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Renal Patient and Provider Perspectives on
**Kidney Disease
and Anemia**

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Abstract

In 2016, the American Kidney Fund (AKF) launched a multi-year health education campaign, [ACT on Anemia](#), to raise awareness about anemia among people living with kidney disease. To gain additional insight into the assumptions, degree of understanding and knowledge gaps related to anemia as a common condition associated with kidney disease, AKF conducted two surveys in 2018 of dialysis and kidney transplant patients and providers. Of 337 providers who responded, the majority confirmed that anemia is a significant health issue for dialysis patients, but recognized barriers to discussing anemia with their patients—including patients' being overwhelmed by other health conditions (86%), low literacy/education level of patients (76%), competing health priorities to address (68%), lack of time (51%) and lack of educational resources and tools (43%). Most of the 776 patients who responded (71%) reported that a doctor or nurse had talked to them about anemia, but of those, only 37% of patients reported their provider consulted with them about anemia treatment options. Seventy-three percent of patients who received consultation by their provider about anemia treatments felt informed of the reasons they were being treated for anemia, compared to only 42% who did not. Those who received consultation were reportedly more informed of the associated risks (95%), compared to those who did *not* (44%). Results indicate a need for targeted educational resources, improved patient-provider communication and further research to validate kidney patient understanding of anemia as a health risk.

Introduction

The American Kidney Fund's (AKF) mission is to fight kidney disease and help people live healthier lives. In support of this mission, AKF provides financial assistance to qualifying dialysis and transplant patients, offers free health screenings nationwide for chronic kidney disease and its common risk factors, produces educational health resources to raise public awareness of kidney disease, its treatments, prevention, and associated conditions and supports clinical research to improve outcomes for kidney patients.

One area in which AKF has focused education and outreach efforts is the connection between anemia and kidney disease. Anemia is a common complication of chronic kidney disease (CKD) and can worsen as the disease progresses. In fact, most people on dialysis have anemia (National Institute of Diabetes and Digestive and Kidney Diseases, 2014). AKF's ongoing [ACT on Anemia](#) campaign seeks to raise awareness about anemia as a common condition among those with CKD and kidney failure by providing thoughtful educational information aimed at patients, caregivers, medical professionals and the public.

An environmental scan of existing information and past research on the connection between anemia and kidney disease revealed that studies assessing kidney patients' knowledge of anemia were limited. In the few studies identified, kidney patients—including those under the specialized care of a nephrologist—had knowledge deficits relating to the reasons they were prescribed certain medications, the meaning of their lab values and the impact of their additional health conditions (Wright,

Wallston, Elasy, Ikizler, Cavanaugh, 2011; Lederer et al., 2015).

To further identify patients' perceived voids in knowledge and gaps in patient-provider communication related to anemia and kidney disease, AKF conducted two surveys: one of dialysis and kidney transplant patients, and another of renal care providers. The survey respondents were sourced from AKF's database of dialysis patients, kidney transplant recipients and renal professionals.

The goal of the surveys was to gain insight on the assumptions, understanding and knowledge gaps related to the association between anemia and kidney disease. Key objectives of the surveys were to:

1. Assess the extent to which kidney patients and their providers engage in discussions about anemia and its treatments;
2. Determine the success of patient-provider discussions about anemia from both the patient and provider perspective;
3. Gain greater understanding of the resources, guidelines and tools that renal providers apply when discussing anemia with their patients and recommending treatments.

Findings from the surveys are intended to be applied toward further development of the [ACT on Anemia](#) campaign, and other educational resources to better inform renal patients and providers about anemia.

Methodology

AKF administered two surveys in July and August, 2018: one developed for and sent to renal health care providers via email and one created for and distributed to dialysis patients and kidney transplant recipients via U.S. mail.

Medical Provider Survey

Medical providers were identified through AKF's constituent database. Constituents with the following professions were selected: nephrologists, nurses, nurse practitioners and physician assistants. Constituents without valid email addresses were removed from the list. In total, 5,629 providers were included in the survey sample. AKF chose to conduct a census survey sample rather than select a random sample to generate a larger respondent yield, and because only a negligible cost increase was incurred in selecting a census rather than a random sample.

The survey was conducted using an online survey platform and remained open from July 23, 2018 through August 14, 2018. Four days prior to sending an invitation to complete the survey, AKF sent an email to the sample to alert them of the forthcoming survey and encourage their participation. Potential respondents were sent invitations with the survey link via email at the beginning of the survey window, followed by three reminder emails targeted at those who had not yet responded.

The survey consisted of 24 multiple-choice items including several skip patterns through which each individual respondent could be presented with anywhere from 1 to 24 items. The survey did not include any stand-alone open-ended questions but did include two multiple-choice items with an "other-specify" response option wherein a respondent could write a short text response.

To maintain the confidentiality of survey respondents, AKF did not have access to any identifiable survey data, nor was AKF aware of which constituents submitted completed surveys.

Patient Survey

The sampling frame was constructed from a list of 83,792 dialysis patients and kidney transplant recipients over the age of 18 living in the United States or Puerto Rico, who had received financial assistance from

AKF in 2017 or 2018. 4,500 patients were randomly selected to be included in the study.

Paper surveys and postage-paid return envelopes were mailed to the survey sample on August 1, 2018. Three weeks before the surveys were mailed, AKF sent a postcard to the survey sample to inform them of the forthcoming survey and encourage their participation. Introductory text in the survey requested that respondents mail their survey by August 22, 2018. Surveys were received, sorted and scanned on a rolling basis and responses were recorded electronically. Surveys received through September 18 were included.

The survey included 15 multiple-choice items. Three of the items instructed respondents to stop the survey instead of moving on to the next question, depending on their responses. These skip patterns were used in cases where the remaining items were not applicable based on a certain response. For example, if a patient responded 'No' to the question, "Has your doctor or nurse ever talked to you about a health condition called anemia?", the instructions directed the respondent to "Stop here and mail survey." In this example, the remaining questions on the survey were inapplicable to someone who had never discussed anemia with their medical provider.

To maintain the confidentiality of survey respondents, AKF did not have access to any identifiable survey data, nor was AKF aware of which constituents submitted completed surveys.

Data Analysis

Provider Survey

Frequencies of survey responses overall and by subgroup are presented in the findings section of this report. When comparisons of survey responses are made between groups (e.g., by years of experience or prescriber status), the Pearson's chi-square test is used to determine whether the differences are statistically significant.

Patient Survey

Frequencies of survey responses overall and by subgroup are presented in the findings section of this report. When comparisons of survey responses are made between groups (e.g., male patients versus female patients, dialysis patients versus kidney transplant patients), the Pearson's chi-square test is used to determine whether the differences are statistically significant.

Results: Provider Survey

AKF received 341 online surveys, including four incomplete surveys which were removed from the sample. The remaining 337 surveys were considered, resulting in a 6% response rate.

Findings from the provider survey are separated into three subsections in this report: 1) renal health care provider characteristics, 2) discussions providers have with their dialysis patients about anemia, and 3) anemia treatments. The item-by-item frequencies for the full survey can be found in Appendix A.

Provider Characteristics

Since the aim of the survey was to better understand the interactions renal providers have with dialysis patients regarding anemia, only those who identified as providing direct care to dialysis patients were routed to complete the entire survey. Medical providers who identified they did *not* provide direct care to dialysis patients were routed to the end of the survey immediately. In total, 76% of respondents were routed through the remaining items in the survey.

The respondents were collectively well-experienced, with 43% of respondents reporting more than 20 years of experience and 21% reporting 11-20 years (Figure 1). Respondents were most likely to be registered nurses (61%) or nephrologists (32%). Figure 2 outlines a breakdown of respondents by profession.

AKF was particularly interested in learning whether providers who were licensed to prescribe medications (e.g., physicians, physician assistants and nurse practitioners) responded differently than non-prescribers. Differences in responses among the two groups that are statistically significant are included in this report.

Non-prescribers reported having significantly more professional experience compared to prescribers, though the sample was well-experienced overall¹. Prescribers were more likely than non-prescribers to indicate possessing five or fewer years of experience (32% compared to 8%). Non-prescribers were more likely than prescribers to report having 11 or more years of experience (72% compared to 52%).

1 $\chi^2(4)=27.04, p<.001$

Anemia Discussions

The survey found 85% of renal provider respondents agreed that anemia is *often* a significant health issue for dialysis patients and another 14% agreed that it *sometimes* is. Nearly all providers indicated that they discussed anemia with all their dialysis patients (72%) or when the discussion was warranted by the condition of the patient (26%). Few respondents (2%) indicated that discussing anemia with dialysis patients was not a part of their professional role and were directed to the end of the survey.

