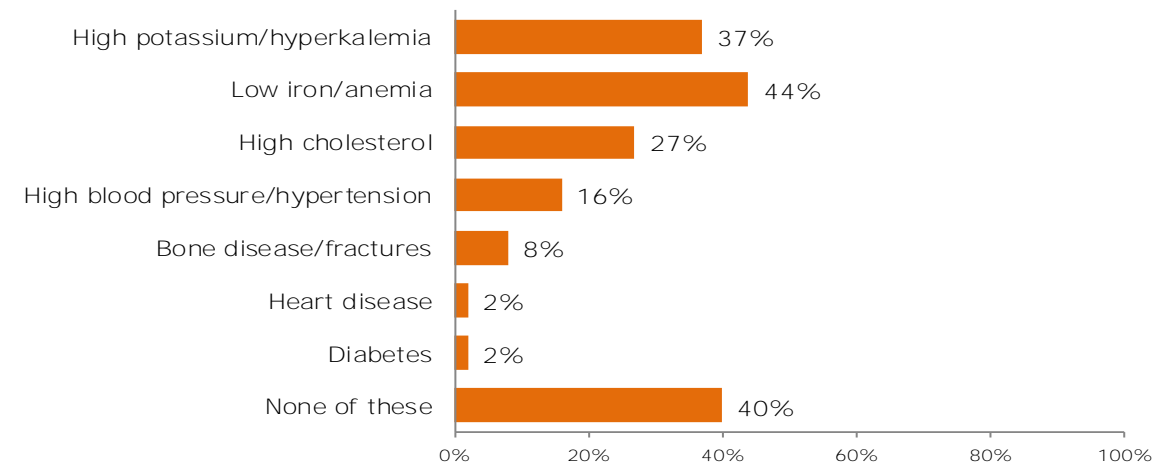
Chart 6: Familiarity with the Term Hyperkalemia



- Only half of the CKD patients who have been diagnosed with high potassium are familiar with the term “hyperkalemia” (51%), including the 30% of them who are “very familiar” with the term. This compares to just 37% familiarity (and 19% “very familiar”) among those who have never experienced hyperkalemia. Those who have not experienced it are as likely to say they have never heard of it (36%) as be at least “somewhat familiar” with the term and what it means (37%).

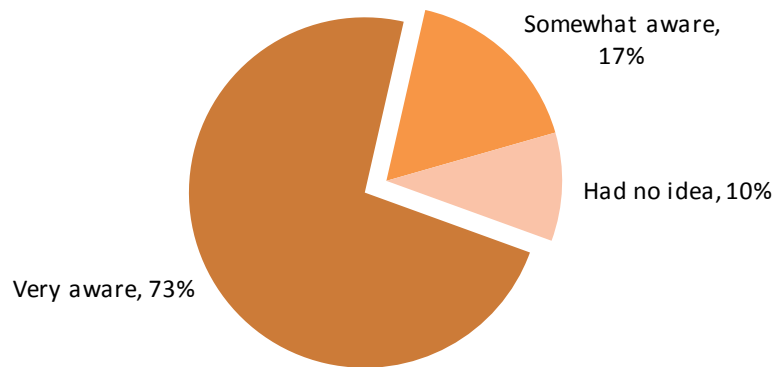
- One-third of those who have been dealing with high potassium for more than five years are not familiar with the term “hyperkalemia” (35%), including 16% who have never even heard the term. Familiarity is even lower among those more recently diagnosed (44%-52%, with 26%-34% never having heard the term).
  - Familiarity is higher among those who:
    - Are “very aware” of the heart risk associated with high potassium (55% vs. 20% no more than somewhat aware of the heart risk). Yet 23% of them (vs. 49% less aware of the heart risk) have never heard the term.
    - Have required emergency care for high potassium (63% vs. 44% for those who have not). Yet 19% of them (vs. 34% when high potassium has not required emergency care) have never heard the term.
    - Have experienced a kidney transplant or dialysis (49% among dialysis patients and 57% among transplant vs. 39% when neither of these). Yet 24% of transplant recipients and 30% who have undergone dialysis (vs. 33% experiencing neither) have never heard the term.
    - Have Stage 5 CKD (55% vs. 35%-41% in an earlier stage). Yet 25% of them (vs. 32%-40% Stage 1-4) have never heard the term.
4. One-third consider elevated potassium to be a short-term issue (37%) along with anemia (44%). By comparison, just 2% see either heart disease or diabetes as a short-term issue and only 8% see bone disease/fractures as a short-term issue. High cholesterol (27%) and hypertension (16%) fall in between. Almost half (40%) feel all of these are long-term health issues. – *Table 15, Question 8—Some health issues are short-term (sometimes called acute) and others are more life-long or long-term (sometimes called chronic). Which of these health issues do you consider to be short-term?*

Chart 7: Health Issues Seen as Short-term



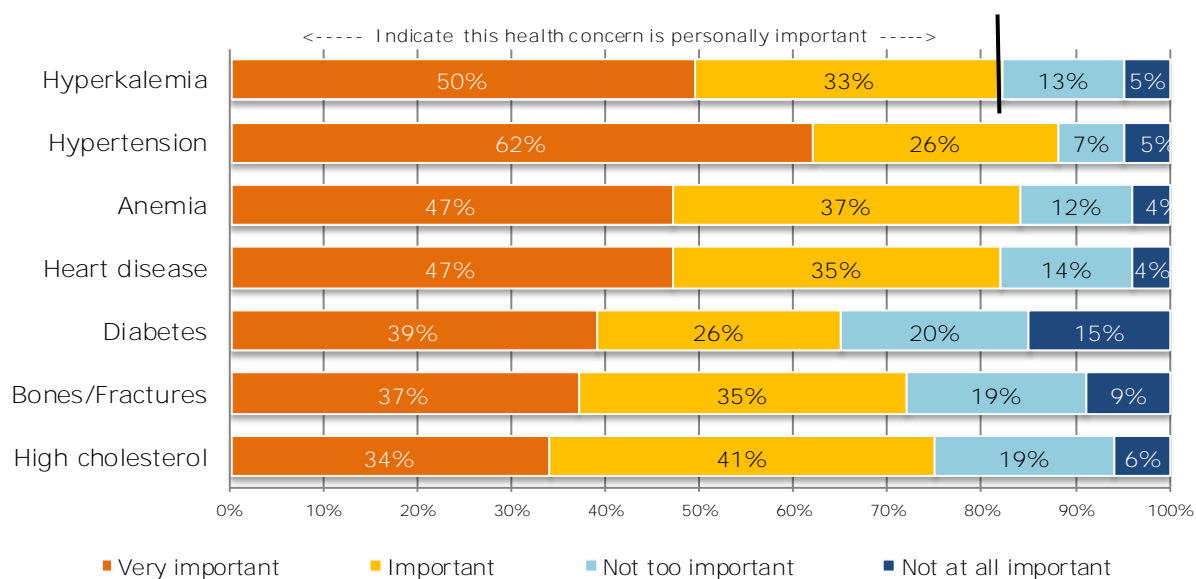
- Minorities are as likely to see high cholesterol as a short-term issue as high potassium (37%-40%). Just 24% of whites see high cholesterol as short-term.
  - Patients tend to share comparable views on health issues other than hyperkalemia, with each subgroup generally having about the same proportion seeing each issue as short-term as other subgroups.
  - One-quarter of the patients who are “extremely concerned” about hyperkalemia see it as a short-term issue (27%) compared to the 37% that is typical of all CKD patients.
  - More identify hyperkalemia as a short-term issue who:
    - Have experienced hyperkalemia (41% vs. 29% who do not recall ever being diagnosed with high potassium).
    - Have been newly diagnosed with hyperkalemia (46% who have been living with it for less than a year vs. 33%-37% when longer).
    - Are “very aware” of the heart risk associated with high potassium (40% vs. 28% no more than somewhat aware of the heart risk).
    - Have undergone a kidney transplant or dialysis (42% among dialysis patients and 47% among transplant vs. 24% when neither of these). Transplant patients are also more likely than the average CKD patient to see anemia (52%) and high cholesterol (35%) as short-term.
    - Have Stage 5 CKD (48% vs. 22%-30% in an earlier stage), about the same proportion as cite anemia as short-term (50% vs. 35%-39% in CKD Stages 1-4).
    - Are under the age of 55 (45% vs. 29% older). More under the age of 55 also see anemia (51% vs. 35% aged 55 or older), high cholesterol (34% vs. 21%), and hypertension (23% vs. 10%) as short-term.
  - Those who see hyperkalemia as short-term make above-average mention of three other issues being short-term: anemia (76% vs. 44% of all patients), high cholesterol (49% vs. 27%), and hypertension (33% vs. 16%).
5. Three-quarters claim to be “very aware” of the serious heart risks associated with high potassium levels (73%) and another 17% are “somewhat aware.” Still, 10% admit they had no idea about this risk. – Table 27, Question 19—Are you aware that high potassium levels can lead to serious heart risks?
- One in twenty “extremely concerned” about their potassium levels had no idea about the serious heart risks (5%), although most are “very aware” (89%).

