

**HEALTH AND SAFETY SURVEY**  
**TO IMPROVE PATIENT SAFETY IN END STAGE RENAL DISEASE**



**REPORT OF FINDINGS FROM THE ESRD PATIENT SURVEY**

**MARCH 2007**



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**PREPARED BY:**



## HEALTH AND SAFETY SURVEY PROJECT

### REPORT OF FINDINGS FOR THE PATIENT SURVEY

#### INTRODUCTION

The Institute of Medicine's ongoing efforts to assess and improve the nation's quality of care have brought to light the dramatic chasm between what is known as good quality care and what is actually delivered. The Health and Safety Survey Project focuses on reducing preventable medical errors and improving patient safety in End Stage Renal Disease (ESRD). The Renal Physicians Association (RPA), the Forum of ESRD Networks, and the National Patient Safety Foundation, collaborated over a two-year period to develop an Action Plan for ESRD Patient Safety. Among the top priorities was to conduct patient and health professional surveys to identify primary ESRD patient safety issues. Results from these surveys would then serve as the foundation for development of national initiatives to reduce errors and establish a culture of safety in ESRD.

This report presents findings from the patient survey conducted in response to the ESRD Action Plan. The patient survey was sponsored by the Renal Physicians Association and the Kidney and Urology Foundation of America (KUFA), in conjunction with the Network of New England, American Association of Kidney Patients (AAKP), American Nephrology Nurses Association (ANNA), Forum of ESRD Networks, and the National Renal Administrators Association (NRAA). Support was provided by an educational grant from Abbott Laboratories. The Centers for Medicaid and Medicare Services (CMS) assisted with support for drawing a random sample of patients from ESRD records.

#### METHODS

A study planning team and the Evaluation Advisory Committee (EAC) were established at the initiation of the Health and Safety Survey Project to provide guidance to the study process. The planning team included representatives from the RPA, ESRD Networks, AAKP, the evaluation contractor and the contractor for the educational campaign. The EAC extended planning team perspectives by including additional representation from the ESRD Network, RPA, ANNA, National Renal Administrators Association, and Abbott Laboratories. Both groups were involved in refining survey goals, developing and refining planning documents, and reviewing and refining survey questions, deployment plans, and analysis plans. Both the patient and professional surveys were designed, implemented, and analyzed by an independent contractor, Management Solutions for Health, Inc, under subcontract to the communications contractor, Captus Communications, LLC. The study director was Marianne H. Alciati, PhD, President of Management Solutions for Health, Inc.

**Survey Design and Pilot Testing:** The survey design process began with development of a hemodialysis process map and an analysis framework. The process map detailed inputs and outputs in each of five major stages in a dialysis session. Inputs reflected actions or factors that might contribute to or help resolve patient safety issues. Outputs in this context reflected potential patient safety issues. This map was reviewed by four patients and members of the EAC

for completeness and accuracy. Development of the process map was important to ensure consideration of all potential sources of safety concern in determining the final set of survey questions as well as other potentially important analysis variables.

Building on this process map, an analysis framework was then developed that presented draft safety survey questions characterized along two dimensions, the stage of a dialysis session as detailed in the process map and characteristics of potential safety issues. Characteristics of safety issues included a) types of safety issues and errors; b) frequency of safety issues and errors; c) factors that might contribute to safety issues and errors; and d) responses and systems for responding to safety concerns and errors. Identification of these characteristics for each survey item was important to ensure that the final set of survey questions would yield actionable information to inform the planned educational campaign.

The final survey included 50 questions and 84 variables. Eight questions included a skip pattern; depending on an individual's response to these questions, they might be directed to skip one or more subsequent questions. The survey was pilot tested among a sample of patients and revised based on interview feedback and review of pilot test findings by the EAC. Additionally, all planning team and EAC members reviewed and commented on the patient survey instrument several times. A copy of the final survey instrument is included in Appendix A.

**Sample Identification and Invitation:** The population of interest was patients receiving hemodialysis for ESRD who had been on hemodialysis for at least three months. The three month minimum was established to ensure that patients had sufficient experience on hemodialysis to provide a relevant perspective about patient safety-related issues, while not biasing the sample by excluding newer patients.

A random sample of patient records meeting these selection criteria was drawn from the CMS Renal Management Information System (REMIS) finder file by Network of New England staff. A total of 3,850 initial records were selected. A letter announcing the survey and ensuring that participation was voluntary and confidential and a brochure explaining the survey and providing contact information was sent to each selected patient on CMS stationery on May 1, 2006. A survey, second informational brochure and a stamped return envelope was mailed on May 19, 2006. A second survey and stamped return envelope was mailed to patients for whom a survey had not yet been received on July 26, 2006. All completed surveys were returned to the Network of New England office.

Promotional posters announcing the patient survey along with Health and Safety Survey brochures and links to a study website were distributed to each Network. These materials were intended to increase awareness of the ongoing Health and Safety Survey among ESRD health professionals and dialysis center staff so that they would be able to answer patient questions and confirm the legitimacy of the survey.

**Survey Receipt and Response Rates:** Of the initial 3,850 randomly selected records to whom the initial CMS letter was mailed, 263 were returned as undeliverable, approximately seven percent of the initial sample. Copies of the survey were sent to the remaining patients in the selection sample on May 19, 2006. Approximately two months after the initial survey mailing, 740 completed surveys had been returned. A reminder mailing including a second survey was

mailed to non-respondents on July 26, 2006. By October 6, 2006 an additional 403 surveys had been received yielding a final, un-cleaned survey sample of 1143 surveys. Using the total number of records for which a valid mailing address was available, the response rate was 32 percent.

**Data Entry, Data Cleaning, and Final Sample:** Surveys including no identifiable information were sent to the evaluation contractor for data entry. Double entry procedures were used to ensure data entry accuracy. Twenty-one surveys were blank and thus were removed during data cleaning and excluded from the sample. Nine additional records were removed from the sample during data cleaning due to ineligibility. Ineligible respondents included four respondents who were no longer receiving dialysis, four respondents who had not been receiving dialysis for at least three months, and one respondent for whom a text response indicated the patient was deceased, suggesting that someone other than the patient completed the survey. After these data cleaning procedures, the sample included 1,113 usable patient surveys.

**Statistical Analysis and Data Presentation:** Data was imported from an excel spreadsheet to SPSS 14.0 with an upgrade to SPSS 15.0 before the completion of analysis. Initial analyses consisted of data cleaning and coding missing values to appropriately account for skip patterns and other unique data characteristics. Univariate frequency distributions were generated for all questions. Upon inspection, decisions were made to derive grouped variables (e.g., level of patient involvement in care) before continuing analysis. Select frequency and cross-tabulation data is presented in the results section of this report.