Figure 1. Renal Provider Years of Experience (n=257)

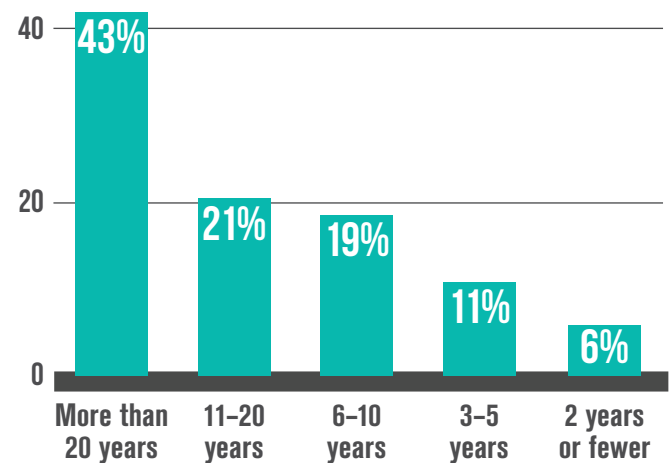


Figure 2. Renal Provider Professions (n=256)

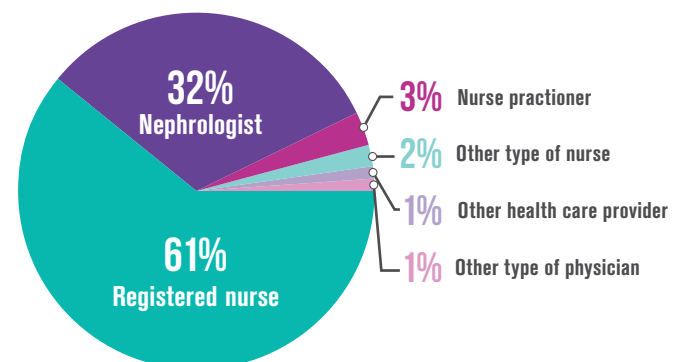
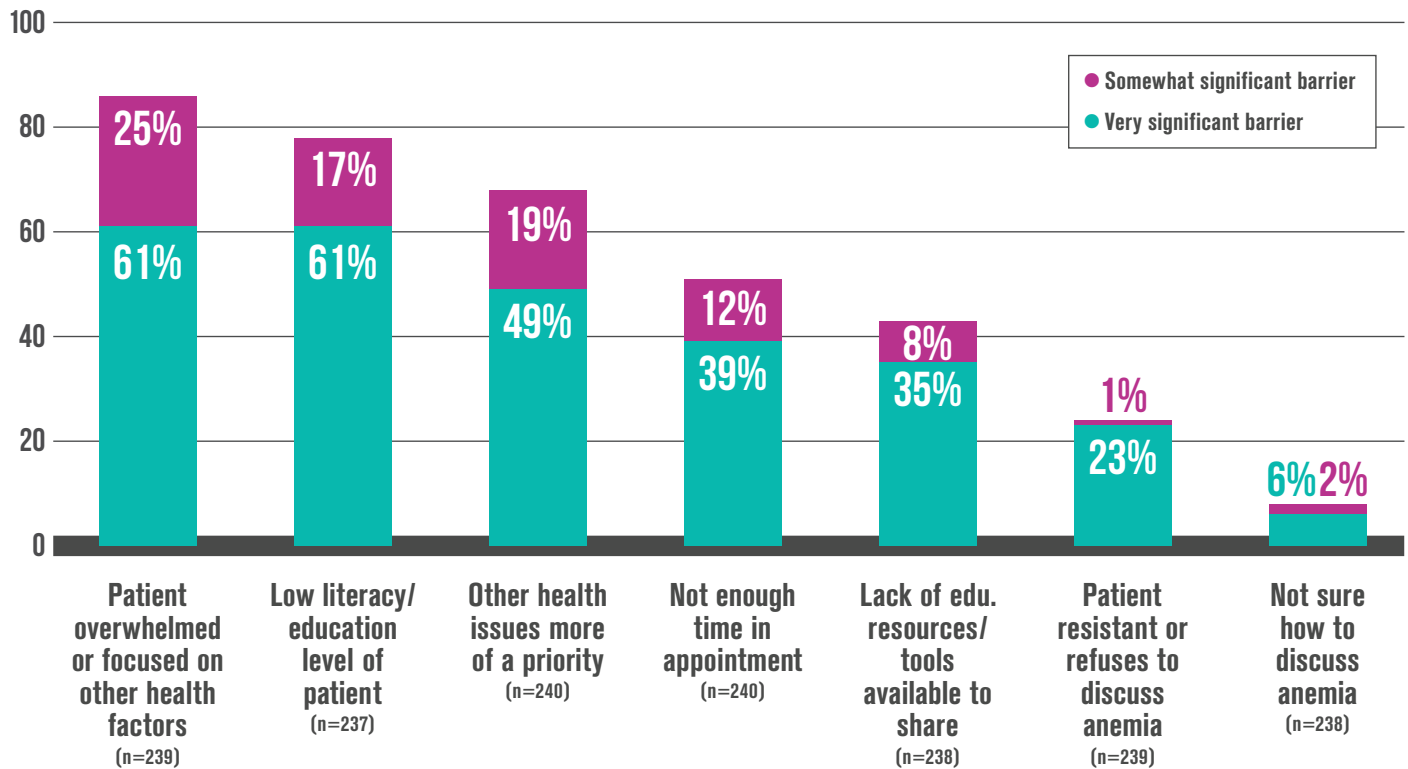


Figure 3. Renal Provider Barriers to Discussing Anemia with Dialysis Patients



To assess the types of barriers providers experience when discussing anemia with their dialysis patients, respondents were asked to select among a list of common barriers (Figure 3). The barrier selected most was that dialysis patients are overwhelmed or focused on other health issues (86% reported this as a very or somewhat significant barrier), followed by low literacy or education levels of the patient (78%) and that the provider had higher priority health issues to discuss (68%).

Although less than half (43%) cited the lack of educational resources/tools available as a barrier to discussing anemia with dialysis patients, 84% of providers reported they would find fact sheets or brochures on anemia for patients helpful (Figure 4). Half of the providers surveyed were interested in training materials about educating patients on anemia, and slightly fewer were interested in educational videos for patients and professional education courses on the topic (41% and 32%, respectively).

In assessing providers' desire for educational resources to aid in conversations about anemia, a pattern emerged in responses from prescribers compared to non-prescribers. Non-prescribing providers indicated significantly more interest in fact sheets and brochures

Figure 4. Resources Renal Providers Would Find Useful During Dialysis Patient Discussions about Anemia (n=243)

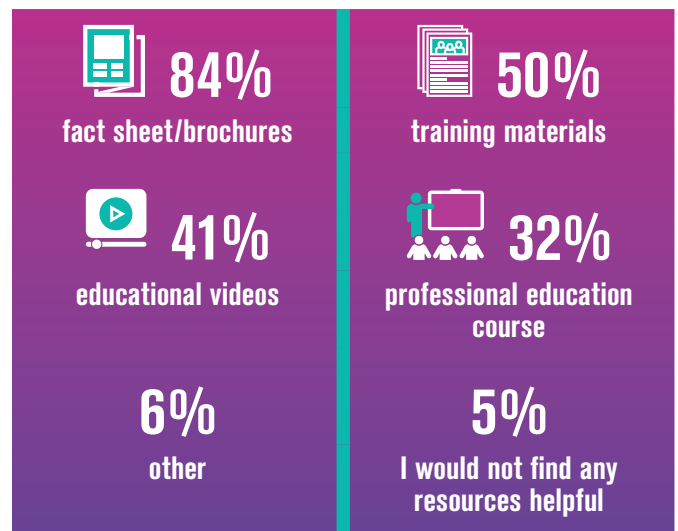
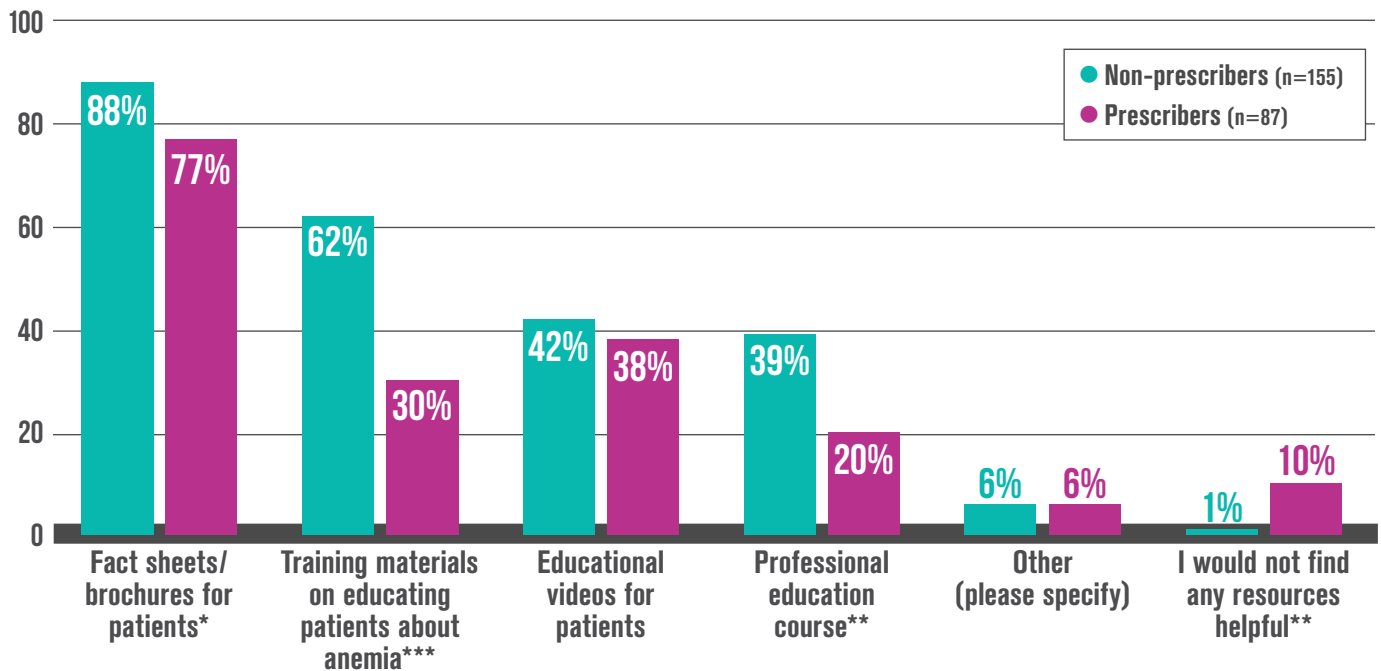