Chart 8: **Awareness of Hyperkalemia’s Serious Heart Risk**



- More are aware of the associated heart risks who:
    - Are familiar with the term “hyperkalemia” and what it means (88% vs. 61% who are not familiar are “very aware” and just 3% vs. 15% had no idea of the heart risk).
    - Have experienced hyperkalemia (83% vs. 53% not diagnosed with hyperkalemia are “very aware” and just 6% vs. 18% had no idea of the heart risk).
    - Have required emergency care for high potassium (94% vs. 76% of those who have not are “very aware” and just 2% vs. 8% had no idea of the heart risk).
    - Have Stage 5 CKD (86% vs. 57%-65% in an earlier stage are “very aware” and just 4% had no idea vs. 20% in Stages 1-3 and 11% in Stage 4 or unsure of their Stage).
    - Have undergone a kidney transplant or dialysis (82% of dialysis patients and 78% of transplant are “very aware” vs. 55% when experienced neither of these). Just 4%-6% who have undergone either kidney dialysis or transplantation had no idea of the risk (vs. 21% who have experienced neither of these kidney treatments).
  - One in twenty CKD patients have no idea about either their current potassium levels or the heart risk associated with high potassium (5%).
6. More than three-quarters say that high potassium is an important health concern to them personally (83%), including 50% who say hyperkalemia is “very important.” A like number see anemia/low iron (84%) and heart disease (83%) as personally important. Even more indicate that high blood pressure/hypertension is important (88%, including 62% who say “very important”). While fewer say diabetes, bone disease/fractures, and high cholesterol are personally important to them (65%-74%), they are still “very important to 34%-39% of the CKD patients. – Tables 7-14, Question 7—How important are each of these health concerns to you personally?”

Chart 9: Personal Importance of Various Health Concerns



#### *High Potassium/Hyperkalemia*

- Minorities are more likely to say hyperkalemia is “very important” to them personally (58% vs. 47% of whites); a total of 87% (vs. 81% of whites) see it as important.
- Importance is higher for those who:
  - Have experienced hyperkalemia (91% vs. 66% who do not recall ever being diagnosed with high potassium), with 59% (vs. 31%) saying it is “very important.”
  - Are “extremely concerned” about their potassium levels (98% compared to the norm of 83%), with 80% saying “very important.”
  - Have required emergency care for high potassium (96% vs. 88% of those who have not), with 73% (vs. 51%) saying “very important.”
  - Have been living with hyperkalemia for no more than five years (92%-94% vs. 84% when longer). Yet the proportion who say hyperkalemia is “very important” to them personally increases with time, from 54% who have lived with it for less than one year to 62% who have lived with it 1-5 years and 68% who have lived with it longer.
  - Are “very aware” of the heart risk associated with high potassium (88% vs. 69% no more than somewhat aware of the heart risk).
  - Have Stage 5 CKD (88%), particularly compared to those with Stages 1-3 (76%). Hyperkalemia is “very important” to 58% in Stage 5 compared to 36% in Stages 1-3.

*High Blood Pressure/Hypertension*

- Three-quarters of the minorities say hypertension is “very important” to them personally (72% vs. 58% of whites) and a total of 92% (vs. 86% of whites) see it as important.
- Importance is higher for those who:
  - Have experienced hyperkalemia (91% vs. 82% not diagnosed with hyperkalemia).
  - Say hyperkalemia is also important to them personally (91% vs. 76% who do not see hyperkalemia as important).
  - Have undergone a kidney transplant (93%vs. 87%-88% who have not).
  - Have Stage 4 CKD (95% vs. 84% in Stages 1-3 and 87%-89% in Stage 5 or unsure of their Stage).
  - Are not familiar with the term “hyperkalemia” and what it means (91% vs. 85% who are familiar with the term).

*Low Iron/Anemia*

- Importance is higher for those who:
  - Have experienced hyperkalemia (87% vs. 77% who do not recall ever being diagnosed with high potassium).
  - Have been required to seek emergency care for high potassium (91% vs. 86% of those who have not).
  - Are “very aware” of the heart risk associated with high potassium (87% vs. 75% no more than somewhat aware of the heart risk).
  - Say hyperkalemia is also important to them personally (90% vs. 57% who do not see hyperkalemia as important), with 53% (vs. 22%) saying **anemia is “very important.”**
  - Are “extremely concerned” about their potassium levels (93% compared to the 84% norm), with 62% saying **“very important.”**
  - Have Stage 5 CKD (89%), particularly compared to those with Stages 1-3 (**78%**). **Anemia is “very important” to 53%-56%** in Stages 4-5 compared to 35% in Stages 1-3.
  - Identify as a racial or ethnic minority (90% vs. 82% of whites), with **57% (vs. 42%) saying anemia is “very important” to them personally.**

*Heart Disease*

- Half of those who are “very aware” of high potassium’s heart risk see heart disease as “very important” to them personally (51% vs. 38% who are only somewhat aware of the heart risks associated with high potassium).
- More than half of those who have required emergency care for their hyperkalemia see heart disease as “very important” to them personally (56% vs. 46% who have not required emergency care to address their hyperkalemia).
- Importance is higher for those who:
  - Have experienced hyperkalemia (86% vs. 76% who do not recall ever being diagnosed with high potassium).
  - Have tried to combat their hyperkalemia by exercising more (93% vs. 83% that is typical).
  - Are “extremely concerned” about their potassium levels (91% compared to the 83% norm), **with 56% saying “very important.”**
  - Say hyperkalemia is also important to them personally (87% vs. 61% who do not see hyperkalemia as important), with 53% (vs. 19%) saying heart disease **is “very important”** to them personally.
  - Identify as a racial or ethnic minority (87% vs. 80% of whites), with **57% (vs. 43%) saying heart disease is “very important”** to them.

*Diabetes*

- Half of those who are “very aware” of high potassium’s heart risk see heart disease as “very important” to them personally (51% vs. 38% who are only somewhat aware of the heart risks associated with high potassium).
- More than half of those who have required emergency care for their hyperkalemia see heart disease as “very important” to them personally (56% vs. 46% who have not required emergency care to address their hyperkalemia).
- Importance is higher for those who:
  - Have experienced hyperkalemia (68% vs. 58% who do not recall ever being diagnosed with high potassium).
  - Say hyperkalemia is also important to them personally (71% vs. 37% who do not see hyperkalemia as important), with 44% (vs. 16%) saying **diabetes is “very important.”**

- Tried to combat their hyperkalemia by exercising more (79% vs. 65% that is typical).
- Are “**extremely concerned**” about their potassium levels (73% compared to the 65% norm), with **46% saying “very important.”**
- Are male (71% vs. 61% of females).
- Identify as a racial or ethnic minority (71% vs. 62% of whites), with 50% (vs. 35%) saying diabetes is **“very important” to them personally.**

*Bone Disease/Fractures*

- Almost half in the South see bone disease as “very important” to them personally (44% vs. 31%-33% in other regions).
- Importance is higher for those who:
  - Have experienced hyperkalemia (75% vs. 66% who do not recall ever being diagnosed with high potassium).
  - Are “very aware” of the heart risk associated with high potassium (75% vs. 64% no more than somewhat aware of the heart risk), with 41% (vs. **28%**) saying bone disease is **“very important” to them.**
  - Say hyperkalemia is also important to them personally (80% vs. 36% who do not see hyperkalemia as important), with 43% (vs. 11%) saying **bone disease is “very important” to them personally.**
  - Are “extremely concerned” about their potassium levels (80% compared to the 72% norm), with **49% saying “very important.”**
  - Are female (76% vs. 66% of males).
  - Identify as a racial or ethnic minority (77% vs. 69% of whites), with 51% (vs. 32%) saying bone **disease is “very important” to them.**