## **RESULTS**

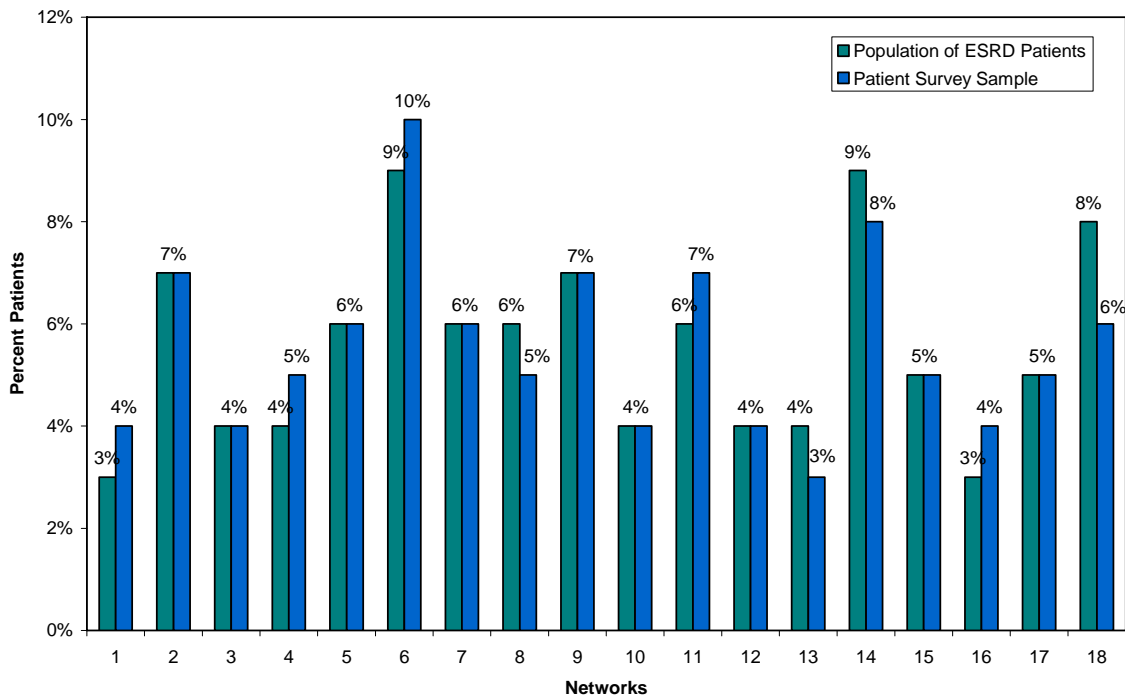
Survey results address ten general categories of information, including

- Sample characteristics – demographics and dialysis-related
- Survey assistance
- Communications
- Patient falls
- Medications
- Needle insertions
- Dialysis events – pre, during, and post
- Staff skills
- Medical mistakes
- Natural events

Results are presented in each of these categories below. Additionally, complete frequency and cross-tabulation analyses and graphics as generated from statistical software are presented in Appendix B.

**Sample Characteristics:** The mean age of patient respondents is 64 years and nearly half of all respondents are between 60 and 79 years of age. Males account for slightly more than half of all respondents (54%). Two-thirds of respondents (67%) are white and about one-quarter (28%) are African American. The vast majority (91%) of all respondents are non-Hispanic. Respondents include patients from all 18 ESRD Networks and, as shown in Figure 1, the distribution of survey respondents across Networks closely matches the distribution of all ESRD patients across Networks.

**Figure 1: Comparison of Population of ESRD Patients to Patient Survey Sample By Networks**



The vast majority of respondents (79%) receive hemodialysis through a vascular access. Less than one-quarter of respondents (21%) receive hemodialysis through a catheter and no respondents receive peritoneal dialysis. As shown in Table 1, most respondents (45%) have been receiving hemodialysis for more than three years and one-third (36%) have been receiving hemodialysis for between one and three years. Half of all respondents (51%) start their dialysis treatments between 5am and 10am and about a third (37%) starts their dialysis treatments between 10am and 3pm.

**Table 1: Percent Respondents by Time Receiving Dialysis**

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Between 3 & 6 months	48	4.2	4.4	4.4
	Between 6 & 12 months	162	14.3	14.9	19.3
	Between 1 & 3 years	392	34.6	36.0	55.3
	More than 3 years	486	42.9	44.7	100.0
	Total	1088	96.0	100.0	
Missing	No Response	45	4.0		
Total		1133	100.0		

**Survey assistance:** Approximately one quarter of respondents (26%) received assistance completing their surveys. Most often, a spouse or family member provided assistance (82%) and most often the type of assistance was reading survey questions (67%) and writing answers on the survey form (51%).

**Communications:** The vast majority of patients (82%) indicate that they are comfortable talking to the nurses, technicians, and dieticians at their dialysis center about problems with their dialysis treatments. The vast majority (80%) indicate that the instructions they receive from nurses, technicians, and dieticians about what to do to manage their kidney disease are clear.

**Involvement in Care:** Two-thirds of respondents (65%) also indicate that they are involved in making decisions about their care; an additional 24 percent indicate that they are somewhat involved in their care decisions.

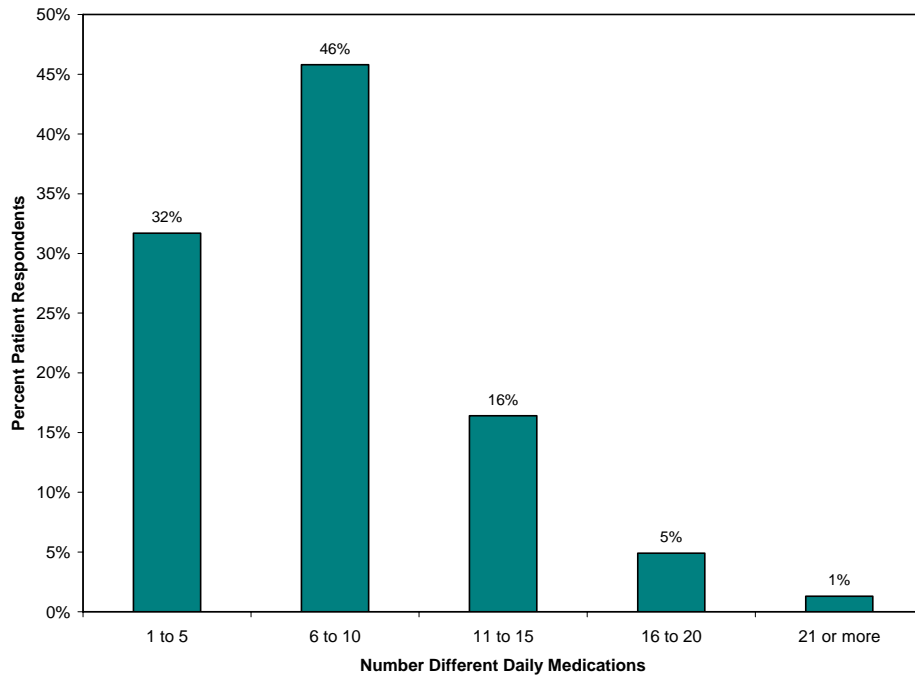
**Patient falls:** Patient falls appear to be an infrequent event. Ninety-five percent of respondents indicate that they have never fallen at their dialysis center in the past three months. Among the 55 patients indicating that they had fallen at their dialysis center in the past three months, the estimated mean number of falls was 1.3. Patients reporting greater levels of involvement in their dialysis care appear to be significantly less likely to report having fallen at their center in the past three months (any # falls = 5% involved vs. 8% uninvolved;  $X^2 = 20.722$ ;  $p=0.055$ ).