Figure 5. Resources Renal Providers Would Find Useful, by Prescriber Status



*p<.05, **p<.01, ***p<.001

compared to prescribers. Specifically, 88% of non-prescribers reported factsheets and brochures would be useful compared to 77% of prescribers². And 62% of non-prescribers reported training materials would be useful compared to 30% of prescribers³. Similarly, 39% of non-prescribers identified that a professional education course on the subject would be useful compared to 20% of prescribers⁴.

Treatment

Only those who identified as prescribers were routed to the survey questions regarding the treatments for anemia; 93% of prescribers reported following specific clinical guidelines to determine a treatment plan for dialysis patients with anemia. Overwhelmingly, prescribers reportedly used the KDIGO guidelines (87%), with about half that number using the KDOQI guidelines (45%) (Figure 6), while 10% of respondents reported using some other guidelines, most commonly those developed within the provider’s own unit or institution.

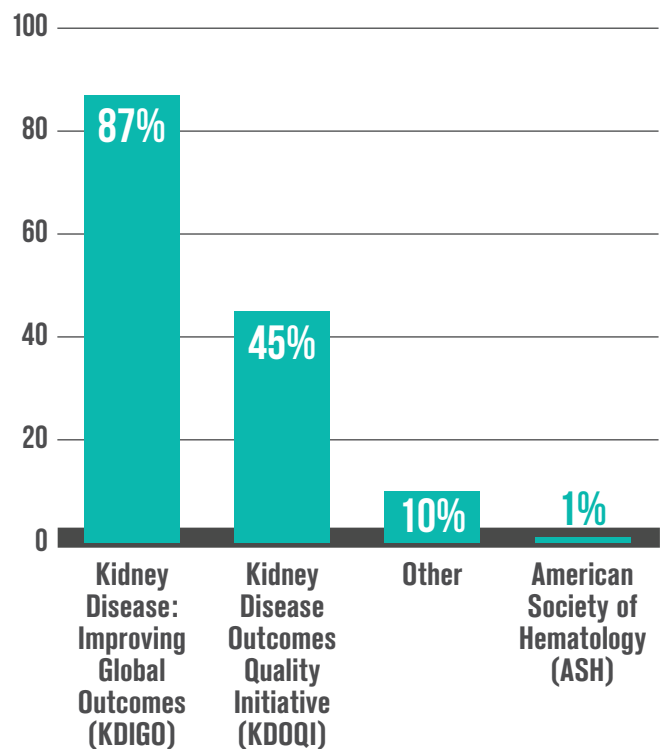
In addition to the clinical guidelines that prescribers consulted, they were asked whether they had ever con-

2 $\chi^2(1)=4.75, p<.05$

3 $\chi^2(1)=22.90, p<.001$

4 $\chi^2(1)=9.44, p<.01$

Figure 6. Clinical Guidelines Used by Renal Providers (n=83)



sulted with a pharmacist about anemia treatment protocols; 27% responded affirmatively.

Nearly all (98%) prescribers reported prescribing iron supplementation as a treatment for anemia in dialysis patients. When asked to identify which factors they consider when prescribing oral or intravenous iron supplementation, providers were most likely to select iron status of the patient (77%), followed by dialysis treatment modality (62%), comorbidities (58%) and hemoglobin levels (53%). Far fewer providers considered other fac-

tors (14%) or the patient's transplantation history (7%) (Figure 7).

As with iron supplementation, nearly all renal prescribers (99%) reported prescribing erythropoiesis stimulating agents (ESAs) to treat anemia in dialysis patients. Prescribers were highly likely to agree or strongly agree with being well versed in the risks associated with ESAs, knowing recommended iron levels for ESAs to be effective, feeling comfortable talking to patients about the risks and benefits of ESAs and feeling informed of current ESA treatment guidelines (Figure 8).

Figure 7. Factors Considered by Renal Prescribers for Prescribing Intravenous Versus Oral Iron Supplementation (n=85)

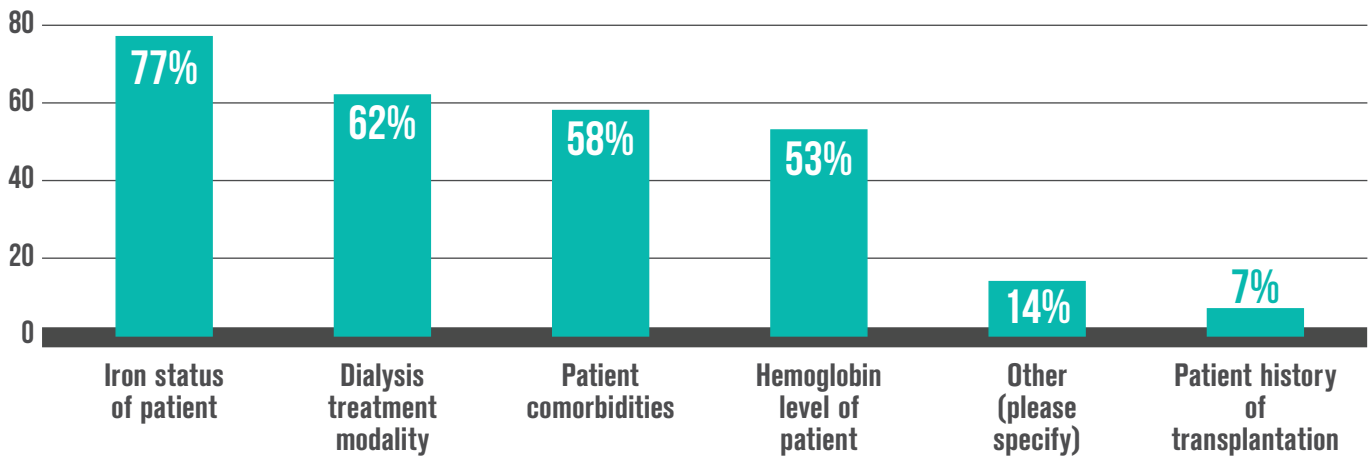
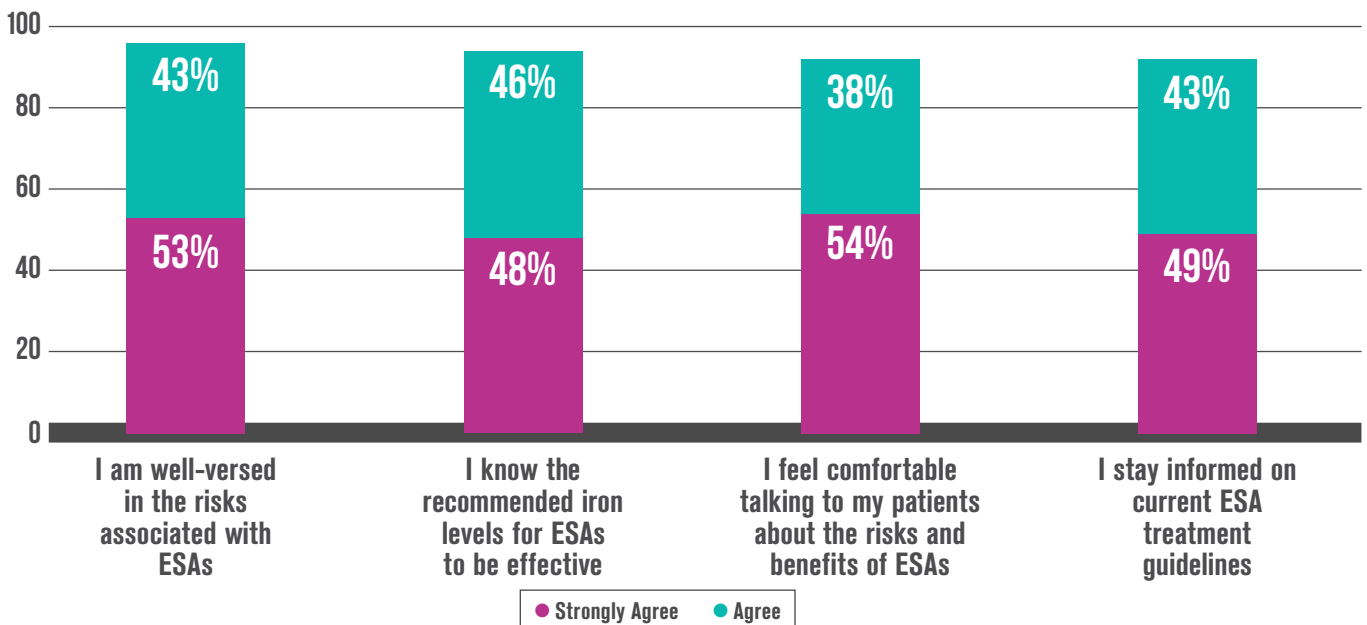
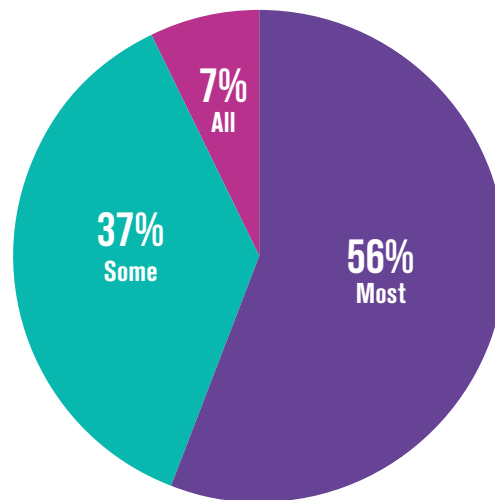