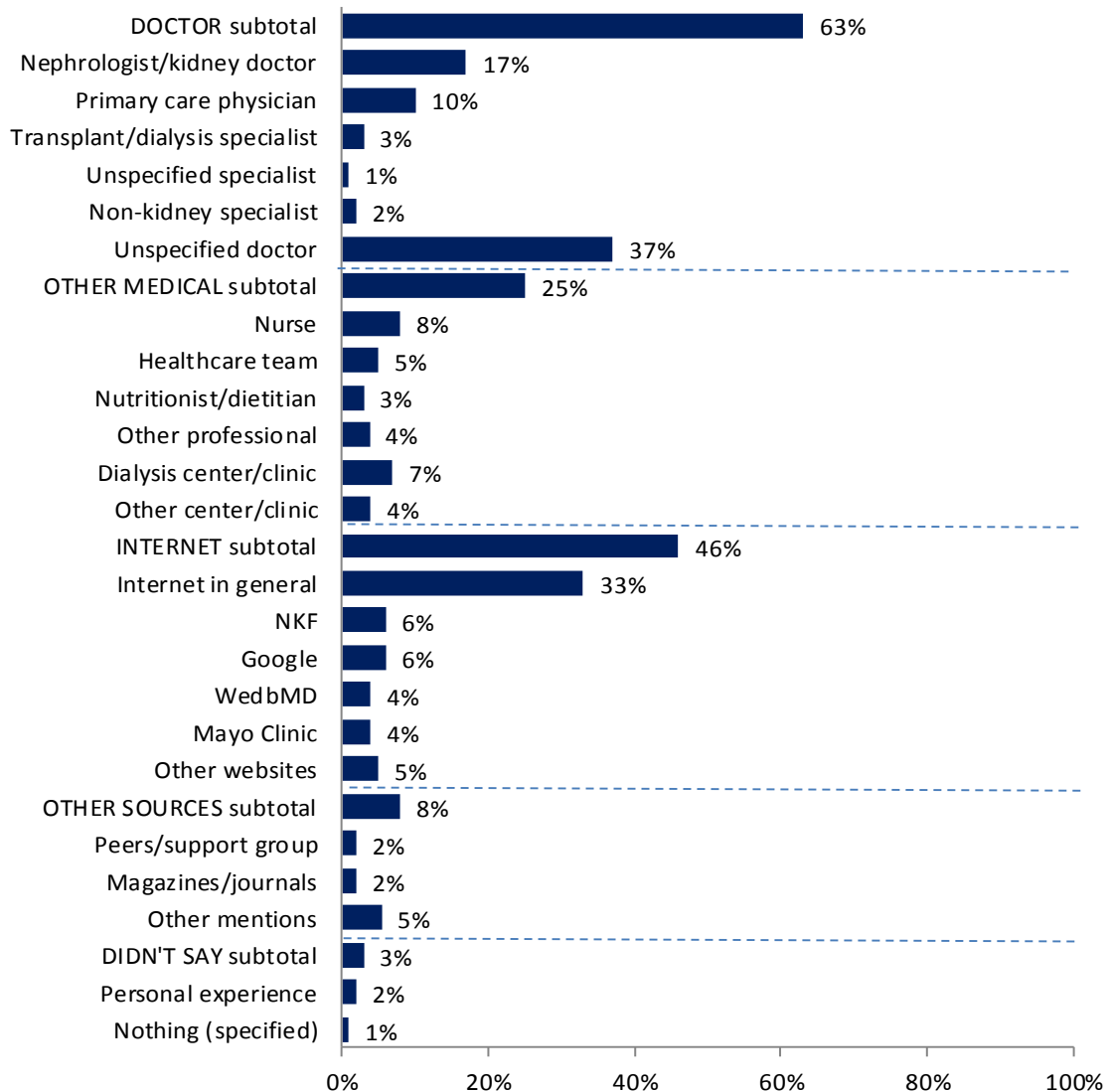
*High Cholesterol*

- Half of the minorities say high cholesterol is “very important” to them personally (49% vs. 29% of whites); a total of 82% (vs. 70% of whites) see it as important.
- More than three-quarters who say high potassium is important to them personally also say the same about high cholesterol (79% vs. 52% who do not see hyperkalemia as important).
- Nine out of ten who have tried to combat their hyperkalemia by exercising more report that high cholesterol is important to them personally (89% vs. 74% that is typical).



7. Most look to their doctor for health information (63%) or to some other medical professional (25%). The most common answer is **“my doctor” (37%)** although others specified their nephrologist (17%) or primary care physician (10%), if not both. Even more may be consulting a doctor when they turn to: their healthcare team (5%), dialysis center/clinic (7%), hospital/medical center (2%), transplant center (1%), kidney center (1%), or personal medical connections (2%). A total of 25% mention some non-physician medical professional such as this. – *Table 28, Question 20—Where do you most likely turn to find health information, such as when you face a health challenge?*

Chart 10: Sources Consulted When Faced with a Health Challenge



- Men are as likely to turn to their primary care physician as their nephrologist (12%-13%) while women are more likely to turn to their nephrologist (21%) rather than to their primary care physician (8%).

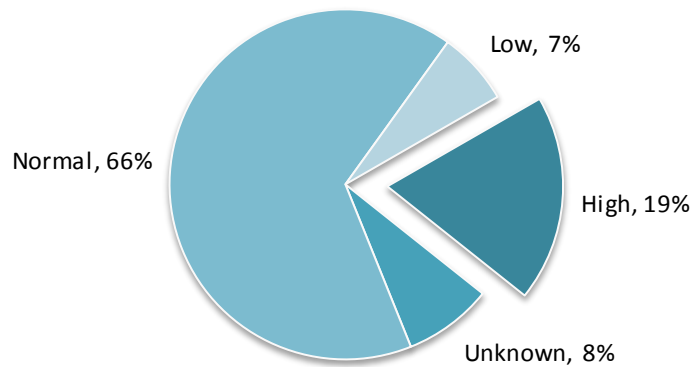
- One-quarter under the age of 55 say they turn to their nephrologist (22%), three times as many as mention their primary care physician (6%). Those who are older, on the other hand, are as likely to say they turn to their primary care physician (14%) as to their nephrologist (12%).
  - **More who are familiar with the term “hyperkalemia” and are “very aware” of its heart risk mention turning to a nephrologist for health information (20%-24% vs. 11%-12% who are not familiar with the term and are no more than “somewhat aware” of the heart risks) rather than to a primary care physician (8% vs. 11%-14% of those less aware).**
8. Half are turning to the Internet, at least in part, for health information (46%), although a number indicate they are very selective in the sites they consult, including 6% who specify they rely on the National Kidney Foundation’s information. The Internet is often seen as a supplement to other sources, with 22%, for example, mentioning both the Internet and their doctor. – Table 28, Question 20—Where do you most likely turn to find health information, such as when you face a health challenge?
- More report turning to the Internet who:
    - **Are no more than “somewhat aware” of high potassium’s heart risks (55% vs. 43% who are “very aware”).**
    - Have never had hyperkalemia (54% vs. 43% whose doctor has told them their potassium level is too high).
    - Have undergone neither kidney dialysis nor transplantation (58% vs. 39% who have had a transplant and 42% who have had dialysis).
9. Few mention consulting other sources (8%) such as support groups (2%) or magazines/journals (2%). – Table 28, Question 20—Where do you most likely turn to find health information, such as when you face a health challenge?

### *Hyperkalemia*

#### Incidence Among CKD Patients

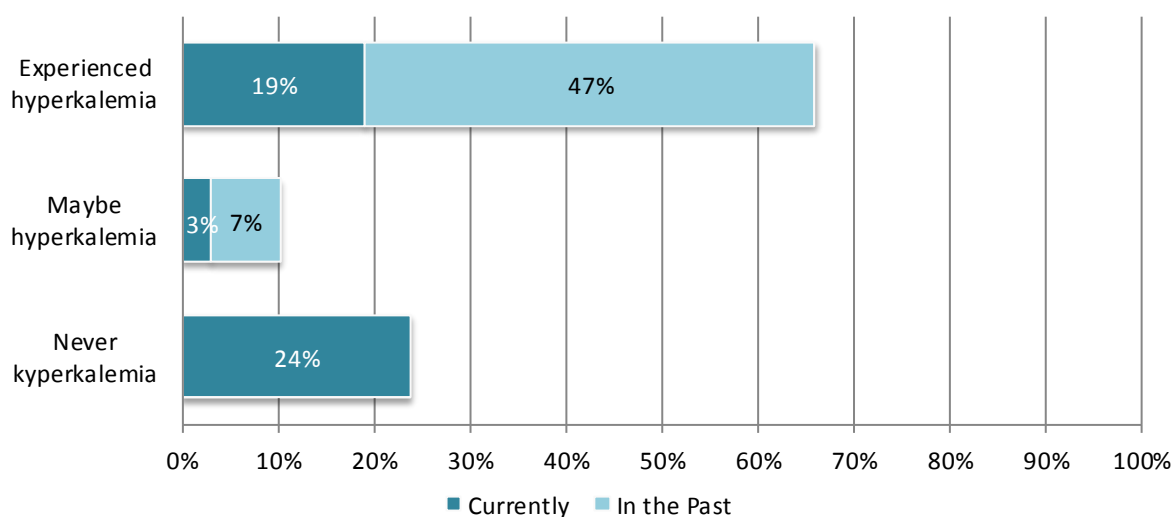
1. At least one in five are currently experiencing hyperkalemia (19%) and possibly as many as 27% (after adding in those who are unsure of their current levels). Most report their potassium levels are currently normal (66%). – Table 16, Question 9—Are your potassium levels currently:

Chart 11: Current Potassium Levels



- More report currently high potassium who:
  - Have been living with hyperkalemia for at least a year (37%-39% vs. 20% who say it has been less than a year).
  - Are “extremely concerned” about their potassium levels (40% compared to the 19% that is typical).
  - Report hyperkalemia is important to them personally (22% vs. 5% who do not see hyperkalemia as important).
  - Have undergone neither kidney dialysis nor transplantation (26% vs. 9% who have had a transplant and 18% who have had dialysis).
  - Have Stage 4 CKD (30% vs. 10%-14% in Stages 1-3 or unsure of their Stage, 21% in Stage 5).
  
- 2. Only one-quarter of the CKD patients consistently indicate that they have not been diagnosed with hyperkalemia (24%). A total of 66% report their potassium levels are either currently high or that they have been high in the past. The remaining 10% either say they are unsure or show their uncertainty by being inconsistent in reporting the high potassium diagnosis by their doctor. A total of 3%, for example, initially say their doctor had told them they had high potassium and then later said that their doctor had never told them that their potassium level is too high. – *Tables 1 & 16-17, Question 1—To make sure we ask you the right questions, has your doctor ever told you that you have one of the following?, Question 9—Are your potassium levels currently:, Question 10—Has your doctor ever told you that your potassium level is too high?*
  
- Residents of the West are a little less likely to have experienced hyperkalemia (60%), particularly when compared to the Northeast and Midwest ( 68%-69%; it is 65% in the South).