Most frequently, these patients fell because they were feeling dizzy or weak (60%). Seventeen respondents provided text responses indicating other reasons for falls. Four of these respondents indicated blood pressure or dizziness problems, four others noted problems getting into or out of a chair or wheel chair, and another four indicated that they tripped on a rug. Eight respondents who indicated that they had not fallen within the past three months provided text responses about reasons for falls. Two of these respondents also indicated problems getting into or out of wheel chairs and two others noted blood pressure problems.

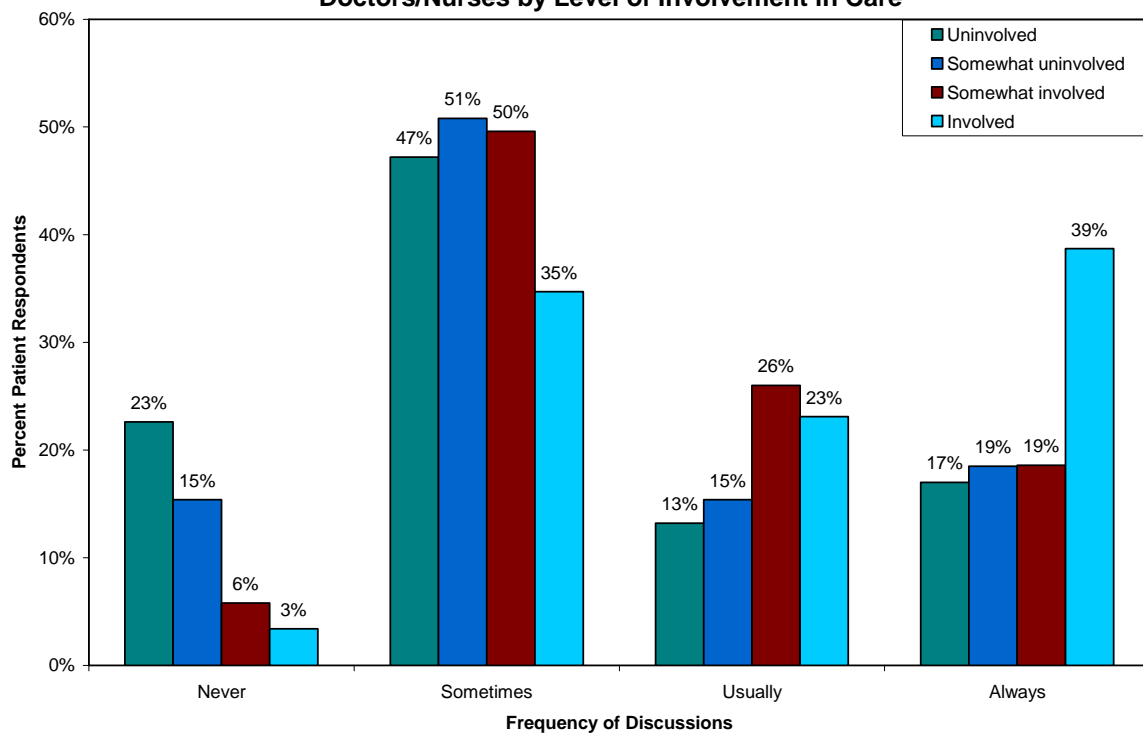
**Medications:** Almost half of patient respondents indicate that they take between 6 and 10 different medications every day. As shown in Figure 2, almost three quarters of all respondents take between one and 10 different medications each day.

A small proportion of all patient respondents (6%) indicate that when they talk to their doctor about the medications they are taking, they never discuss all the medications they are taking, including prescription and over-the-counter medicines. Forty percent of patients indicate that they discuss all their medications only ‘sometimes’ when talking with their doctor about their medications. However, as shown in Figure 3, analysis of the frequency of patient-reported discussion of medications with doctors or nurses varies as a function of the patients’ involvement in their dialysis care. Patients reporting higher levels of involvement in their own dialysis care are significantly more likely to discuss all their medications with their doctor or nurse ( $X^2 = 94.415$ ;  $p=0.000$ ).

**Figure 2: Percent Patients by Number of Different Daily Medications**



**Figure 3: Frequency of Patients Discussing All Medications with Doctors/Nurses by Level of Involvement in Care**

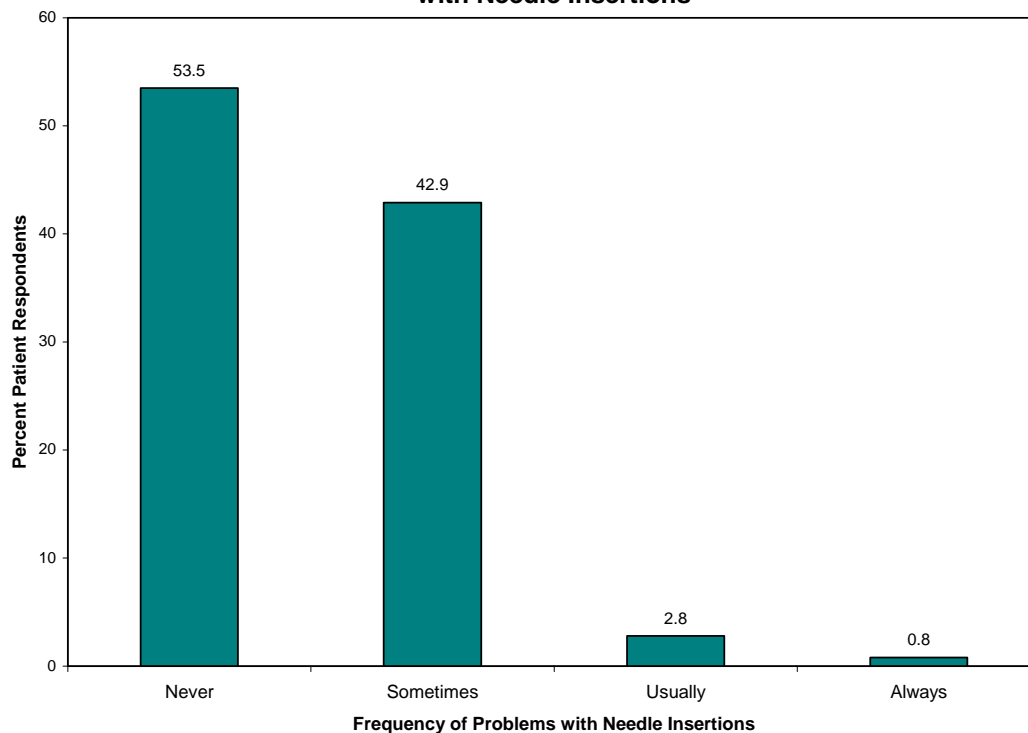




**Needle insertions:** Almost all patients (99%) have a nurse or technician at their dialysis center insert the needles for their dialysis treatments. Only about one-third of these patients (36%) indicate that the same nurse or technician usually or always inserts the needles for their dialysis treatments. As shown in Figure 4, only 4 percent of patients indicate that the nurse or technician usually or always has problems inserting the needles for their treatment. More than 40 percent of patients, however, indicate that the nurse or technician sometimes has problems inserting their needles. Thirty percent of patients indicate that staff tries more than twice to insert needles before getting assistance or successfully inserting the needles for their treatment (Table 2).