Figure 8. Renal Prescriber Perspectives on ESAs (n=87)



To assess renal prescribers' perspectives on dialysis patients' knowledge of anemia, participants were asked to estimate the proportion of their dialysis patients who understood why they were being treated for anemia. As this item requires providers to make assumptions about patient understanding, the accuracy of their interpretations can be disputed. As shown in Figure 9, 7% of providers reported *all* their dialysis patients understand why they were treated for anemia, 56% reported *most* and 37% reported *some*.

Figure 9. Renal Prescriber Perceptions of Dialysis Patient Understanding of Reasons for Anemia Treatment (n=89)



Results: Patient Survey

Among the surveys sent, 471 were deemed “undeliverable” by the U.S. Postal Service. Of the remaining 4,029 surveys that were successfully mailed, 780 surveys were returned. Due to insufficient data, 14 surveys were removed, leaving 766 surveys included for data analysis. The final dataset reflects a 19% response rate.

Findings from the patient survey are separated into three subsections in this report: 1) patient characteristics, 2) discussions providers have with their patients about anemia, and 3) anemia treatments. The item-by-item frequencies for the full survey can be found in Appendix B.

Patient Characteristics

The distribution of male and female respondents was 55% male and 45% female. Forty-six percent of respondents identified as White or Caucasian, 30% identified as Black or African-American and 12% identified as Hispanic or Latino (more detail in Appendix D). The average age of patient respondents was 61.

Nearly all (93%) patients who responded reported they were on dialysis. Fifty four percent of patients made medical visits more than once a week, 12% of patients made a medical visit weekly, 27% of patients made a medical visit 1–3 times per month, and 6% of patients made a medical visit less than once a month (figure 10). The remaining 7% indicated they were living with a kidney transplant. Disaggregating the data by patient type (i.e., dialysis patients versus kidney transplant recipients), resulted in differences in the frequency of medical office visits. Among dialysis patients, 71% reported

making medical visits at least weekly, compared to 16% of transplant patients⁵.

Discussing Anemia

Patients were asked whether their doctor or nurse had ever talked to them about anemia. A majority (71%) of patients reported that their doctor or nurse had discussed anemia with them, while 20% reported that a provider had not and 9% were unsure. Significantly more female patients than male patients reported that a doctor or nurse had talked to them about anemia (77% and 66% respectively⁶).

Among patients who *did* speak with a doctor or nurse about anemia, nearly three-quarters (74%) reported that they discussed general information about anemia (Figure 11). The next most reported topic of discussion was the relation of anemia to kidney disease (56%), followed by treatments for anemia (48%) and symptoms (44%). Just over a quarter of patients reported talking with their provider about how anemia is diagnosed (27%), and a small percentage discussed something else about anemia (3%).

Kidney patients were then asked to recall the conversations they had with providers about anemia. Eighty-five percent of patients reported that their doctor or nurse explained information about anemia clearly and 87% reported having enough time to ask questions of their provider (Figure 12). Nearly all patients (96%) said they felt comfortable asking their medical provider questions about anemia. Women were slightly more likely to say they were comfortable asking questions compared to men (97% compared to 94%)⁷.

5 $\chi^2 (4)=111.73, p<.001$

6 $(\chi^2 (2)=13.41, p<.01$

7 $\chi^2 (2)=6.20, p<.05$

Figure 10. Frequency of Renal Patient Visits to Nephrologist, Dialysis Center or Other Medical Professional

(n=746)

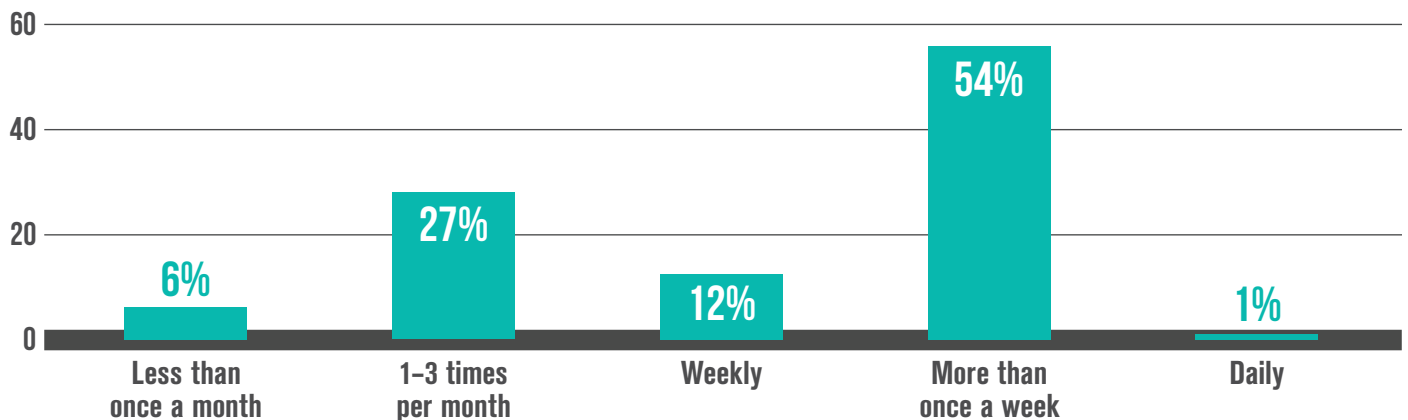


Figure 11. Topics Covered in Renal Patient Conversations with Doctors or Nurses About Anemia (n=530)