Chart 12: Current or Past Experience with Hyperkalemia

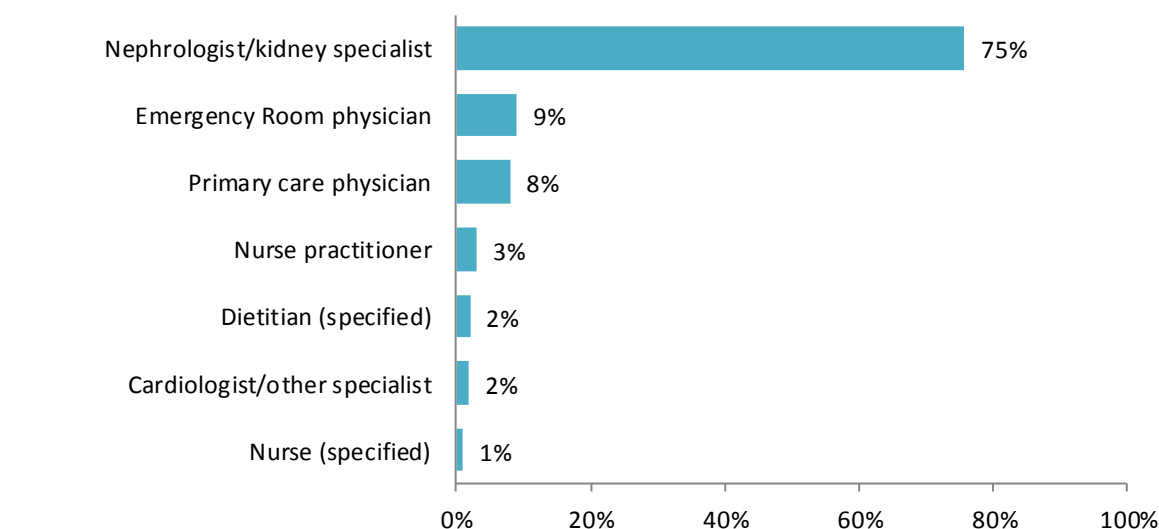


- The incidence of current or past hyperkalemia increases for those who:
  - Are familiar with the term “hyperkalemia” and what it means (73% vs. 60% who are not familiar).
  - Are “very aware” of the heart risk associated with high potassium (75% vs. 42% who are only somewhat aware of the risk).
  - Report hyperkalemia is important to them personally (73% vs. 34% who do not see hyperkalemia as important).
  - Have undergone a kidney transplant or dialysis (75%-78% vs. 48% who have experienced neither kidney transplant or dialysis).
  - Have Stage 5 CKD (76% vs. 47% in Stages 1-3 and 63%-64% in Stage 4 or unsure of their Stage).
  - Identify as white (68% vs. 59% of minorities).

#### Experience of those Diagnosed with Hyperkalemia

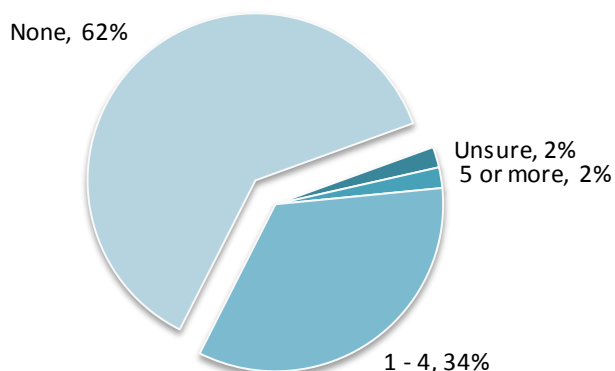
1. Three-quarters of the CKD patients who have been diagnosed with high potassium say it was their nephrologist who first diagnosed the hyperkalemia (75%). Others are as likely to be diagnosed by an emergency room physician (9%) as by their primary care physician (8%). – *Table 19, Question 11—Was the person who first diagnosed you as having high potassium a:*

Chart 13: Who First Diagnosed Their Hyperkalemia



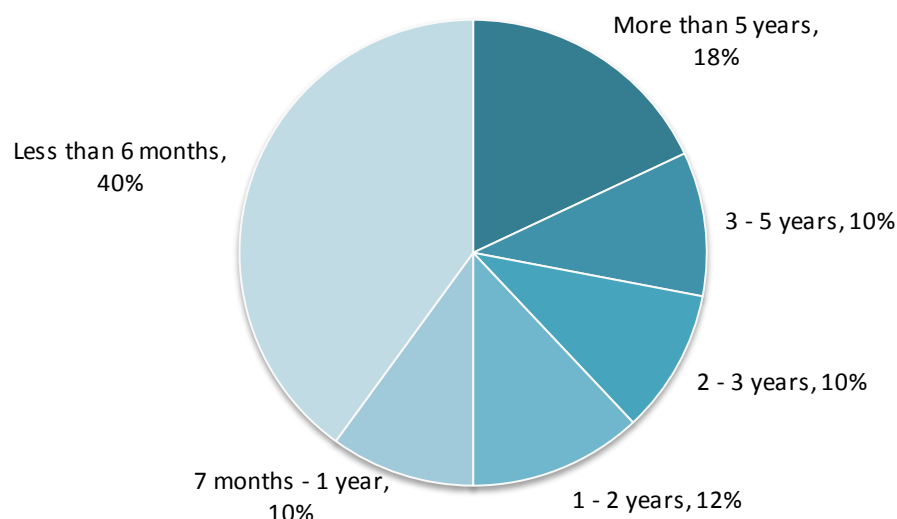
- One in five who have undergone emergency care related to high potassium say their hyperkalemia was first diagnosed by an emergency room physician (20% vs. 3% who have never required emergency care for their hyperkalemia). Even more were first diagnosed by a nephrologist (63% vs. 80% who have not required emergency care for high potassium).
  - One in five who have never had a kidney transplant or dialysis say their hyperkalemia was first diagnosed by their primary care physician (18% vs. 5% who have had either a kidney transplant or dialysis). Even more were first diagnosed by a nephrologist (69% vs. 74%-76%).
  - Men are more likely than women to have their high potassium diagnosed by their primary care physician (13% vs. 5%), although the nephrologist remains the top answer for both men (67%) and women (78%).
  - Primary care physician diagnosis is also more common in the earlier stages of CKD (21% in Stages 1-3 vs. 12% in Stage 4 and 4% in Stage 5), although the nephrologist remains the top answer at all stages (62% in Stages 1-3, 71% in Stage 4, and 76% in Stage 5).
  - Virtually no minorities were diagnosed by their primary care physician (one person or 1% vs. 10% of whites); a total of 84% of the minorities say their hyperkalemia was diagnosed by a nephrologist (vs. 70% of whites).
2. Those who have experienced hyperkalemia rarely report needing emergency care due to high potassium levels, with 62% saying it has never led to emergency care and another 34% suggesting it may have been only one time. Still, 2%-4% have needed emergency care at least five times due to high potassium. – *Table 22, Question 14—How many times, if any, have your potassium levels been so high that you needed emergency care?*

Chart 14: Times Emergency Care Needed Due to High Potassium



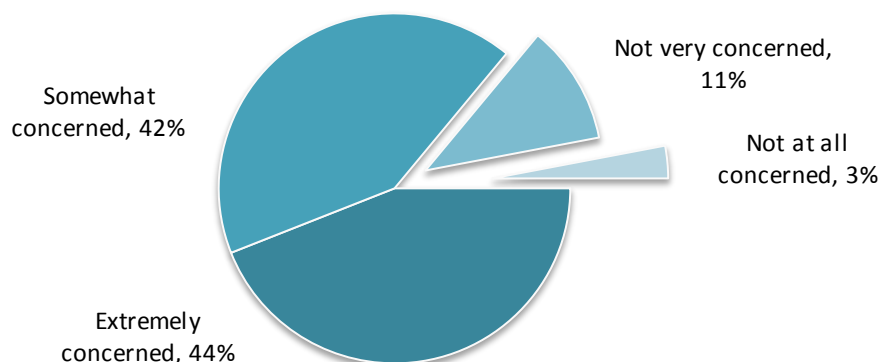
- Half of those who are “extremely concerned” about high potassium have required emergency care to address it (48%), most often 1-4 times (40%), although others say 5 or more times (4%) or are unsure how many (4%).
  - Emergency care is more common for those who:
    - Have lived with hyperkalemia longer, rising from 32% who may have had such care when they have been living with high potassium for less than a year to 41% when it is 1-5 years and 51% when more than 5 years. One in ten (9%) who were first diagnosed more than five years ago are unsure the number of times they have required emergency care due to high potassium (vs. 1%-2% diagnosed more recently).
    - Have undergone a kidney transplant or dialysis (41%-43% indicate emergency care for hyperkalemia vs. 28% who have experienced neither kidney transplant or dialysis).
    - Are familiar with the term “hyperkalemia” and what it means (47% vs. 29% who are not familiar indicate they may have had such care, including 44% vs. 27% who say it was at least once).
    - Are “very aware” of the heart risk associated with high potassium (44% vs. 13% who are only somewhat aware of the risk indicate they may have had such care, including 41% vs. 11% who say it was at least once).
    - Are male (47% vs. 32% of females indicate such care).
    - Identify as minority (48% vs. 37% of whites indicate such care).
3. Half have been living with high potassium for at least a year (50%), including 18% who say it has been more than 5 years. – *Table 20, Question 12—How long have you been living with high potassium?*

Chart 15: Length of Time Living with Hyperkalemia



- More have been living with hyperkalemia in excess of five years who:
    - Are familiar with the term “hyperkalemia” and what it means (22% vs. 13% who are not familiar).
    - Have been required to seek emergency care for high potassium (24% vs. 14% of those who have not required such care).
    - Have undergone a kidney transplant (24% vs. 15%-17% who have never had a kidney transplant). Half (46%) of those who have undergone kidney dialysis say they have only begun experiencing high potassium within the past six months (vs. 37% who have a kidney transplant and 24% who have experienced neither of these treatments).
    - Identify as white (21% vs. 9% of minorities).
    - Reside in the Northeast (26% vs. 13%-14% in the West and South, 19% in the Midwest).
4. Nearly all who have experienced hyperkalemia are concerned about their potassium levels (86% are at least “somewhat concerned”), including 44% who say they are “extremely concerned.” Just 3% are “not at all concerned.” – Table 21, Question 13—How concerned are you about your potassium levels?
- One in five who have had a kidney transplant or dialysis did not express concern about their potassium levels (17%-20% vs. 6% who have undergone neither of these are less than “somewhat concerned”).