Patients who insert their own needles appear to have problems inserting their needles less frequently than the majority of patients for whom a nurse or technician inserts their needles. Sixty-one percent of those inserting their own needles never have problems with needle insertion compared to 54 percent of those having a nurse or technician insert their needles.

**Figure 4: Percent Patients by Frequency of Patient-Reported Problems with Needle Insertions**



**Table 2: Number of staff needle insertion attempts before getting help or successfully inserting**

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1	115	10.2	27.1	27.1
	2	184	16.2	43.3	70.4
	3	102	9.0	24.0	94.4
	4	13	1.1	3.1	97.4
	5	5	.4	1.2	98.6
	More than 5	6	.5	1.4	100.0
	Total	425	37.5	100.0	
Missing	No Response	206	18.2		
	Skipped – Never have problem	494	43.6		
	Skipped – Insert own needles	8	.7		
	Total	708	62.5		
Total		1133	100.0		

**Dialysis events:** The occurrence and frequency of safety-related events was assessed over the prior three months before, during, and following patients' dialysis treatments.

*Pre-Dialysis:* Adverse pre-dialysis events appear rare. Only 17 percent of patients indicate that there were problems with the settings on their dialysis machine in the past three months, and fewer than 5 percent indicate that the wrong dialyzer or dialyzing solution was set up for their treatment (3% and 2%, respectively) in this same time period. Further, more than 90 percent of patients indicate that their blood pressure and weight was always taken prior to dialysis sessions in the past three months (94% and 97%, respectively). Seventy-one percent of patients indicate that staff always asks if they are having any health problems before starting dialysis.

Interestingly, patients indicating greater levels of involvement in their dialysis care are significantly more likely than those who are less involved to report having their blood pressure recorded prior to dialysis (always = 94% involved vs. 87% uninvolved;  $X^2 = 17.988$ ;  $p=0.035$ ), and to be asked by staff about any health problems they are having (always = 76% involved vs. 54% uninvolved;  $X^2 = 57.149$ ;  $p=0.000$ ). Patients involved in their dialysis care also are significantly less likely to report having had problems with machine settings (yes = 16% involved vs. 32% uninvolved;  $X^2 = 102.279$ ;  $p=0.000$ ), or having had the wrong dialyzing solutions set up (yes = 3% involved vs. 6% uninvolved;  $X^2 = 57.149$ ;  $p=0.000$ ). In all cases, involved patient were significantly less likely to indicate that they did not know whether each of these events had occurred prior to any dialysis session in the past three months.

*During Dialysis:* While nearly 40 percent of patients (39%) indicate that they have felt pain at their access site during dialysis in the past three months, smaller proportions of patients report the occurrence of other problems during their dialysis sessions. Twenty-two percent of respondents indicate that in the past three months, there has been a problem with the flow of blood between their access site and the dialysis machine; 20 percent have had to stop treatment because of clotting; 15 percent have had to stop treatment because of a problem with the

machine; and 5 percent have had the needle come out of their access site before their treatment was finished.

Despite lower frequencies of patients reporting problems during dialysis, differences were observed as a function of patients' level of involvement in their dialysis care, similar to the patterns noted for pre-dialysis events. Patients involved in their dialysis care were significantly less likely to report having a problem with the flow of blood between their access site and the dialysis machine (yes = 21% involved vs. 26% uninvolved;  $X^2 = 63.528$ ;  $p=0.000$ ), having their dialysis session stopped due to machine problems (yes = 17% involved vs. 20% uninvolved;  $X^2 = 31.986$ ;  $p=0.000$ ), having the needle come out of their access site (yes = 3% involved vs. 15% uninvolved;  $X^2 = 23.792$ ;  $p=0.001$ ), and feel pain at their access site (yes = 38% involved vs. 56% uninvolved;  $X^2 = 16.109$ ;  $p=0.013$ ).

In the case of patients having a dialysis session stopped because of a clotting problem, similar overall patterns of significance were observed, however, differences appear stronger between both involved categories and those indicating they are somewhat uninvolved in their care (yes = 20% involved, 20% somewhat involved, 11% somewhat uninvolved, 17% uninvolved;  $X^2 = 24.812$ ;  $p=0.000$ ). In all these cases, involved patient also were significantly more likely to indicate they did not experience each problem and less likely to indicate that they did not know whether each of these events had occurred during any dialysis session in the past three months.

The vast majority of patients (89%) indicate that nurses and technicians always wash their hands or change gloves before touching their access site. Importantly, 86 percent of patients indicate that they never had a problem during dialysis that required medical help from a doctor. Seventy-two percent of patients indicated that the last time they had a problem during dialysis, it was easy to get help and another 20 percent of patients indicated it was somewhat easy to get help. Patients indicating greater levels of involvement in their care were significantly more likely to indicate it was easy to get help (easy = 78% involved vs. 59% uninvolved;  $X^2 = 34.493$ ;  $p=0.000$ ).