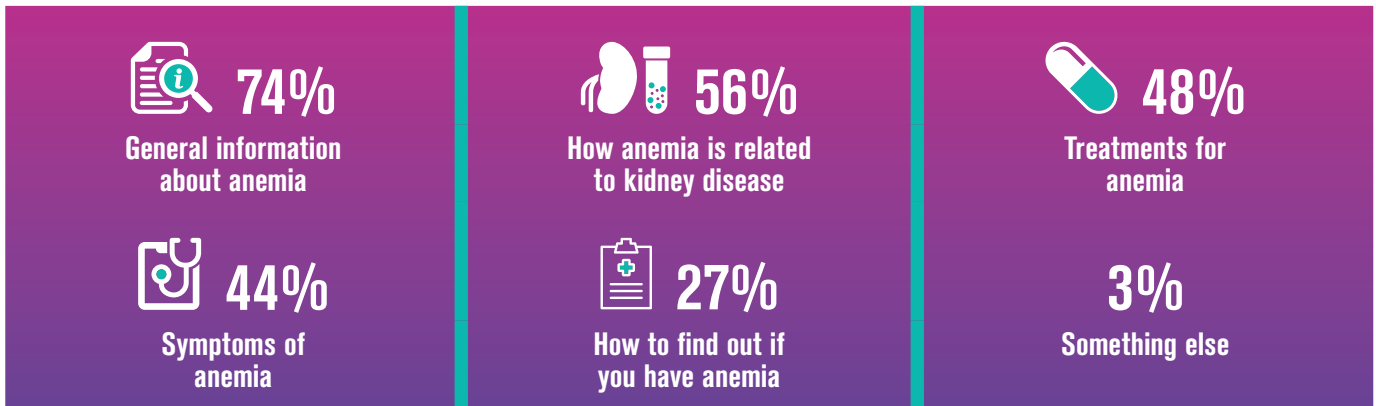
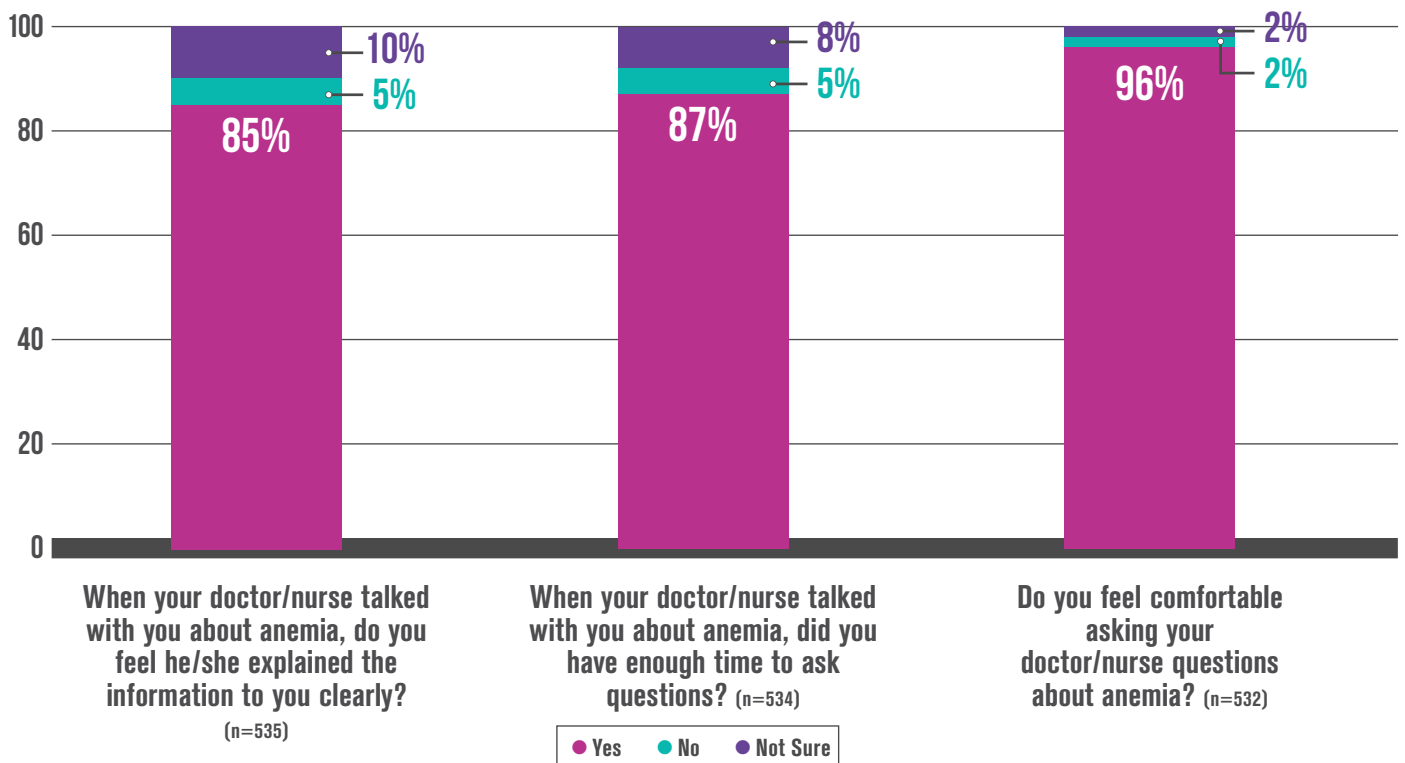
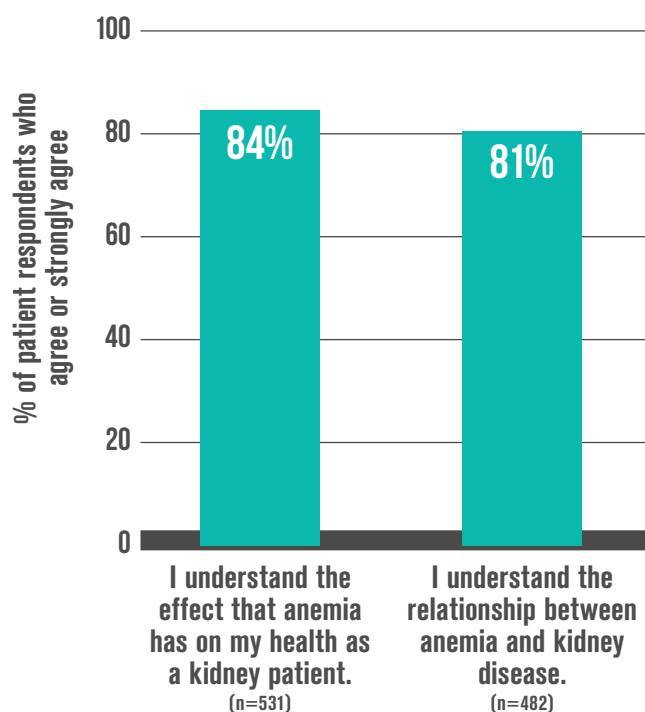


Figure 12. Renal Patient Reports of Communication About Anemia with Providers



Patients were asked to assess their own understanding of the health effects of anemia and their relation to kidney disease (Figure 13). Eighty-four percent of patients agreed or strongly agreed that they understood the effect that anemia has on their health and 81% agreed or strongly agreed that they understood the relationship between anemia and kidney disease.

Figure 13. Renal Patient Understanding of Anemia



Treatment

More than three-quarters (77%) of patients who reportedly discussed anemia with their doctor or nurse said that they had been diagnosed with anemia at some point. Nineteen percent reported they were never told they had anemia and 4% reported they were unsure.

More women reported having been told they had anemia than men (82% compared to 72%)⁸.

Of patients who had been diagnosed with anemia, almost all (93%) reported that they had been treated for the condition with medications or other interventions (Figure 14). Specifically, patients reported being treated with intravenous iron (66%), followed by iron pills (41%), ESAs (37%) and blood transfusions (32%). A small percentage of patients reportedly received another type of treatment or were unsure of the treatment used (7% and 3%, respectively).

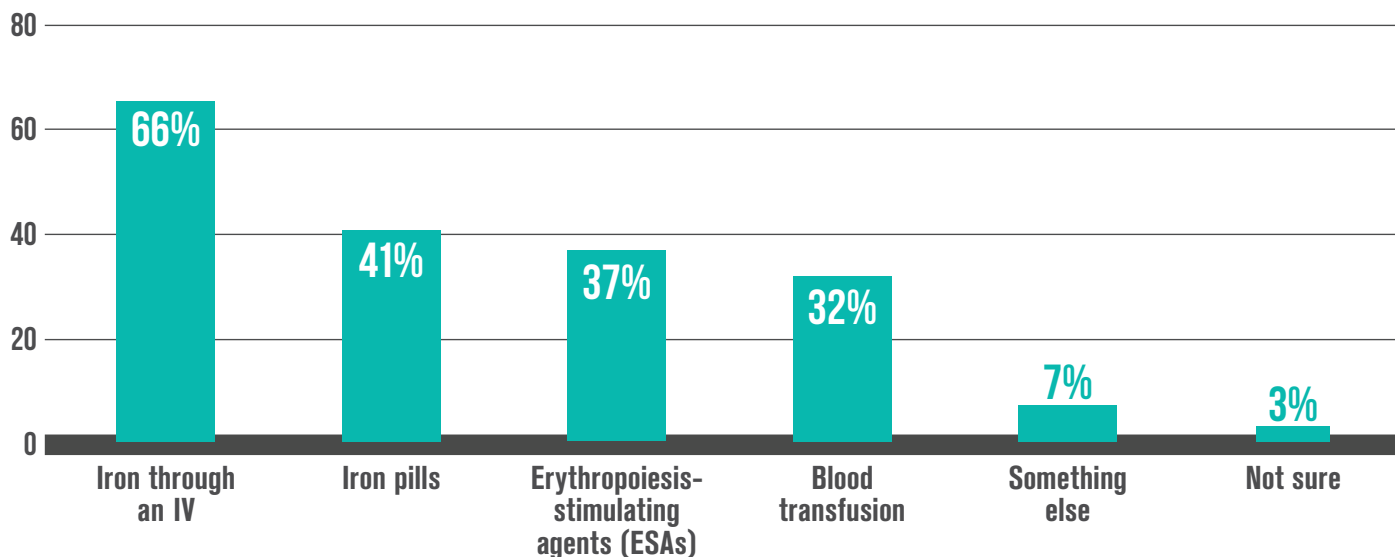
Though most patient respondents indicated they had been treated for anemia, 37% of patients reported their doctor or nurse consulted with them about anemia treatment options. Women were significantly more likely to report receiving consultation about anemia treatments from a provider compared to men (44% and 32% respectively)⁹.