Chart 16: Concern about Potassium Levels



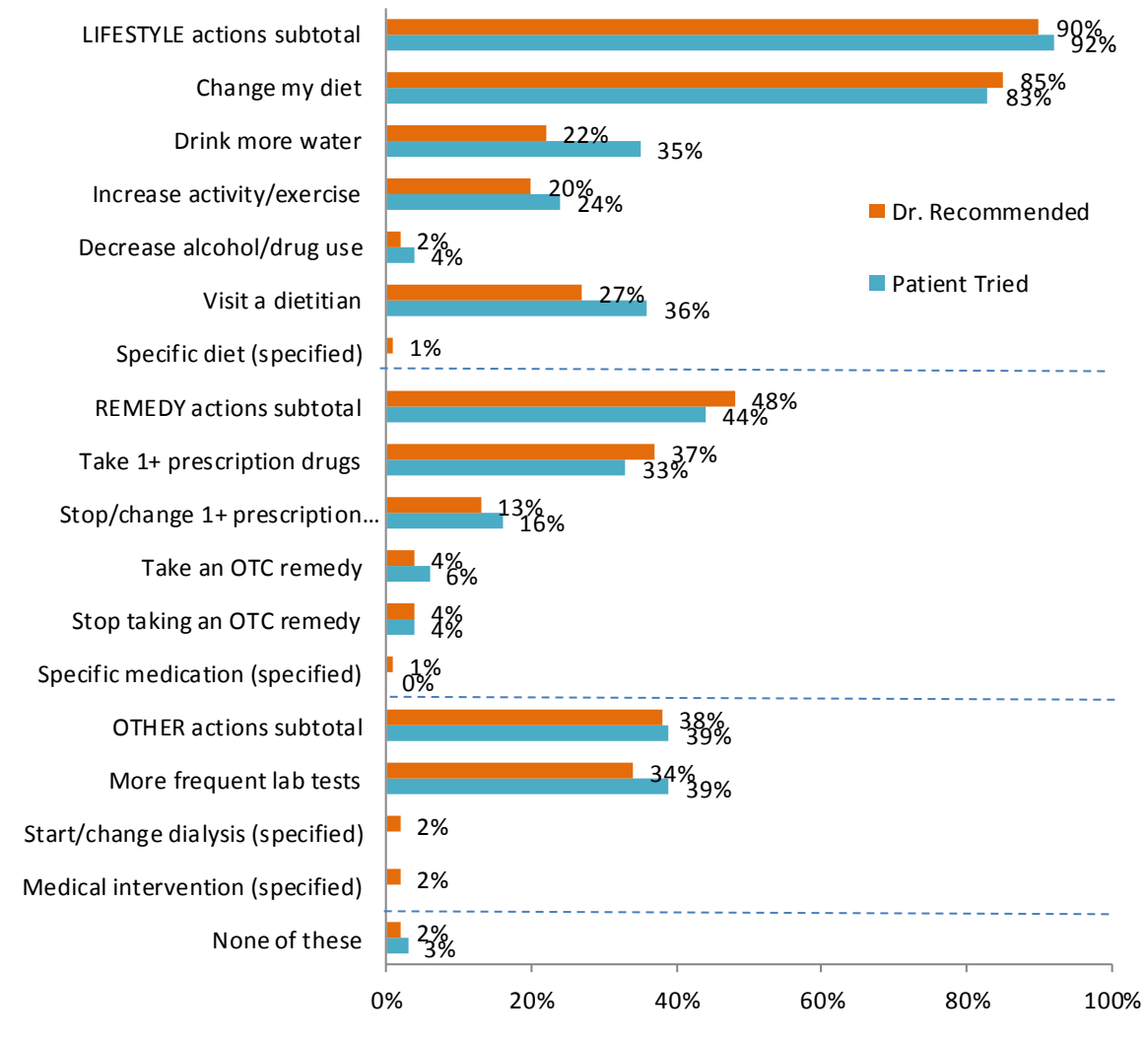
- Extreme concern increases for those who:
    - Have required emergency care for high potassium (55% vs. 37% of those who have not required such care).
    - Are “very aware” of the heart risk associated with high potassium (47% vs. 30% who are only somewhat aware of the risk).
    - Are older than 54 (50% vs. 39% who are younger).
    - Have lived longer with high potassium, rising from 37% when less than one year to 49% dealing with it for 1-5 years and 54% when longer.
    - Do not identify hyperkalemia as a short-term issue (54% vs. 30% who list it as short-term).
5. Half are willing to provide additional insight into their experience with hyperkalemia (54% of those who have experienced it). These 170 people provided their email address for future follow-up. – *Table 33, Question 25—One last special favor: Would you be willing to share you experience with high potassium in greater detail to help other people who might be facing it? Your answer will not impact your receipt of the \$5 Amazon gift card.*

### Approach

1. Nearly all who have experienced hyperkalemia say their doctor recommended they change their diet or make some other lifestyle change (85% recommended a diet change and a total of 90% recommended one or more lifestyle changes). Half of the doctors (48%) made a recommendation that involved a remedy, most often to take one or more prescription drugs (37%). By comparison, 34% of the patients say their doctors recommended more frequent lab tests to monitor their potassium levels. Only 2% of the patients report their doctors did not recommend any action to address the potassium levels. – *Table 23, Question 15—What did your doctor or nurse practitioner recommend you do to address your potassium levels?*



Chart 17: Selected Doctor Recommendations & Patient Actions



- One in ten with Stage 1-3 CKD reported receiving no recommendations for actions to address their high potassium when they talked to their doctor or nurse practitioner (9% vs. 1% who now are in Stage 5 and 4% in Stage 4).

*Lifestyle*

- Only those who have been living with high potassium for 1-5 years were told to decrease their alcohol and recreational drug use (7% of them were given this advice vs. 0% when living with hyperkalemia more or less time). More were also told to increase activity or exercise (28% vs. 16%-18%).
- The earlier the CKD Stage, the more who recall being told to drink more water, falling from 38% in Stages 1-3 to 25% in Stage 4 and 16% in Stage 5.
- One-third of those who are no more than “somewhat aware” of the heart risk were told to drink more water (35% vs. 20% when “very aware”).

- Recommendations to increase water intake and exercise are both given more often to those who have experienced neither kidney transplantation nor dialysis (39% were told to drink more water vs. 17% who have undergone dialysis and 26% a transplant; 32% were told to exercise more vs. 15%-16% when undergone dialysis or transplant).
- Minorities and those under the age of 55 are less likely to be told to increase their activity or exercise more (11% of minorities vs. 22% of whites; 14% less than 55 years of age vs. 26% who are older).

*Remedy*

- More received a recommendation to take a prescription drug who:
  - Are familiar with the term “hyperkalemia” and what it means (44% vs. 30% who are not familiar).
  - Have lived longer with high potassium, rising from 26% when less than one year to 46% dealing with it for 1-5 years and 53% when longer.
  - Have required emergency care for high potassium (51% vs. 28% of those who have not required such care). More of them also were instructed to increase lab testing to monitor it (44% vs. 28% when have not required emergency care for high potassium).
  - Have undergone a kidney transplant or dialysis (40%-43% vs. 29% who have experienced neither kidney transplant or dialysis).

*Other*

- One-third of those who are “extremely concerned” about their potassium levels were told to visit a dietitian (34% vs. 22% when less concerned).
2. Patients are most likely to try lifestyle changes to address their potassium levels (92%), particularly changing their diet (83%). They are almost as likely to have tried more frequent lab tests (39%) as a remedy change (44%). Only 3% of the patients report that they have not taken any action to address the potassium levels. – *Table 24, Question 16—Which of these have you tried so far?*
- One in ten in the West report taking no action to combat high potassium (8% vs. 0%-3% elsewhere).

*Lifestyle*

- Virtually everyone who has not experienced either kidney transplantation or dialysis has made at least one lifestyle change (99% vs. 90%-91% when undergone dialysis or transplant). They are much more likely, for example, to say they have tried drinking more water (65% vs. 25% who have undergone dialysis and 43% a transplant) and exercising more (35% vs. 19% who have undergone dialysis and 23% a kidney transplant), although the top action for all three groups is a diet change (80%-88%).

- Nearly all who are “extremely concerned” about their potassium levels have made at least one lifestyle change (96% vs. 88% when less concerned), most often changing their diet (87% vs. 79%).
- Correlations between lifestyle changes and other actions include:
  - Those who make diet changes are more likely to also visit a dietitian (38% vs. 23% not changing their diet) and exercise more (26% vs. 13%), but are less likely to try a remedy change (41% vs. 57%).
  - Those who drink more water are more likely to also exercise more (39% vs. 15% not drinking more water), stop/change a prescription drug (23% vs. 13%), and get more frequent lab tests (46% vs. 36%).
  - Those who exercise more are more likely to also change their diet (91% vs. 80% who did not exercise more), drink more water (58% vs. 28%), and visit a dietitian (50% vs. 31%). They are less likely to take a new prescription drug (20% vs. 37% who do not exercise more).
  - Those who visit a dietitian are more likely to also change their diet (89% vs. 79% who did not visit a dietitian), exercise more (33% vs. 18%), take an over-the-counter medication/supplement/herb (10% vs. 3%), and decrease alcohol/recreational drug use (7% vs. 2%). They are less likely to take a new prescription drug (26% vs. 37% who have not visited a dietitian).
- Diet changes occur more often among patients who are familiar with the term “hyperkalemia” and what it means (87% vs. 78% unfamiliar).
- Fewer who see high potassium as a short-term issue increased their activity level (17% vs. 28% who see it as longer term).
- The earlier the CKD Stage, the more who have tried to drink more water, falling from 53% in Stages 1-3 to 45% in Stage 4 and 26% in Stage 5.
- More who are less aware of the heart risk have tried to drink more water and less alcohol (52% are drinking more water vs. 32% **when “very aware”**; 9% vs. 3% are decreasing their alcohol and recreational drug use).
- The proportion who have tried to decrease their alcohol and recreational drug use increases as they live longer with high potassium, rising from 1% diagnosed within the past year to 6% living with hyperkalemia 1-5 years and 9% living with it longer.
- Only whites say they have tried to decrease their alcohol and recreational drug use (5% mention it).