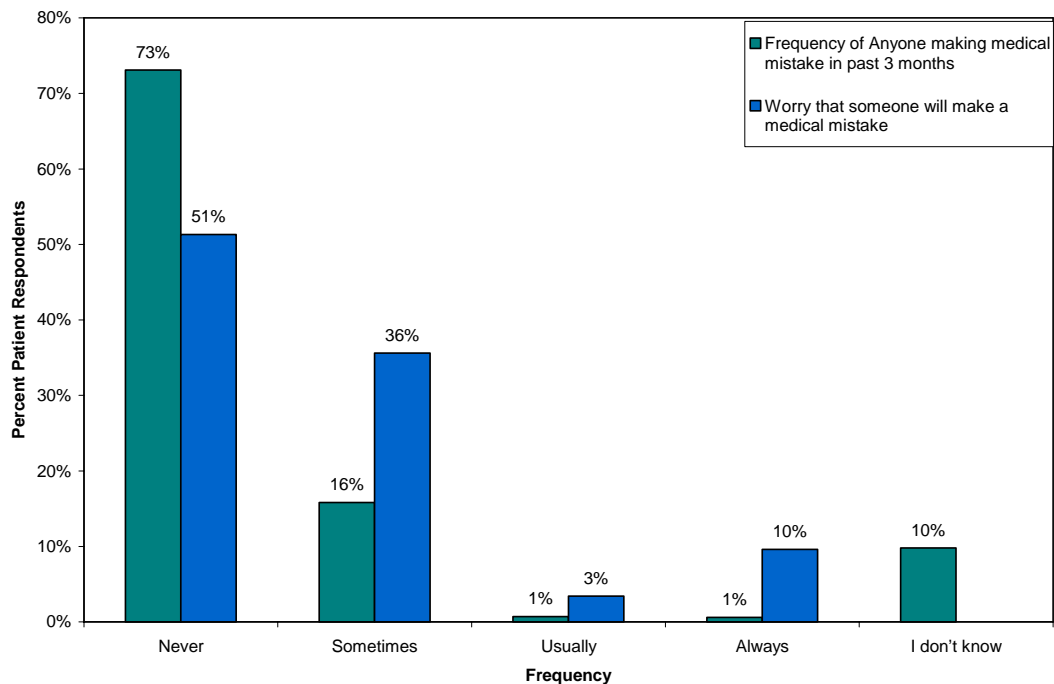
*Post-Dialysis:* Problems following dialysis treatment also appeared to be infrequent. Twenty-three percent of patients reported that in the past three months they experienced clotting problems following treatment and 17 percent reported having a problem with their access site bandage. Patients involved in their dialysis care are significantly less likely to indicate having each of these problems (clotting failure: yes = 21% involved vs. 49% uninvolved;  $X^2 = 31.819$ ;  $p=0.000$ ; bandage problems: yes = 14% involved vs. 23% uninvolved;  $X^2 = 10.889$ ;  $p=0.000$ ).

Similar to pre-dialysis levels, 92 percent of patients report that staff have always taken their blood pressure and 96 percent report that staff have always recorded their weight following dialysis treatments over the past three months. Patients more involved in their dialysis care were significantly more likely to report staff taking each of these measures (blood pressure: always = 95% involved vs. 89% uninvolved;  $X^2 = 33.254$ ;  $p=0.000$ ; weight: yes = 93% involved vs. 97% uninvolved;  $X^2 = 19.845$ ;  $p=0.019$ ).

**Staff skills:** Patients are generally favorable in their rating of the skills of staff at their dialysis center. More than half of respondents (55%) indicated that staff skills are excellent, and an additional 36 percent indicated that staff skills are good.

**Medical mistakes:** Nearly three-quarters (73%) of patients indicate that in the past three months no one has made a medical mistake at their dialysis center. An additional 16 percent indicate that mistakes sometimes occurred. Interestingly, 10 percent of patients indicate they don't know if a medical mistake was made in the past three months (Figure 5). Three quarters of patients indicate that they definitely would report a medical mistake if one occurred during their dialysis treatment. Almost half of all respondents indicate that they sometimes, usually, or always worry that someone will make a medical mistake during one of their dialysis treatments. As shown in Figure 5, patients are more likely to worry that someone will make a medical mistake than to indicate that a mistake has been made.

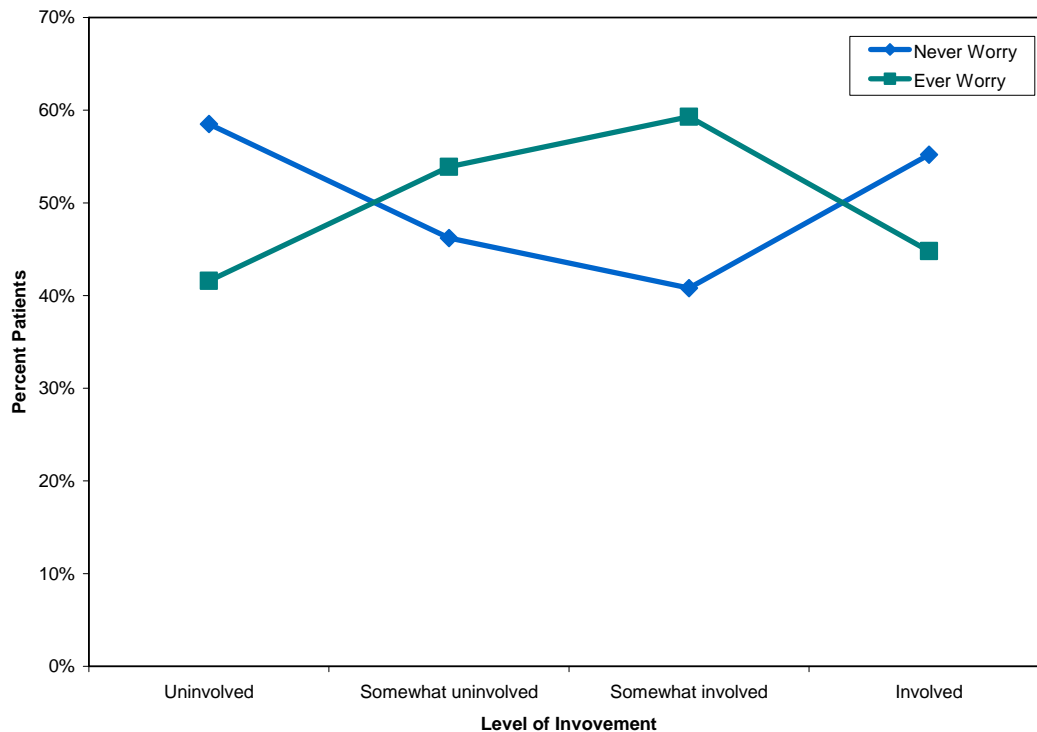
**Figure 5: Frequency of Patient Perceptions and Worry About Medical Mistakes**



Similar to patterns observed for dialysis events, patients who are more involved in their dialysis care, compared to those less involved, are less likely to indicate that a medical mistake has occurred at their dialysis center in the past 3 months (mistake never occurred = 77% involved vs. 56% uninvolved;  $X^2 = 49.747$ ;  $p=0.000$ ). However, as shown in Figure 6, worry about medical mistakes is lowest among patients indicating they are either uninvolved in their dialysis care or involved in their care ( $X^2 = 42.263$ ;  $p=0.000$ ). Larger proportions of patients indicating intermediate levels of involvement (somewhat involved or somewhat uninvolved) are more likely to worry about medical mistakes.

**Feel safe:** Sixteen percent of respondents indicate that some things make them feel unsafe at their dialysis center. Patients' indication about their feeling of safety at their dialysis center was not influenced by their level of involvement in their dialysis care.