Generally, kidney patients reported understanding the reasons they were treated for anemia, why a specific

8 $\chi^2 (2)=7.60, p<.05$

9 $\chi^2 (2)=7.38, p<.05$

Figure 14. Anemia Treatments Reported by Renal Patients (n=384)



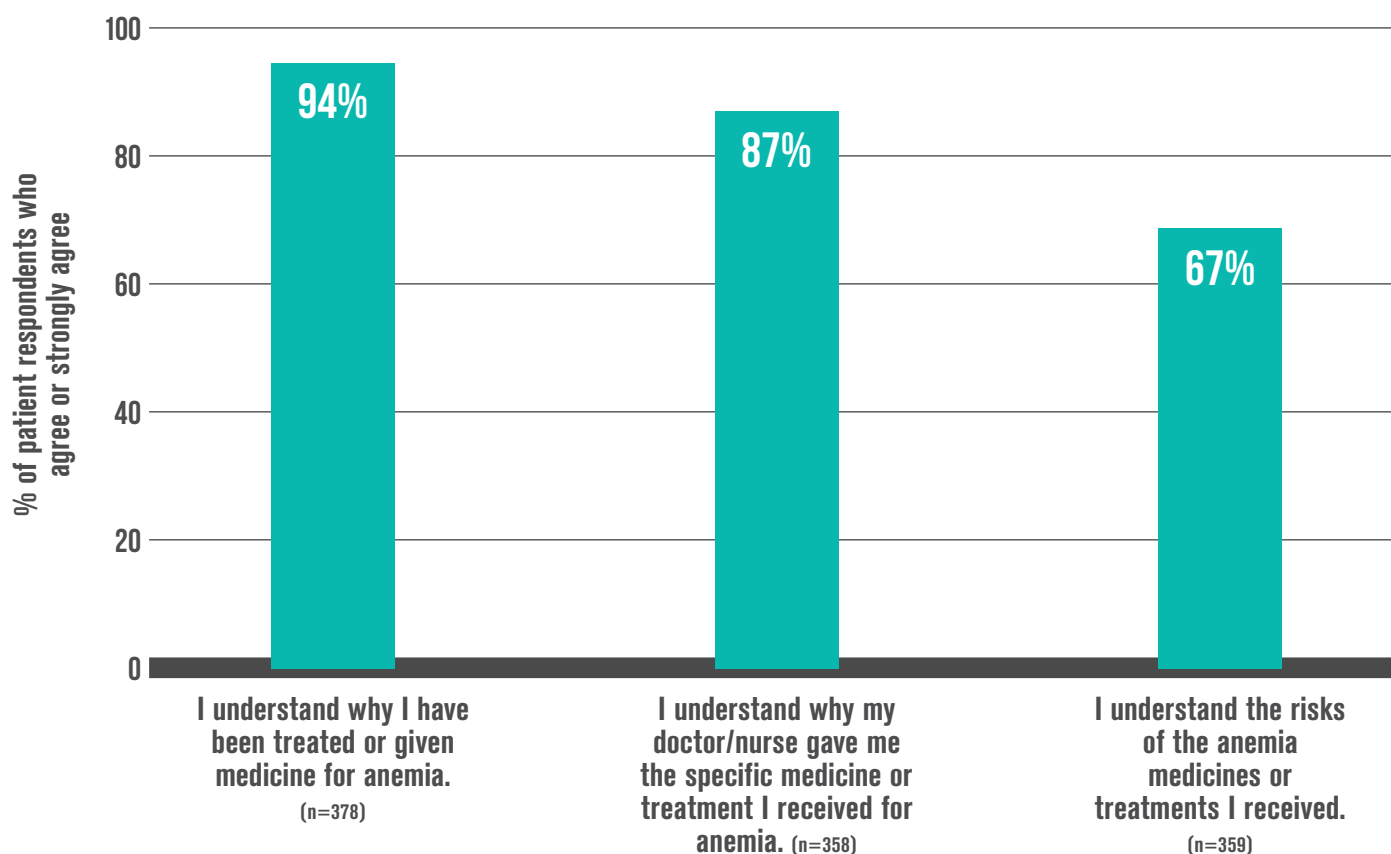
treatment was chosen and the associated risks of anemia treatments (Figure 15). Ninety-four percent of patients agreed or strongly agreed (40% and 54%, respectively) that they understood why they were treated for anemia. Slightly less (87%) agreed or strongly agreed they understood why a specific treatment was selected and only about two-thirds (67%) of patients agreed or strongly agreed they understood the risks associated with their anemia treatment.

Of the three items assessing patient understanding, only one varied significantly by gender; 59% of women agreed or strongly agreed that they understood the risks of their treatment, compared with 74% of men¹⁰.

A correlation between whether patients reported receiving consultation from a provider regarding anemia treatments and how well they understood their anemia treatments and the risks was found (Figure 16). Specifically, 73% of patients who reported

10 $\chi^2(2)=13.29, p<.01$

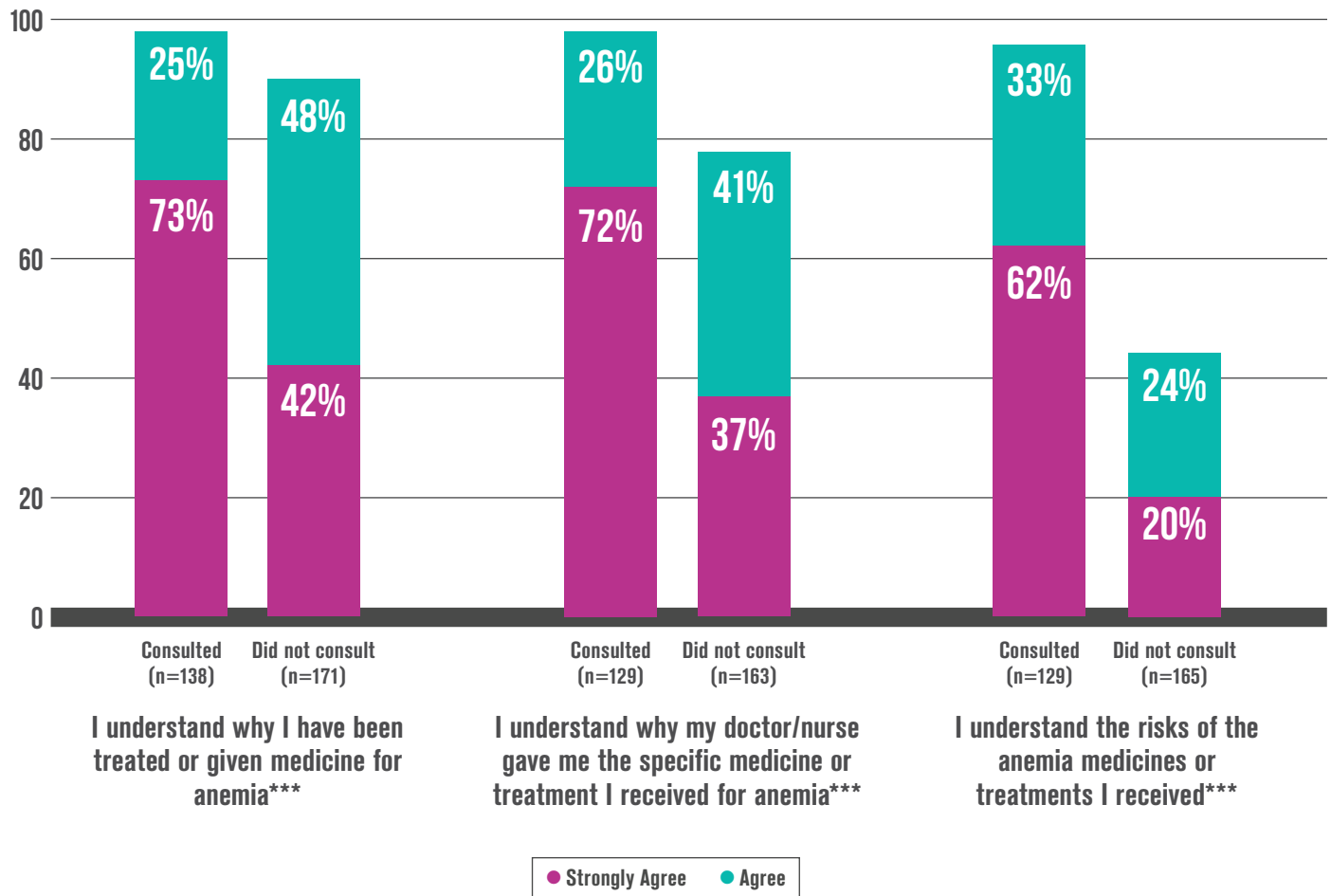
Figure 15. Renal Patient Self-Reported Understanding of Anemia Treatments and Medications



receiving consultation from a doctor or nurse about anemia treatment options strongly agreed that they understood why they had been treated, compared to only 42% of patients who said they had *not* received consultation¹¹. Seventy-two percent of patients who reportedly consulted with a provider strongly agreed that they understood *why* they received a specific

treatment for anemia, compared to 37% of patients who reportedly were *not* consulted¹². Finally, 95% of patients who reportedly consulted with a provider agreed or strongly agreed that they understood the treatment risks, compared to 44% of those who reportedly did *not* receive consultation¹³.

Figure 16. Renal Patient Self-Reported Understanding of Anemia Treatments and Medications, by Provider Consultation



*p<.05, **p<.01, ***p<.001

Patients who identified as 'not sure' about whether their doctor or nurse consulted with them about treatment are excluded from the analysis.