*Remedy*

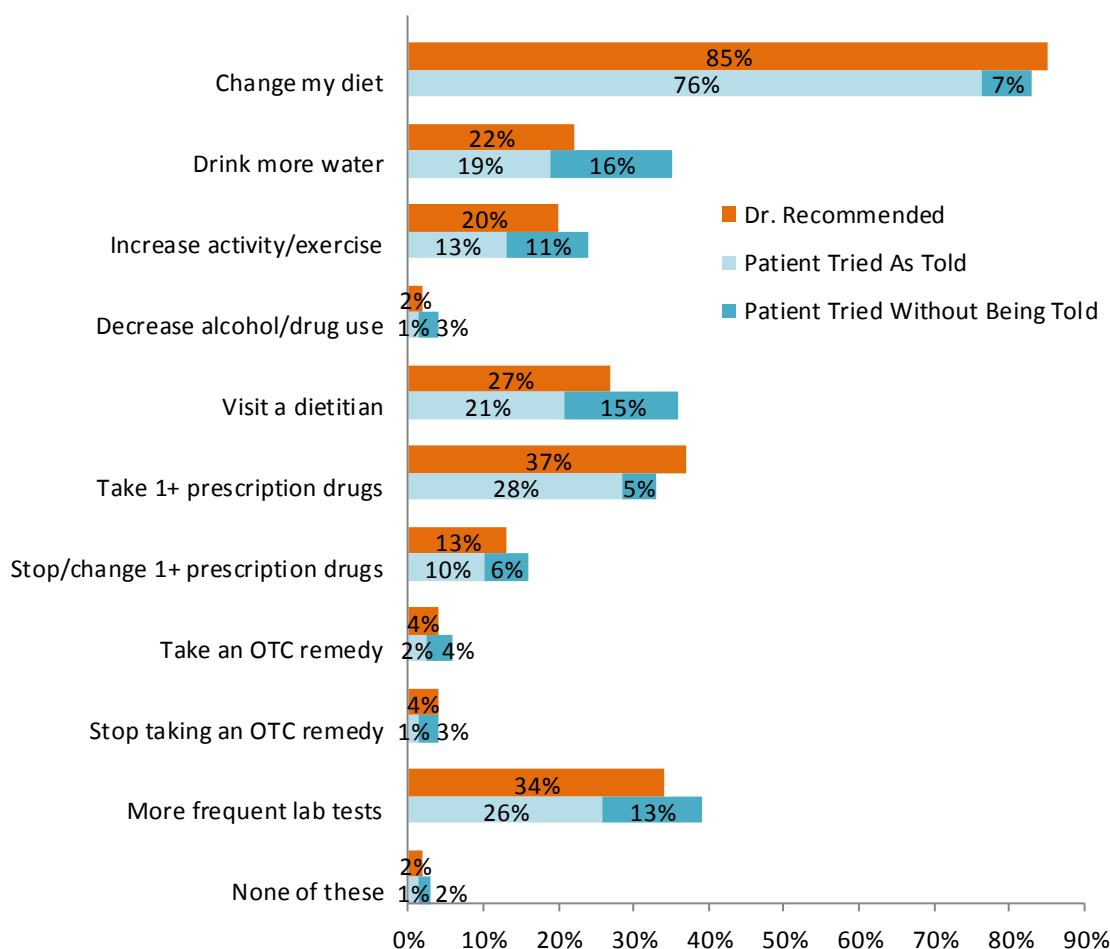
- More than half who have been living with high potassium for more than a year have taken a remedy-related action (56% vs. 32% diagnosed within the past year), most notably taking one of more prescription drugs (41%-47% vs. 24%) and stopping or changing one or more prescription drugs (23%-24% vs. 9%).
- Remedy approaches are less common among those who have not experienced either kidney transplantation or dialysis. They are less likely to have tried taking a prescription drug (25% vs. 36%-37% when undergone dialysis or transplant) and more likely to have stopped taking an over-the-counter medication, supplement, or herb (10% vs. 2%-3%).
- Correlations between remedy changes and other actions include:
  - Those who add a prescription drug are more likely to also increase their lab frequency (47% vs. 36% not adding a prescription drug), stop or change a prescription drug (26% vs. 12%), take an over-the-counter medication/supplement/herb (12% vs. 2%), and decrease alcohol/recreational drug use (7% vs. 2%). They are less likely to change their diet (78% vs. 85% with no new prescription drug), visit a dietitian (28% vs. 40%), or exercise more (14% vs. 28%).
  - Those who change a prescription drug are more likely to also increase their lab frequency (64% vs. 35% not changing a prescription drug), add a prescription drug (53% vs. 29%), drink more water (49% vs. 33%), take an over-the-counter medication/supplement/herb (19% vs. 3%), stop taking an over-the-counter medication/supplement/herb (9% vs. 3%), and decrease alcohol/recreational drug use (9% vs. 3%).
  - Those who make a change in their over-the-counter medications, supplements, or herbs are more likely to also increase their lab frequency (56% vs. 39% without an OTC change), add a prescription drug (56% vs. 31%), stop or change a prescription drug (47% vs. 13%), and decrease alcohol/recreational drug use (16% vs. 2%).
- One in ten with Stage 1-3 CKD discontinued an over-the-counter medication, supplement, or herb to combat high potassium (11% vs. 0%-4% in later stages).
- More in the West began taking an over-the-counter medication, supplement, or herb to combat high potassium (12% vs. 1% in the Northeast and 4%-7% elsewhere).
- Both new prescriptions and increased testing are undertaken more often when emergency care has been required (42% vs. 28% who have never

required emergency care for their high potassium have tried at least one new prescription drug; 50% vs. 33% have gotten more frequent tests).

*Other*

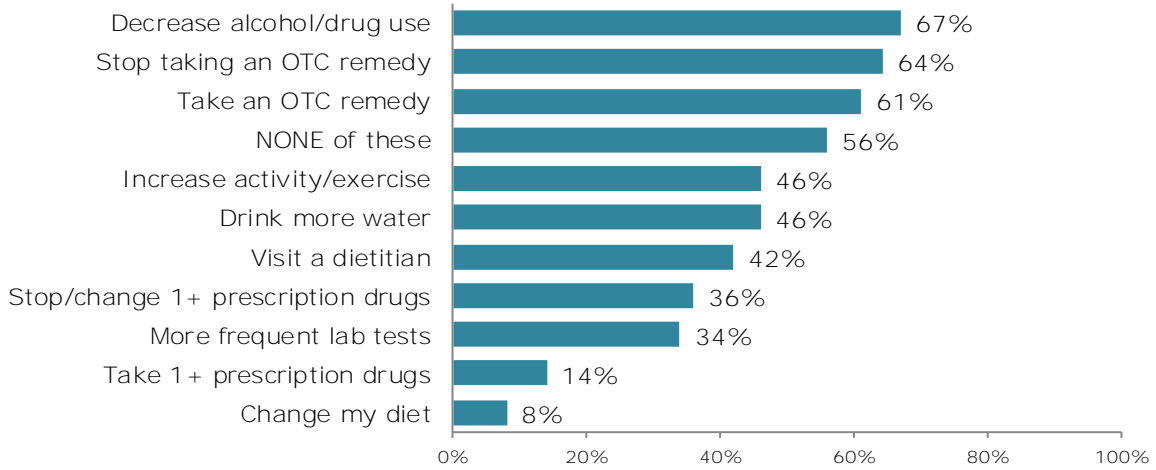
- Men are more likely than women to try more frequent lab tests to monitor their potassium levels (47% vs. 33%).
  - More who are older have increased lab frequency (46% vs. 31% under 55).
  - Half of those who increased lab frequency also made a remedy change (53% vs. 38% who have not increased lab frequency), including add a new prescription drug (39% vs. 29%), stop or change a prescription drug (27% vs. 10%), and take an over-the-counter medication, supplement or herb (9% vs. 3%). They are also more likely to drink more water (42% vs. 31% who have not increased lab frequency) and decrease alcohol/recreational drug use (6% vs. 2%).
3. When faced with high potassium, CKD patients are sometimes taking actions beyond doctor recommendation. A total of 35%, for example, have tried to drink more water, although only 22% say their doctor recommended this action. More also visited a dietitian (36%) than received the recommendation **to do so (27%)**. They also “over-achieved” on increasing the frequency of lab test (39% tried vs. 34% recommendation) and exercise (24% tried vs. 20% recommendation). – Tables 23-24, Question 15—*What did your doctor or nurse practitioner recommend you do to address your potassium levels?*, Question 16—*Which of these have you tried so far?*
  4. Even when more doctors are recommending an action than there are patients taking that action, there are still some patients taking the action without receiving a recommendation from their doctor to do so. A total of 7% of all the CKD patients diagnosed with hyperkalemia, for example, have changed their diet without receiving a specific recommendation to do so by their doctor, representing 8% of the 83% of patients who have tried changing their diet. Similarly, 5% of those diagnosed with hyperkalemia have tried at least one new prescription drug to address their high potassium (or 36% of the 33% who have taken this action). – Tables 23-24, Question 15—*What did your doctor or nurse practitioner recommend you do to address your potassium levels?*, Question 16—*Which of these have you tried so far?*