**Figure 6: Patients Worry About Medical Mistakes by Level of Involvement in Care**



**Natural events:** The effects of natural events, such as a snow storm, flood or hurricane, on patients' dialysis treatments in the past year also was assessed. Fourteen percent of respondents indicated that their dialysis treatments had been affected by a natural event sometime within the past year. Among those indicating that their dialysis treatments had been affected by a natural event in the past year, these events were most often hurricanes (43%) or snow storms (31%). While only 154 respondents indicated that their treatments had been affected by a natural event, between 335 and 402 respondents ignored skip instructions and marked responses to each of 4 subsequent questions about the effects of the most serious natural event on their dialysis treatments. For this reason, results are presented in two ways, first, including only those indicating that their treatments had been affected by a natural event in the initial question, and second, for all respondents providing an answer to subsequent questions regardless of their response to the initial question.

*Patterns among those indicating treatments affected by any natural event in the past year:* A majority (84%) of those who indicated their treatments were affected by a natural event indicated that staff provided information before the most serious event to help them continue their treatments. However, nearly one quarter of these respondents (24%) also indicated that they missed treatments because of the most serious natural event. Only about 15 percent of these respondents found it difficult or somewhat difficult to contact their dialysis center following the most serious event and the same proportion indicated that they were very afraid or afraid that they would become very sick or die due to the most serious natural event.

*Patterns among all respondents providing answers to questions about the consequences of natural events in the past year:* Similar to the selected analysis above, a majority (80%) of all respondents indicated that staff provided information before the most serious natural event to help them continue their treatments. A slightly smaller proportion of all respondents compared to those indicating their treatments had been affected by a natural event in the past year, missed treatments due to the most serious natural event (13% vs. 24%, respectively). A smaller proportion of all respondents compared to those indicating their treatment had been affected by a natural event in the past year also found it difficult or somewhat difficult to contact their dialysis center following the most serious event (8% vs. 15%, respectively). However, the same proportion of all respondents compared to those indicating their treatments had been affected by a natural event in the past year, indicated that they were very afraid or afraid of becoming very sick or dying due to the most serious natural event (15%).

## **CONCLUSIONS**

This survey assessed dialysis patients' perspectives about in-center dialysis events that might be associated with patient safety problems. Individuals taking the survey were randomly selected from the population of ESRD patients and matched the distribution of patients across ESRD Networks. However, conclusions based on the survey should consider a small number of sample characteristics that might limit representativeness.

**Limitations:** Despite sample representativeness in terms of distribution across Networks, patient characteristics such as severity of ESRD and cognitive impairment associated with ESRD could influence survey responses. It is estimated that 30 to 40 percent of ESRD patients have cognitive impairments. To minimize the impact of disease severity and/or cognitive impairment, this patient survey was written at a 6<sup>th</sup> to 7<sup>th</sup> grade level, confirmed by literacy review, and final print layout and format was simple with large font size. Additionally, survey respondents were encouraged to get assistance in completing the survey, recognizing the trade-offs between participation and potential influence from those providing assistance. In general, the bias introduced by these factors is estimated to be small. Only about one quarter of respondents indicated they received assistance completing their surveys and most often assistance was provided by a family member.

Perhaps a more limiting factor than patient characteristics, however, is the final survey response rate. This survey achieved a 32 percent response rate, better than the projected 25 percent and good by current standards. But this rate still omits 68 percent of individuals invited to participate. To the extent that this non-response is systematic, bias may be introduced. While comparison of the final sample to the population in terms of distribution across Networks and other demographic characteristics suggests a highly representative sample, caution is warranted in light of the large non-response rate observed.

**Patient Safety Threats:** Generally, the proportion of patients indicating that potentially adverse events occurred during their dialysis visits over the prior 3 months is low. Fewer than 5 percent of patients indicate that a wrong dialyzing solution was set up for their treatment or that the needle came out of their access site. About 15 percent indicate that there have been problems with machine settings prior to or during dialysis sessions. And about 20 percent of patients indicate that they have had their session stopped due to clotting or blood flow problems.

However, these generally low frequency events may still pose a patient care concern. Considering that there are 304,799 prevalent patients receiving hemodialysis, these data suggest that nearly 61,000 patients experience at least one stopped dialysis session due to clotting or blood flow problems during the prior three months. Further, it is unclear how many times these events may occur for the same patient. While machine and blood flow problems in particular may be normal aspects of a dialysis session, these events also might reflect near misses or the initiation of events that ultimately cause patient harm. Data about potential contributing factors or actions taken to address or mitigate consequences of these events are not available from the patient safety survey. But at a minimum, these data do highlight machine stopping and potentially machine setting issues as important issues for further evaluation.

Needle insertion difficulties and patient pain at their access site remain problematic for patients. Almost half of patients indicate that the nurses or technicians inserting the needles for their dialysis treatments experience problems and 40 percent of patients indicate that they have experienced pain at their access site during treatment. Survey data also suggests that the same nurse or technician inserts needles for only about one third of patients. It is unclear if increased continuity of individuals inserting patient needles would reduce insertion problems or how frequently individual patients experience these problems. It is clear, however, that large numbers of patients experience the discomfort of needle insertion and site pain. While not a safety issue per se, these episodes likely contribute to reduced patient satisfaction with their health care experience and potentially could contribute to long-term problems providing care. Additional exploration of potential remedies to needle problems and the consequences related both to patient satisfaction and long-term care complications is warranted.

Patient falls have been reported as an important safety concern in dialysis centers. Data from this survey support the general rates of patient falls reported elsewhere, about 5 percent of patients reporting falls in the past 3 months. Extrapolated to the prevalent patient population, this suggests that more than 15,000 patients fall each quarter. The significance of this finding is the high likelihood of harm to patients from falls and the potential ease of preventing falls. Most patients indicate that they fall following treatment and fall because they are feeling dizzy or weak. Additional attention to post-dialysis blood pressure levels, assistance as patients initially stand coupled with queries about their steadiness, and removal of physical obstacles to patient navigation could all serve to reduce patient falls.

Another issue for consideration in efforts to improve patient safety relates to patient medications. Most dialysis patients take large numbers of different medications each day; almost half take between 6 and 10 different medications each day. But about half of patients indicate that they never or only sometimes discuss all medications with their doctor or nurse. The foundation for such discussions appears to be strong; more than 80 percent of patients indicate they are comfortable talking to dialysis center staff about problems with their dialysis treatments. Increased attention to patient medications and management of the large volume of daily medications may yield positive patient safety outcomes.

Survey data also indicated an important distinction between the occurrence of medical mistakes and patients' concern about such events. While only about one quarter of patients indicate that a medical mistake has been made in their dialysis center in the past 3 months, more than double

this proportion indicate they worry about medical mistakes. Further, reports of medical mistakes appear directly related to patients' level of involvement in their dialysis care, with those being more involved in their care also being less likely to indicate that a mistake has been made. But worry about medical mistakes is highest among those patients 'in the middle,' those who are only somewhat involved or somewhat uninvolved in their care and lowest among those either involved or uninvolved. Further assessment of distinctions between perceived frequency of adverse events and worry about events may provide a basis for reducing patient worry and increasing patient satisfaction.