11 $\chi^2(6)=37.33, p<.001$

12 $\chi^2(8)=52.58, p<.001$

13 $\chi^2(8)=117.96, p<.001$

Discussion

Results of the patient and provider surveys provide insight into renal patients' assessment of their anemia knowledge, the ways patients and providers communicate about anemia and the barriers to successful communication. The findings suggest a need for targeted educational resources, improved patient-provider communication and further research to validate kidney patient understanding of anemia as a health risk. The following are key findings and subsequent recommendations for addressing anemia in kidney disease patients.

Anemia Knowledge

Though kidney patients reported their knowledge of anemia and its treatments to be strong overall, there was still a portion of the population who were reportedly less informed. Between 15% and 20% of patients indicated that they could not be sure they knew the effect of anemia on their health or understood the relationship between anemia and kidney disease. A third of patients (33%) reported they could not be sure they understood the risks of the medications or treatments they had received for anemia. It is possible that social desirability bias may have affected survey responses, (see limitations section), which may have caused patient respondents to *underreport* their knowledge deficits.

Findings reveal a disconnect between kidney patients' self-reported understanding of anemia treatments and providers' assessment of patient knowledge. Overall, 94% of patients who had been treated for anemia agreed or strongly agreed that they understood why they had been treated, whereas only 7% of renal providers reported that *all* of their patients understood why they were treated for anemia, 56% indicated that *most* did, and 37% reported only *some* did. This revelation is limited, however, considering the degree of overlap between the two sets of survey respondents (i.e., how many of the surveyed providers treated patients who were also surveyed) is unknown.

Limitations of the survey indicate the self-reported understanding of anemia by patients in the current survey may be inflated. In the limited research available assessing kidney patients' anemia understanding, knowledge deficits were identified (Wright, Wallston, Elasy, Ikizler, Cavanaugh, 2011); Lederer et al., 2015). For these reasons, further research is needed to validate kidney

patients' actual understanding of anemia and its treatments to effectively address knowledge gaps.

Educational Resources

Though most renal providers surveyed agreed that anemia is a significant health issue for kidney patients, they also reported barriers to engaging in effective discussions about anemia with their patients. Patients' focus on other competing health issues and lack of time during appointments were reported as barriers, along with providers' perception of their patients' low literacy/educational levels and a lack of patient-facing educational resources.

The fact that low literacy was perceived as a contributing factor to poor patient and provider communication is consistent with other research. An estimated 28% of white adults and 65% of Hispanic adults have been identified as having basic or below basic health literacy by a large, comprehensive national assessment of the U.S. population's health literacy (Kutner, Greenberg, Jin, & Paulsen, 2006). In fact, over a third of U.S. adults are estimated to have difficulty understanding common health-related tasks such as following instructions on a prescription (Kutner, Greenberg, Jin, & Paulsen, 2006).

Based on reviews of research on the topic, an estimated 10–50% of kidney patients have limited or low health literacy (Dageforde & Cavanaugh, 2013; Taylor et al., 2017). Even more concerning is that low literacy is associated with poor health outcomes such as low eGFR among kidney patients in early stages of kidney disease, reduced blood pressure control, increased risk of death and lower chances of receiving a successful kidney transplant (Jain & Green, 2016). Such findings in prior research and the current survey highlight the need for services, programs and resources customized for individuals with limited health literacy.

When asked about the utility of educational resources for educating patients, renal providers identified fact sheets, brochures and training materials as being the most useful. Notably, non-prescribers reported a significantly greater desire for such resources compared to prescribers. Considering that nurses comprised most of the non-prescribers who were surveyed, an opportunity exists to fill an unmet need by creating resources designed for nurses to use with their patients.

Patient and Provider Anemia Discussions

Although conversations about anemia are reportedly occurring between kidney patients and renal providers, findings from the surveys suggest that opportunities remain to increase the frequency and enhance the quality of such discussions.

The renal providers surveyed agree that anemia is a significant health issue for their patients on dialysis; however, about three-quarters (72%) of providers discuss anemia with *all* their dialysis patients. This echoes kidney patients' responses as 71% indicated a health care provider had talked to them about anemia, leaving nearly one in four dialysis patients surveyed reporting they have never discussed the condition. Given the high prevalence of anemia among dialysis patients, and the condition's lack of highly distinguishable symptoms (i.e. weakness and fatigue), anemia should be a topic that providers discuss with *all* of their dialysis patients instead of most.

Kidney patients positively rated the quality of conversations they have with doctors and nurses regarding anemia that *do* occur. According to patient respondents, their providers explained anemia clearly, allowed time for questions and overall, made them feel comfortable enough to ask questions.

A correlation was discovered between whether patients reported having a conversation with their doctor and nurse about anemia, and their reported understanding of anemia treatments and its risks. Only 37% of patients who reported discussing anemia with a doctor or nurse talked to them about which specific treatment would be best for them. Patients who reported receiving this treatment consultation from a provider indicated significantly better understanding of why they were treated for

anemia and the associated risks of treatment than those who did not.

Consultations between dialysis patients and providers about anemia treatment options and the risks and benefits should be a standard practice among prescribers providing anemia care.

Pharmacist Involvement

In a literature review conducted prior to survey development, pharmacists were commonly identified as well-positioned to interact with kidney patients regarding anemia treatment management (Debenito, Billups, Tran, Price, 2014; Salgado, Moles, Benrimoj, Fernandez-Llimos, 2012). In our survey, prescribers were asked whether they consult with pharmacists when managing a kidney patient's care; 27% of prescribers reported doing so. Further research into the roles and interactions of each member of the renal health care team, especially related to educating patients about anemia could inform if there are treatment team roles that are better positioned to effectively leverage patient-facing educational materials and tools than others.

Gender Differences

There were significantly more female patients than male patients who reported having conversations with their providers about anemia, indicated feeling comfortable asking their provider questions about anemia and confirmed receiving an anemia diagnosis. However, significantly fewer women than men reported that their provider consulted with them about anemia treatment options. Fewer women also reported understanding the risks of anemia treatment compared to men. These gender-specific findings among patients may be worth exploring further.

Limitations

One limitation in this survey is the lack of generalizability of findings to the renal patient and provider populations at large. Due to non-response bias, or the differences that might exist between the patients and providers who completed a survey and those who opted not to complete a survey, the generalizability of the results is threatened. Appendices C and D demonstrate the extent to which there was evidence of non-response bias in the surveys. There was conflicting evidence as to whether non-response bias existed.

Related to generalizability, channels through which respondents were reached may have presented bias. Contact with respondents was made through mailing addresses and email addresses provided several months prior to the survey period. As discussed in the methodology section, some mailing addresses were determined to be “undeliverable” at the time of survey administration and some email addresses were invalid or bounced. Therefore, transient patients and providers were less likely to have received the survey intended for them.

Social desirability bias, the tendency to answer questions in a way that respondents perceive is more socially acceptable, may have been present due to the self-report format of the survey. For example, patient respondents may have overestimated their knowledge of anemia and kidney disease, whereas providers may have overestimated their ability to communicate with patients, resulting in responses that appear more favorable than reality.

Dialysis and transplant patients were asked to report on their own knowledge of anemia and kidney disease, and not how they acquired such knowledge. Patient

respondents' knowledge may have been acquired by other means than provider discussions (e.g. from online resources, or friends and family). Therefore, patients' reported understanding of anemia should not be assumed to be solely related to conversations with providers they did or did not have.

Bias may have been present due to the patient survey population. Though the majority of those surveyed were dialysis patients (93%), a small minority (7%) were recent transplant patients who had previously been on dialysis. Given that anemia is not a primary concern post-transplant, transplant patients' providers may not make anemia a priority during consultations. Therefore patients' assessments of how their doctors discussed anemia with them may have been affected by whether or not they were on dialysis or post-transplant. Since only 7% of respondents were post-transplant patients, the results are still valid.

Inherent to any survey conducted with people, recall bias may have affected findings. For example, patients may not have accurately recalled conversations about anemia they had with their providers. Therefore, it should not be assumed that a patient's account is entirely accurate regarding whether certain conversations with their provider about anemia took place.

Finally, only closed-ended questions were used in this study. The conclusions drawn from closed-ended items are inherently limited because they prevent researchers from probing further into the motivation or additional factors behind a response. In future studies, a deeper understanding could be gained by conducting open-ended surveys, interviews or focus groups, enabling respondents to elaborate on a topic of interest.

Appendix A: Provider Survey Responses by Survey Item

Do you currently provide direct care to dialysis patients as part of your professional role? (n=337)

Yes **76%**
 No..... **24%**

For how many years have you provided direct care to dialysis patients? (n=257)

2 years or fewer **6%**
 3-5 years **11%**
 6-10 years **19%**
 11-20 years **21%**
 More than 20 years **43%**

Which of the following best describes your professional role? (n=256)

Nephrologist **32%**
 Other type of physician **1%**
 Registered Nurse **61%**
 Nurse Practitioner..... **3%**
 Other type of nurse **2%**
 Physician Assistant **0%**
 Dialysis Technician..... **<1%**
 Other health care provider **<1%**

Based on your experience, is anemia a significant health issue for patients on dialysis? (n=256)

Yes, often..... **85%**
 Yes, sometimes..... **14%**
 No, not usually **1%**

Do you discuss anemia with your dialysis patients? (n=256)

Yes, all of them **72%**
 Yes, if warranted by the condition of the patient. . . **26%**
 No, never..... **0%**
 Not applicable: I do not consider discussing anemia with dialysis patients to be part of my professional role. . **2%**

Please indicate the extent to which the following are barriers to discussing anemia with your dialysis patients.