Chart 18: Whether Actions Are Based on Doctor Recommendations



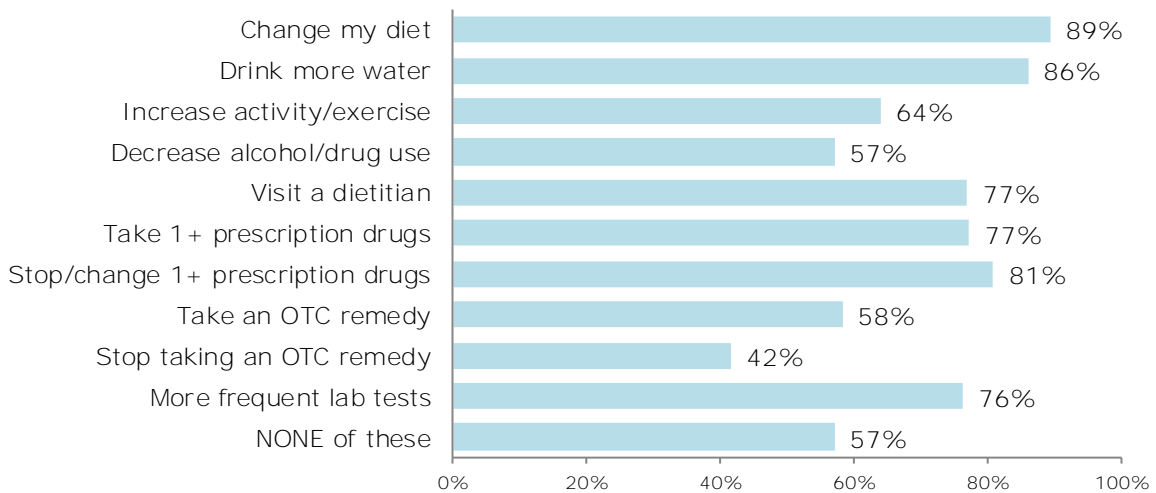
5. Looking at it another way, two-thirds of the patients who decreased their use of alcohol and over-the-counter remedies did so without their doctor’s specific recommendation (64%-67%). Half or more who tried taking an over-the-counter remedy (61%), became more active (46%), and drank more water (46%) did not recall their doctor or nurse practitioner recommending these actions to them. At least one-third visited a dietitian (42%) or increased their lab frequency (36%) without being prompted by their doctors. Patients even suggest that they have tried some actions related to prescription drugs that were not specifically recommended by their doctor or nurse practitioner to address their potassium levels (14% have begun taking a new prescription drug and 36% have stopped or changed a prescription drug). Only 8% who changed their diet did so on their own, possibly because all but 15% of all diagnosed with hyperkalemia received this recommendation. The 56% of those who did none of these things **were acting “on their own initiative” to do nothing** despite their doctor recommending specific actions to them. – *Tables 23-24, Question 15—What did your doctor or nurse practitioner recommend you do to address your potassium levels?, Question 16—Which of these have you tried so far?*

Chart 19: Action Taken on Own Initiative



6. While some are taking the initiative to address their high potassium, others are failing to do what their doctor has recommended. Less than half who were told to stop taking an over-the-counter remedy (42%) have stopped at least one such a remedy. Compliance rates are higher, although not universal, for diet changes (89%), drinking more water (81%), prescription drug changes (81%), adding a prescription drug (77%), visiting a dietitian (77%), and getting more frequent lab tests (76%). At least one-third have resisted their doctor's advice to decrease alcohol or recreational drug use (57% have complied), take an over-the-counter remedy (58% have complied), and increase activity or exercise (64% have complied). The fact that only 57% (and not 100%) **"complied" with their doctor's lack of** recommend action reinforces that at least some patients are willing to go beyond what they recall hearing their doctor recommend. – Tables 23-24, Question 15—What did your doctor or nurse practitioner recommend you do to address your potassium levels?, Question 16—Which of these have you tried so far?

Chart 20: Patient Compliance with Doctor Recommended Actions



7. Nearly all shared at least one challenge in dealing with high potassium (8% specified they had none and 1% elected to skip the question), particularly when they have been living with high potassium for at least a year (95% shared at least one vs. 88% diagnosed within the past year). Patients often described several challenges and offered some suggestions. A few of their comments are extracted below. – *Table 25, Question 17—What is your biggest challenge in dealing with high potassium?*

*It seems like potassium is in a lot of things and usually not on food labels.*

*I used to use the USDA nutrition database to look up foods before I ate them but the database has been changed and it is not so user-friendly as it was.*

*Choosing the right foods for each meal. Need printed menu suggestions for a week, at least. Meals for one person. Meals when eating out. Since I can't have yogurt, bananas, hot dogs. things you can grab in a hurry, what kind of fast, snack foods are best.*

*1. Need to lose weight and it is difficult to do so on a low potassium diet. 2. Limited menu 3. Unable to ring out my level without a blood test. Would like a tester like diabetics have if such a thing exists.*

*The diet restrictions from diverticulitis along with the potassium restrictions make for a very small menu of foods that are allowed. Other than that, the biggest challenge seems to be the lack of knowledge of which foods are higher in potassium. I stay away from tomatoes, potatoes, spinach, avocado, oranges, and bananas, but I'm not so conversant on what the next level of foods high in potassium is.*

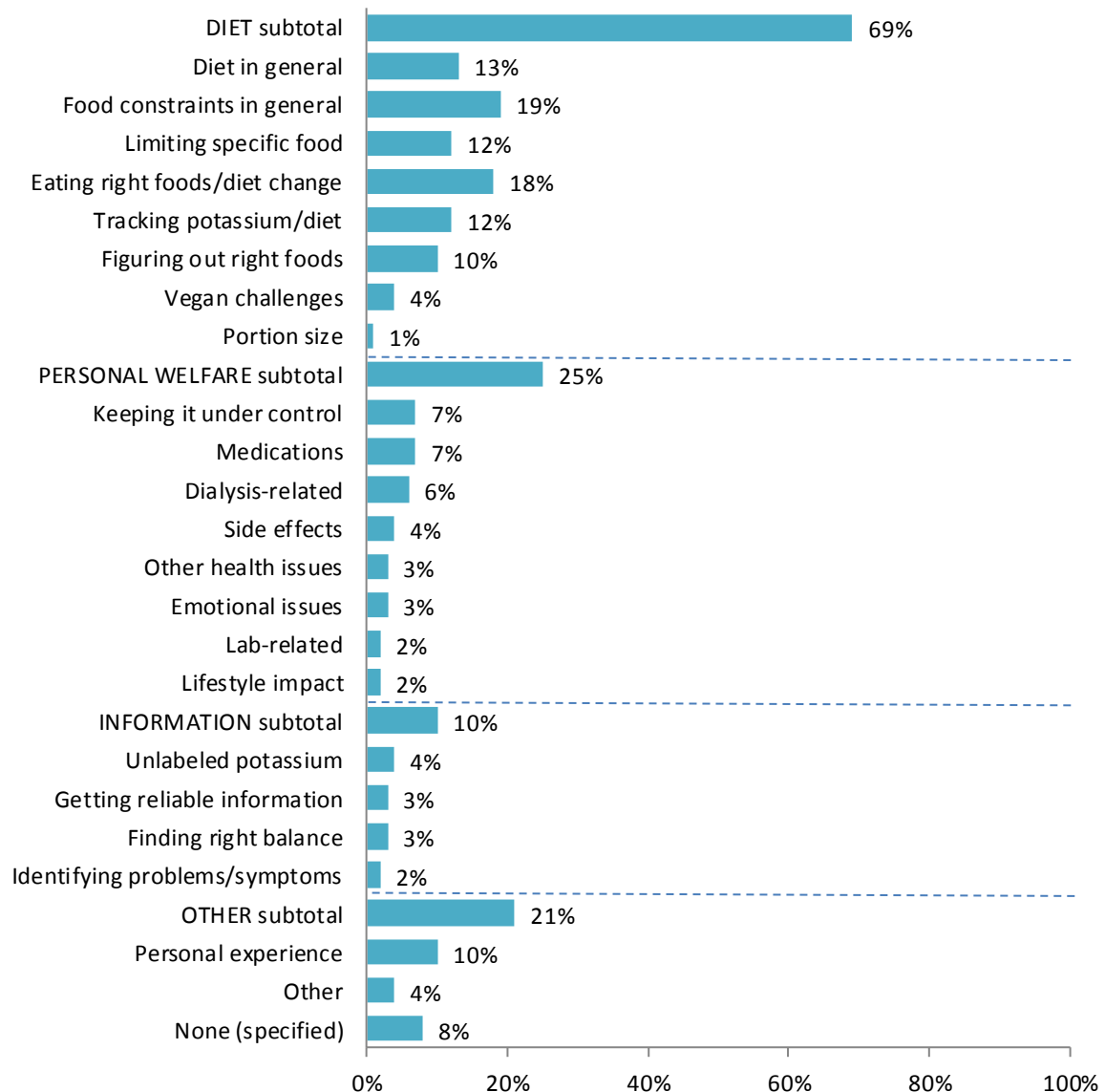
*I LOVE to eat!!!!!!Being on dialysis is soooooo hard. We have to limit what we eat every day. Bananas are the worst, I love bananas, beans, fruits, potatoes, etc. Everything has K (in food). I read labels all the time. Going through a K attack is scary.*

*Bringing my potassium level down and not panicking about the horrible things that could go wrong.*

8. Two-thirds mention diet when listing their biggest challenge in dealing with high potassium (69%), most often food constraints (31%, including 12% who mention one or more specific foods and 19% who mention food constraints in general). Others mention the challenge of eating the right foods (18%), figuring out the right foods (10%), and tracking what they eat (12%). A small group (4%) specified the special challenges created by a vegan diet. – *Table 25, Question 17—What is your biggest challenge in dealing with high potassium?*



Chart 21: Biggest Challenges in Dealing with High Potassium



- Three-quarters who have changed their diet to address their high potassium list a diet challenge (74% vs. 46% who did not say they had tried changing their diet). They make greater mention than do those who have not changed their diet of both food constraints in general (21% vs. 6%) and tracking potassium (13% vs. 4%).
- Three-quarters who have visited a dietitian list a diet challenge (76% vs. 66% who did not say they visited a dietitian), including 6% who say they are vegan (vs. 2% without a dietitian visit).