Perhaps most important across all these issues is the pattern of lower rates of potential adverse events, increased awareness of events and potential safety issues, and higher frequency of discussions with doctors and nurse about medications among patients who are more involved in their dialysis care. This pattern persisted across each item discussed above and provides an important tool for addressing safety issues. Not only can patients be encouraged to become more involved in their care as an approach to reducing potential adverse events, but certain safety prevention efforts, such as falls prevention, might be targeted to those patients who are less involved in their own dialysis care. Further, patient satisfaction might be enhanced by efforts to increase patient involvement in their care.

**Summary:** In summary, the patient safety survey highlighted five specific areas for attention including session stopping, needle insertion and site problems, patient falls, discussion about medications and discrepancies between patients' reports of medical mistakes and worry about such mistakes. The survey also provided important and consistent information about the positive role of patient involvement in potentially reducing the occurrence adverse events and in enhancing patient satisfaction with care.



**APPENDIX A: SURVEY INSTRUMENT (NOTE FORMATTED IN BOOKLET LAYOUT)**

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**If you have any questions about this survey,  
please call or write the Patient Services Manager:**

**Roberta Bachelder, MA  
ESRD Network of New England  
30 Hazel Terrace  
Woodbridge, CT 06525  
Toll-free: 866-286-ESRD (3773)  
rbachelder@nw1.esrd.net**

# **Patient Health & Safety in Hemodialysis Centers**

## **It's Important!**



**Your answers to all questions in this survey will remain confidential. Any information that might identify you will be kept private. None of your doctors, nurses, or anyone at your dialysis center will see your answers.**

**You can choose not to take this survey. Your decision will not affect your Medicare benefits in any way.**

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**Si usted habla español, recuerde que un miembro de la familia, amigo, o personal del centro de diálisis puede ayudarle a leer el cuestionario para que usted pueda marcar sus repuestas.**

**Pero la persona que le esta ayudando no debe contestar por usted ninguna de las preguntas.**

## **Instructions**

- ◆ Answer the questions in this survey by checking the box next to your answer, like this:  
☒ your answer
  
- ◆ Sometimes you will skip questions in the survey. When you see an arrow next to your answer, the arrow tells you which question to answer next. In the example below, if you answered **No, you skip questions** and answer Question 5 next.

Example:

- ☐ Yes
- ☒ No **Go ➡ to Question 5**

- ◆ You should check only one answer for each question, except when you see a note like this: *(You can check more than one answer)*
  
- ◆ Remember that a family member, friend, or the staff at your dialysis center can help you read the survey and mark your answers. But they **should not tell you how to answer** any of the questions.

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1. Has a doctor ever said you have permanent kidney failure or End Stage Renal Disease (ESRD)?

- ☐ No ⇨  
☐ Yes

**Do not take the survey. Mail the survey to us in the envelope we provided.**

2. Which type of dialysis do you currently get?  
(Check each type of dialysis that you currently get)

- ☐ hemodialysis through a vascular access  
☐ hemodialysis through a catheter (temporary or permanent)  
☐ peritoneal dialysis through my stomach ⇨  
☐ I do not get hemodialysis any more ⇨

**Do not take the survey. Mail the survey to us in the envelope we provided.**

3. How long have you been receiving hemodialysis?

- ☐ Less than 3 months ⇨  
☐ Between 3 and 6 months  
☐ Between 6 and 12 months  
☐ Between one and three years  
☐ More than 3 years

**Do not take the survey. Mail the survey to us in the envelope we provided.**

- 4.** Is anyone helping you with this survey?
- ☐ No ➡ **Go to Question 7**
  - ☐ Yes
- 5.** Who is helping you with this survey? (*Check only one answer*)
- ☐ My spouse or family member
  - ☐ A friend who does not receive dialysis
  - ☐ A friend who also receives dialysis
  - ☐ A nurse, technician, or dietician at my dialysis center
  - ☐ Other – Who: \_\_\_\_\_
- 6.** How is this person helping you? (*You can check more than one answer*)
- ☐ Translating the survey instructions and questions into my language
  - ☐ Reading the survey questions and the choices to me
  - ☐ Writing my answers on the survey
  - ☐ Helping me answer the questions
  - ☐ Other – How: \_\_\_\_\_
- 7.** How many different medicines do you take every day?
- ☐ 1 to 5
  - ☐ 6 to 10
  - ☐ 11 to 15
  - ☐ 16 to 20
  - ☐ 21 or more

**Page 4**

- 8.** When you talk to your doctors or nurses about your medicines, how often do you talk about all the medicines you are taking including prescription and over-the-counter medicines?

☐ Never  
☐ Sometimes  
☐ Usually  
☐ Always

**Before Your Dialysis Treatment Starts**

- 9.** In the past 3 months, how often did staff take your blood pressure before you started your dialysis treatment?

☐ Never  
☐ Sometimes  
☐ Usually  
☐ Always

- 10.** In the past 3 months, how often did staff record your weight before you started your dialysis treatment?

☐ Never  
☐ Sometimes  
☐ Usually  
☐ Always

- 11.** In the past 3 months, how often did someone on the staff at your dialysis center ask you if you were having any health problems before you started your dialysis treatment?

☐ Never  
☐ Sometimes  
☐ Usually  
☐ Always

**Page 5**

**12.** In the past 3 months, were there any problems with the settings on your dialysis machine?

- ☐ No
- ☐ Yes
- ☐ I don't know

**13.** In the past 3 months, did anyone ever set up the wrong dialyzer for your dialysis treatment?

- ☐ No
- ☐ Yes
- ☐ I don't know

**14.** In the past 3 months, did anyone ever set up the wrong dialyzing solution (bath) for your dialysis treatment?

- ☐ No
- ☐ Yes
- ☐ I don't know

### **When Your Dialysis Treatment Starts**

**15.** When do you usually **begin** your dialysis treatment?

- ☐ Between 5:00am and 10:00am
- ☐ Between 10:00am and 3:00pm
- ☐ Between 3:00pm and 8:00pm
- ☐ Between 8:00pm and Midnight
- ☐ Other – When: \_\_\_\_\_

**16.** Who usually inserts the needles for your dialysis treatments?

- ☐ A nurse or technician ➡ **Go to Question 18**
- ☐ I do

**Page 6**

**17.** In the past 3 months, how often did you have a problem inserting the needles for your dialysis treatment?

- ☐ Never ➡ **Go to question 21 on page 8**
- ☐ Sometimes ➡ **Go to question 21 on page 8**
- ☐ Usually ➡ **Go to question 21 on page 8**
- ☐ Always ➡ **Go to question 21 on page 8**

**18.** How often does the **same** nurse or technician insert the needles for your dialysis treatments?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always

**19.** In the past 3 months, how often did the nurse or technician have a problem inserting the needles for your dialysis treatment?

- ☐ Never ➡ **Go to question 21 on page 8**
- ☐ Sometimes
- ☐ Usually
- ☐ Always

**20.** Think of the last time staff had a problem inserting the needles for your treatment. How many times did they try to insert the needles before getting help or successfully inserting the needles?

- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ More than 5

**Page 7**



### **During Your Dialysis Treatment**

**21.** In the past 3 months, how often did the nurse or technician wash their hands or change gloves before touching your access site?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always
- ☐ I don't know

**22.** In the past 3 months, were there ever any problems with the flow of blood between your access site and the dialysis machine?

- ☐ No
- ☐ Yes
- ☐ I don't know

**23.** In the past 3 months, was your dialysis treatment ever stopped because of blood clotting or thickening?

- ☐ No
- ☐ Yes
- ☐ I don't know

**24.** In the past 3 months, was your dialysis treatment ever stopped because of a problem with your dialysis machine?

- ☐ No
- ☐ Yes
- ☐ I don't know

**25.** In the past 3 months, did the needle ever come out of your access site before your dialysis treatment was finished?

- ☐ No
- ☐ Yes
- ☐ I don't know

**26.** In the past 3 months, did you ever feel pain at your needle access site during your dialysis treatment?

- ☐ No
- ☐ Yes
- ☐ I don't know

**27.** In the past 3 months, how often did you have a problem with your dialysis treatment that needed medical help from a doctor?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always

**28.** Think of the last time you had a problem during your dialysis treatment. How difficult or easy was it for you to get help?

- ☐ Difficult
- ☐ Somewhat difficult
- ☐ Somewhat easy
- ☐ Easy

### **After Your Dialysis Treatment**

**29.** In the past 3 months, did you ever have any problems because your blood would not clot after your dialysis treatment?

- ☐ No
- ☐ Yes
- ☐ I don't know

**30.** In the past 3 months, how often did staff take your blood pressure after your dialysis treatment?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always

**31.** In the past 3 months, how often did staff record your weight after your dialysis treatment?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always

**32.** In the past 3 months, did you have any problems with the bandage on your access site after your dialysis treatment?

- ☐ No
- ☐ Yes
- ☐ I don't know

### **Anytime While You Are At Your Dialysis Center**

**33.** In the past 3 months, how many times did you fall at your dialysis center?

- ☐ Never ➡ **Go to question 35**
- ☐ One time
- ☐ Two times
- ☐ Three or four times
- ☐ Five or more times

**34.** Think of the last time you fell at your dialysis center. Why did you fall? *(You can check more than one answer)*

- ☐ I was feeling dizzy or weak
- ☐ I tripped on tubing or an electric cord
- ☐ I tripped getting off the scale
- ☐ The floor was wet
- ☐ I had to walk too far
- ☐ I had trouble walking up or down stairs
- ☐ I don't know
- ☐ Other – How: \_\_\_\_\_

**35.** How comfortable do you feel talking to the nurses, technicians or dieticians at your dialysis center about problems with your dialysis treatments?

- ☐ Uncomfortable
- ☐ Somewhat uncomfortable
- ☐ Somewhat comfortable
- ☐ Comfortable

**36.** How involved are you in making decisions about the care you receive for your kidney disease?

- ☐ Uninvolved
- ☐ Somewhat uninvolved
- ☐ Somewhat involved
- ☐ Involved

**37.** How clear are the instructions that the nurses, technicians, or dieticians give you about what you need to do to manage your kidney disease?

- ☐ Unclear
- ☐ Somewhat unclear
- ☐ Somewhat clear
- ☐ Clear

**38.** Overall, how would you describe the skills of the nurses and technicians who give you your dialysis treatments?

- ☐ Poor
- ☐ Fair
- ☐ Good
- ☐ Excellent

**39.** In the past 3 months, how often did anyone make a mistake in **your** dialysis treatment?

- ☐ Never ➡ **Go to question 41**
- ☐ Sometimes
- ☐ Usually
- ☐ Always
- ☐ I don't know

**Page 12**

**40.** What happened when someone made a mistake during **your** dialysis treatment? *(You can check more than one answer)*

- ☐ Nothing
- ☐ The nurse or technician got help from other staff at the center
- ☐ A different nurse or technician completed my dialysis treatment
- ☐ The center staff used a different machine to complete my dialysis treatment
- ☐ The center staff had to repeat my dialysis treatment
- ☐ The problem went away by itself
- ☐ The dialysis center reviewed or changed its policies
- ☐ I decided to go to a different dialysis center
- ☐ I don't know

**41.** If someone made a medical mistake during your dialysis treatment, would you report it?

- ☐ Definitely not
- ☐ Probably not
- ☐ Maybe
- ☐ Definitely yes

**42.** Overall, how often do you worry that someone might make a medical mistake during one of your dialysis treatments?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always

**Page 13**

**43.** Does anything make you feel unsafe when you go for treatments at your dialysis center?

- ☐ No ⇔  
☐ Yes

**Go to question 45  
on page 15.**

**44.** What makes you feel unsafe when you go for treatments at your dialysis center? *(Write your answer below)*

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**These last few questions ask about any natural events, such as hurricanes, snow storms or flooding that can make it difficult to get your dialysis treatments.**

**45.** In the past **6 months**, were your dialysis treatments affected by any natural events, such as hurricanes, snow storms, or flooding?

- ☐ No ➡  
☐ Yes

**Thank you. Please  
return the survey in the  
envelope provided.**

**46.** What types of natural events affected your dialysis treatments? *(Check All That Apply)*

- ☐ Flooding  
☐ Snow storm  
☐ Blizzard  
☐ Tornado  
☐ Wind storm  
☐ Hurricane  
☐ Other: \_\_\_\_\_

**47.** Think of the most serious natural event that affected your dialysis treatments **in the past 6 months**. Did staff at your dialysis center give you any information before the event to help you continue your dialysis treatments during or after the event?

- ☐ No  
☐ Yes

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**48.** Think of the most serious natural event that affected your dialysis treatments **in the past 6 months**. Did you miss any of your dialysis treatments because of the event?

- ☐ No
- ☐ Yes
- ☐ I don't know

**49.** Think of the most serious natural event that affected your dialysis treatments **in the past 6 months**. After the event, how difficult was it to contact your dialysis center?

- ☐ Difficult
- ☐ Somewhat difficult
- ☐ Somewhat easy
- ☐ Easy
- ☐ I don't know

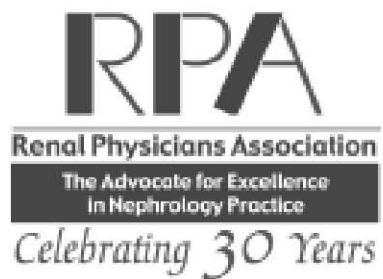
**50.** Think of the most serious natural event that affected your dialysis treatments **in the past 6 months**. How afraid were you that you would become very sick or die because you could not get your dialysis treatments?

- ☐ Very afraid
- ☐ Afraid
- ☐ Somewhat afraid
- ☐ Not at all afraid



**Thank you. Please return  
the survey in the  
envelope provided.**

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**APPENDIX B:**  
**HEALTH AND SAFETY SURVEY PROJECT: PATIENT SURVEY RESPONSE FREQUENCIES**

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**Included as a separate document.**