	Very Significant Barrier	Somewhat Significant Barrier	Not a Barrier
Not enough time with the patient during the appointment (n=240)	12%	39%	49%
Lack of educational resources/tools available for me to share with patients (n=238)	8%	35%	57%
Low literacy/education level of the patient (n=237)	17%	61%	22%
Patient is overwhelmed with or focused on other health factors (n=239)	25%	61%	15%
Other health issues are more of a priority to discuss with patient (n=240)	19%	49%	32%
Patient is resistant to or refuses to discuss anemia (n=239)	1%	23%	76%
I am not sure how to have a discussion about anemia with patients (n=238)	2%	6%	92%

Which of the following resources, if any, would you find useful to enhance your discussions about anemia with your dialysis patients? (n=243)

- Fact sheets/brochures for patients **84%**
- Educational videos for patients..... **41%**
- Training materials on educating patients about anemia **50%**
- Professional education course **32%**
- N/A: I would not find any resources helpful **5%**
- Other (please specify) **6%**

Do you follow specific clinical guidelines to determine a treatment plan for your dialysis patients with anemia? (n=89)

- Yes **93%**
- No..... **7%**
- I am not aware of any specific guidelines **0%**

Which guidelines do you use? (n=83)

- Kidney Disease: Improving Global Outcomes (KDIGO) **87%**
- Kidney Disease Outcomes Quality Initiative (KDOQI)..... **45%**
- American Urological Association (AUA) **0%**
- American Society of Health-System Pharmacists (ASHP) **0%**
- American Society of Hematology (ASH)..... **1%**
- Other (please specify) **10%**

Do you agree or disagree with the following statements about prescribing ESA treatment for dialysis patients? (n=87)

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
I am well-versed in the risks associated with ESAs	53%	43%	3%	1%	0%
I know the recommended iron levels for ESAs to be effective	48%	46%	3%	2%	0%
I feel comfortable talking to my patients about the risks and benefits of ESAs	54%	38%	7%	1%	0%
I stay informed on current ESA treatment guidelines	49%	43%	7%	1%	0%

In your opinion, do your dialysis patients understand the reason they are being treated for anemia? (n=89)

- All of them do **7%**

Have you ever consulted with a pharmacist about recommended anemia treatment protocols for your dialysis patients? (n=88)

- Yes **27%**
- No..... **73%**

Do you prescribe iron supplementation as a treatment for anemia for your dialysis patients? (n=88)

- Yes **98%**
- No..... **2%**

Which of the following factors determine whether you prescribe oral or intravenous iron supplementation for your dialysis patients? (n=85)

- Dialysis treatment modality **62%**
- Iron status of patient..... **77%**
- Hemoglobin level of patient..... **53%**
- Patient history of transplantation **7%**
- Patient comorbidities **58%**
- Other (please specify) **14%**

Do you prescribe erythropoiesis-stimulating agents (ESA) to treat anemia in any of your dialysis patients? (n=88)

- Yes **99%**
- No..... **1%**

- Most of them do **56%**
- Some of them do **37%**
- None or almost none of them do **0%**

Appendix B: Patient Survey Responses by Survey Item

Please choose the statement that describes you best.
(n=749)

- I am living with a kidney transplant **7%**
- I am on dialysis **93%**

How often do you visit a nephrologist, dialysis center, or some other medical professional responsible for treating your kidney disease? (n=746)

- Less than once a month. **6%**
- 1 -3 times per month **27%**
- Weekly. **12%**
- More than once a week **54%**
- Daily **1%**

Has your doctor or nurse ever talked to you about a health condition called anemia? (n=750)

- Yes **71%**
- No. **20%**
- Not Sure **9%**

What have your doctors or nurses told you about anemia? (n=530)

- General information about anemia **74%**
- How anemia is related to kidney disease. **56%**
- Symptoms of anemia **44%**
- How to find out if you have anemia. **27%**
- Treatments for anemia **48%**
- Something else **3%**

When your doctor or nurse talked with you about anemia, do you feel he or she explained the information to you clearly? (n=535)

- Yes **85%**
- No. **5%**
- Not Sure **10%**

When your doctor or nurse talked with you about anemia, did you have enough time to ask questions? (n=534)

- Yes **87%**
- No. **5%**
- Not Sure **8%**

Do you feel comfortable asking your doctor or nurse questions about anemia? (n=532)

- Yes **96%**
- No. **2%**
- Not Sure **2%**

How much do you agree or disagree with the following statements?

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
I understand the effect that anemia has on my health as a kidney patient. (n=531)	43%	41%	9%	6%	1%
I understand the relationship between anemia and kidney disease. (n=482)	41%	40%	10%	8%	2%

Have you ever been told by your doctor or nurse that you have anemia? (n=526)

- Yes **77%**
- No. **19%**
- Not Sure **4%**

Have you ever taken medicine for anemia or been treated in another way for it? (n=404)

- Yes **93%**
- No. **4%**
- Not Sure **3%**

What kind of medicine or treatment have you used for anemia? (n=384)

- Iron pills **41%**
- Iron through an IV (iron given through a needle in your vein) **66%**
- A medicine given by a shot (erythropoiesis-stimulating agents (ESAs)) **37%**
- Blood transfusion **32%**

- Something else..... **7%**
- Not sure..... **3%**

Did your doctor or nurse ask you which anemia medicine or treatment you thought would be best for you? (n=381)

- Yes **37%**
- No..... **45%**
- Not Sure **18%**

How much do you agree or disagree with the following statements?

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
I understand why I have been treated or given medicine for anemia. (n=378)	54%	40%	4%	2%	0%
I understand why my doctor or nurse gave me the specific medicine or treatment I received for anemia. (n=358)	51%	36%	8%	4%	1%
I understand the risks of the anemia medicines or treatments I received. (n=359)	37%	30%	15%	15%	4%

Appendix C: Non-Response Bias Analysis, Provider Survey

With a 6% response rate, concern that the subset of respondents was in some way different from the subset of non-respondents is valid. If these two groups were fundamentally different, the survey results may not be generalizable to the renal provider population at large. Two analyses were performed to assess whether such differences exist.

One analysis compared known characteristics of both respondents and non-respondents. Results from the non-response bias analysis revealed that respondents were significantly different from non-respondents based on professional classification. As displayed in Figure C,

nurses were overrepresented in the group of respondents and physicians were underrepresented.

The second non-response bias analysis compared respondents who completed the survey early in the survey window to respondents who completed the survey once they had received multiple reminders, just before the deadline. No significant differences were found comparing the responses of those who took the survey early to those who took the survey late.

Given that some non-response bias was present, data collected on providers in this survey are not necessarily generalizable to the larger group of AKF's list of provider constituents or to renal providers at large.

Figure C. Classification of Medical Providers in Survey Population

	Population (n=5,629)	Respondents (n=341)	Non-Respondents (n=5,288)
Classification-Source List¹			
Physicians	53%	30%	54%
Other Medical Providers	2%	2%	2%
Nurses	45%	68%	44%

¹ $\chi^2 (2)=78.66, p<.001$

Appendix D: Non-Response Bias Analysis, Patient Survey

Analyses were conducted to determine whether distributions of race, gender and age differed by response status. The two groups did not differ significantly in terms of gender. However, the two groups did differ significantly on race and age. Respondents were more likely to be White/Caucasian, and less likely to be Black/African-American or Hispanic, than non-respondents. Respondents were also slightly older than non-respondents (Figure D). These differences were relatively small; therefore, researchers chose not to apply weights to the data to compensate for over- or under-represented categories of respondents.

There was little variation in survey responses by a respondent's age or race (i.e., there was only one survey item that varied by race and one that varied by age). There were some differences in responses by gender (i.e., males and females gave significantly different responses on five survey items).

Given that the variation of data was minimal, there is some evidence that results can be generalizable to AKF's pool of grant recipients. Still, caution should be used when generalizing results from the survey to the dialysis and transplant patient population at large.

Figure D. Demographic Characteristics of Patients in Survey Sample

	Sample (n=4,500)	Respondents (n=780)	Non-Respondents (n=3,720)
Race¹			
Black or African-American	37%	30%	38%
White or Caucasian	33%	46%	30%
Hispanic or Latino	19%	12%	21%
Asian	3%	3%	3%
Native Hawaiian or Other Pacific Islander	1%	1%	2%
Multiracial	<1%	<1%	<1%
Not Available	5%	6%	5%
Gender²			
Male	58%	55%	59%
Female	42%	45%	42%
Mean Age³	58.4	60.7	58.0

¹ χ^2 (7)=90.93, p<.001

² χ^2 (1)=3.42, p>.05 (Not Sig)

³ t (1245)=-6.04, p<.001

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