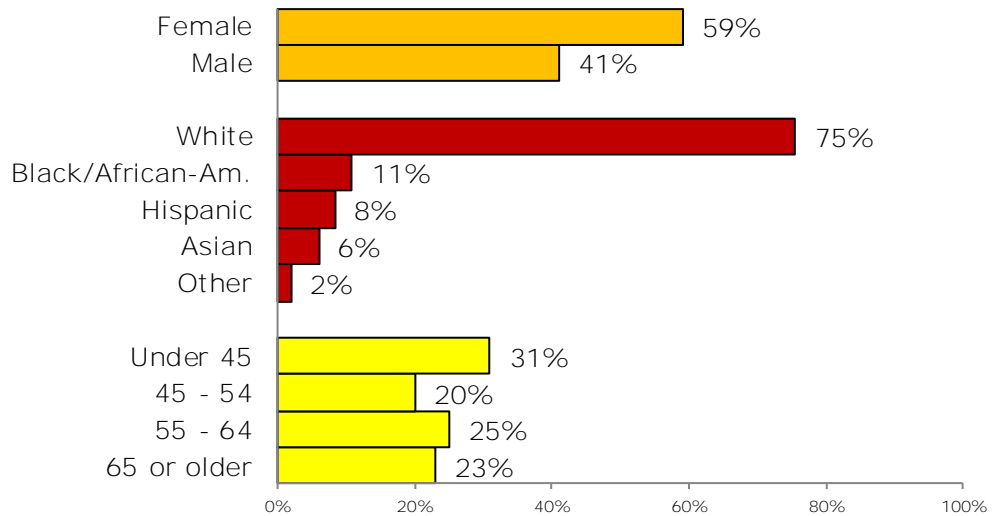
- More than three-quarters in the Midwest list a diet challenge (80% vs. 64%-68% elsewhere), being more likely than residents in other regions to mention diet in general (19% vs. 4% in the Northeast, 10%-13% elsewhere), limiting specific foods (18% vs. 8%-12%), and figuring out the right foods (15% vs. 7%-12% elsewhere).
  - Women are more likely than men to mention food constraints (35% vs. 25%-25% of men), particularly food constraints in general (22% vs. 14%).
  - More in CKD Stage 5 mention food constraints (35% vs. 25%-28% in earlier stages), particularly food constraints in general (22% vs. 14%-15%).
  - The longer they have been living with high potassium, the more likely they are to mention the challenge of limiting specific foods and tracking potassium (7% diagnosed in the past year mention specific foods vs. 16%-19% living with it longer; 9%-10% living with potassium for no more than 5 years mention tracking vs. 21% living with it longer).
  - One-quarter in the Northeast mention tracking potassium (24% vs. 5% in the Midwest and 10%-11% elsewhere).
  - Tracking potassium is mentioned more often by those who have tried exercising more (18% vs. 9% not exercising more).
  - Fewer who see hyperkalemia as a short-term issue mention either tracking it or figuring out the right foods (6% vs. 13%-15% who do not list high potassium as short-term).
  - The earlier the CKD Stage, the more who mention figuring out the right foods, falling from 19% in Stages 1-3 to 12% in Stage 4 and 7% in Stage 5.
  - More who have not experienced either kidney transplantation or dialysis mention eating the right foods (28% vs. 14%-15% when undergone dialysis or transplant) and being vegan (8% vs. 2%-3%).
  - One-quarter of those aged 55 or older mention the challenge of eating the right foods (24% vs. 13% who are younger). They also are more likely to mention tracking potassium (16% vs. 8% younger).
9. One-quarter mention something that relates to their sense of personal welfare in listing their biggest challenges in dealing with high potassium (25%). This includes the struggle to keep it under control (7%) while they deal with medications (7%), dialysis (6%), side effects (4%), other physical (3%) and mental (3%) health issues, labs (2%) and other impacts on their lifestyle (2%). Another one in ten (10%) wanted to share their personal experience even if it did not really answer the question. – *Table 25, Question 17—What is your biggest challenge in dealing with high potassium?*

- One-third in the West make a personal welfare mention (37 vs. 16% in the Midwest and 24%-25% elsewhere), most often keeping potassium under control (10% vs. 1% Midwest and 7% elsewhere).
  - One in ten who added a prescription drug to address their high potassium list something related to medications as their biggest challenge (12 vs. 4% not adding a prescription drug).
  - One in ten in the South mention medications (11 vs. 1% in the Midwest and 6%-8% elsewhere).
  - Those who increased their lab test frequency are more likely than those who have not to mention side effects (6% vs. 2%) and less likely to mention dialysis (2% vs. 8%).
  - One out of every twenty requiring emergency care for their high potassium mention an emotional issue (5% vs. 1% not requiring emergency care).
  - Lab-related and emotional issues are listed more often by those in CKD Stages 1-3 (6% mention each of these) than in the later stages (0%-2%).
  - More in CKD Stage 5 list other health issues (5% vs. 0%-2% in Stages 1-4).
  - One in seven who are unsure of their CKD stage mention a dialysis-related challenge (15% vs. 1%-5% in Stages 1-5), boosting their total mentions of personal welfare challenges to 37% (vs. 22%-23% with a known stage).
  - Only those under the age of 55 mention a lifestyle impact (3% mention).
  - One in ten who have made a change in their over-the-counter remedies mention a lifestyle impact (9% vs. 1% not changing these remedies) and a like number mention side effects (9% vs. 3%).
  - Those who have undergone emergency care for their high potassium are more likely to share a personal experience (15% vs. 7% not requiring **emergency care**) **as are those who are “very aware” of the heart risk from high potassium** (11% vs. 4% less aware of the risk).
10. One in ten list lack of information as a big challenge in dealing with high potassium (10%). They describe the frustrating lack of potassium labeling (4%), reliable sources of information (3%), knowledge of the right balance (3%), and the ability to identify problems and symptoms (2%). – *Table 25, Question 17—What is your biggest challenge in dealing with high potassium?*
- More who are less aware of the heart risk mention information-related challenges (17% vs. 9% **when “very aware”**), most often the struggle to find the right balance (7% vs. 2%).

- Information-related challenges are mentioned more often by those who have increased their activity (16% vs. 9% who are not exercising more), particularly potassium not always being labeled (8% vs. 2%).
- Only those who have been diagnosed within the past year and required emergency care for their high potassium mention the difficulty in identifying the problem or symptoms (5% requiring emergency care and 4% recently diagnosed list it).
- More in the West mention the difficulty in identifying the problem or symptoms (6% vs. 0%-1% elsewhere).
- Unlabeled potassium is mentioned more often by those who have been living with potassium for more than a year (5%-7% think to list it vs. 1% diagnosed in the past year).
- Those drinking more water are more likely than those who are not to mention finding the right balance (5% vs. 1%).

*Demographic Profile*

Chart 22: Personal Characteristics of Respondents



## METHODOLOGY

This report is based on the findings of an Internet survey among 488 adults across the United States with chronic kidney disease (CKD).

### Universe

The universe is adults diagnosed with CKD.

### Sampling

The sample for this study came from two opt-in internal National Kidney Foundation (NKF) sources:

1. **NKF sent an email blast from “NKF News” to people who had previously** expressed interest in receiving information from them. It invited people whose healthcare provider had told them that they had kidney disease or that their kidneys were not working as they should to click on the link to the survey. The invitation noted that the study was **“to learn more about your experience and understanding of high potassium in your blood” and that the first 400** who completed the survey would receive a \$5 Amazon.com gift card.
2. NKF posted on their Facebook page a link to the survey, inviting CKD patients to participate to help NKF **“learn more about your experience and understanding of high potassium in your blood.” It noted that the first 400** who completed the survey would receive a \$5 gift card from an online retailer.

### Questionnaire

Chléire helped design a questionnaire to meet the research objectives. The exact **wording and question number are included in the “Detailed Findings” section.**

### Responses

Responses were collected February 6-7, 2017, a period of approximately 24 hours. Survey invitations were e-mailed on the morning of February 6 and posted to Facebook that same afternoon.

	<u>Count</u>	<u>Of Q1 Responses</u>
Went to the survey	3538	
Answered Q1	647	
Disqualified (no CKD)	<u>-125</u>	19%
Qualified	522	81%
Only answered a few questions	<u>-34</u>	5%
Included in the report	488	75%

### Incentive

All who participate and provided a valid email address were sent a \$5 electronic gift card from Amazon.com.

### Analysis

This report highlights differences between groups that would be statistically significant based on statistical tests had this study been based on a random sample. A randomly drawn sample of 488 allows us to say with 95% confidence that the maximum sampling error is  $\pm 4.4\%$  for results based on the total. Since the sample for this study was not randomly drawn, such statistical tests are more suggestive than definitive.