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Evaluation of the Content of the Dialysis Facility Compare Website: Final Report

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EXECUTIVE SUMMARY

This final report presents our findings and recommendations based on data collected from patients, family members, and professionals as part of the Dialysis Facility Compare (DFC) website evaluation. This evaluation is being conducted for the Centers for Medicare & Medicaid Services (CMS) by Research Triangle Institute (RTI) and the Medical Education Institute (MEI). It began in September 2002 and is scheduled to conclude in November 2004. The study has four general objectives:

- Gain feedback on current DFC content and features from patients, family members, and professionals;
- Identify who uses, processes, or retrieves the information on DFC;
- Study the information needs of potential DFC users; and
- Identify ways to improve the DFC.

This executive summary includes four sections: 1) methods; 2) cross-cutting themes and recommendations; 3) detailed findings and recommendations (including website presentation and navigation, facility characteristics, quality measures, and dialysis and kidney disease-related information and links); and 4) conclusions.

Methods

During the period from December 2002 through May 2003, we conducted four site visits, of approximately one week each, in four cities in different regions of the country (Washington, D.C., Atlanta, Chicago, and Phoenix). Data collection with dialysis and pre-ESRD (chronic kidney disease) patients, family members, and professionals included focus groups, triads (small focus groups), and in-person interviews. We showed them the DFC website live on the Internet, and led them through it to get their reactions and recommendations for improvement.

Focus groups, triads, and interviews are qualitative research methods. We selected those methods for this study since our research objectives include mainly subjective and exploratory issues on a topic (the DFC website) with which most respondents had little or no experience.

From April through July 2003 we also conducted telephone interviews with representatives of dialysis chains, managed care organizations (MCOs), renal disease management organizations (DMOs), and national dialysis stakeholder organizations.

Overall, we collected information from a total of 270 participants during the data collection phase of this project. Table ES 1 presents the numbers of participants by type.

Table ES 1
Study Participants by Type

Participant type	**Number**
Dialysis patients & family members	98
Dialysis professionals & technicians	98
Pre-ESRD patients & family members	42
Pre-ESRD professionals	8
Senior staff of dialysis chains, MCOs & DMOs	18
Senior staff of national renal organizations	6
TOTAL	270

With small samples of respondents, the results of qualitative research are not intended to be interpreted quantitatively or generalized to the population under study. They are instead intended to generate more depth of insight into a topic, which can be especially useful in guiding development or enhancement of services such as the DFC website.

Cross-Cutting Themes

In reviewing the findings across all of our data collection efforts, we identified 13 cross-cutting themes. The first nine are general themes, that cut across most of the respondent types; the last four are more specific, focusing on fewer respondent types. Pre-ESRD themes are highlighted in the latter group due to the pressing need for improved education and intervention efforts for that population.

After reviewing the DFC website, patients and family members indicated they have a strong interest in its continuing development. Hemodialysis and pre-ESRD patients were pleased to have access to the data on DFC, and saw it as relevant for their needs, although they wanted access to more data and to have it presented in a more user-friendly fashion. All respondents indicated that they view an enhanced DFC as having the potential to aid them in better understanding and managing the care they receive, in being more knowledgeable consumers of dialysis services, and in becoming more effective collaborators with their clinical providers.

Few patients, family members, or professionals are currently using the DFC website. Those who are using it are mostly professionals. This highlights the need for CMS to get the word out about DFC, and to make it more user-friendly and more responsive to the needs of the intended audience, patients and family members, and to professionals who often serve as their information intermediaries.

All types of respondents provided many recommendations for ways to improve DFC. Both the number and range of respondents' recommendations for improvements to the DFC were striking. As expected, dialysis patients and family and dialysis professionals were the respondents with the most ideas, although each of these groups presented over 100 recommendations, many more than expected. This indicates the depth of their interest in the DFC as a medium for communication regarding dialysis issues, and the potential benefits they see as possible.

Medicare is perceived as an honest broker of dialysis, kidney disease, and dialysis facility information. Many respondents commented on the value of receiving information directly from Medicare. Moreover, none were critical or suspicious of either Medicare or CMS as a source of information. Other sources of dialysis information were often viewed as somewhat suspect, given the perceptions that the sponsoring organizations may have underlying agendas. It appears that Medicare is a powerful and trusted "brand name," that makes it an appropriate sponsor for a website such as DFC, that contains a range of quality of care, service characteristics, and dialysis and kidney disease information.

The goal of DFC is to provide information to give patients more choices; however, we found that patients' ability to choose dialysis facilities varied by site. We found several variations across the sites in which we conducted our focus groups, triads, and interviews. Chicago and Phoenix participants reported more choice available for dialysis patients among facilities than did participants in Washington, DC and Atlanta. This was consistent across both patient and professional respondents. It may reflect differences in the supply of dialysis facilities in those communities. Nonetheless, it was clear that patients' ability to make choices between dialysis facilities is not uniform across all cities. Nephrologists' affiliations with particular dialysis facilities were reported to be looser in Phoenix, providing patients more facility options if they wanted to avoid switching nephrologists.

At the same time, across all sites dialysis patients were perceived to have less choice among facilities when first starting dialysis, but more after they have been on dialysis for a while. One consistent finding regarding patient choice was that their options increase with more experience on dialysis. This seemed to be a combination of two factors. First, during the transition to dialysis and the first several months, patients often feel very sick and emotionally distraught. That makes it hard for them to be active participants in managing their care and treatment choices. Second, patients learn more about the range of options they have over time. Hemodialysis patients, who receive treatment three times per week, have many opportunities to talk to providers and to other patients about alternate facilities that are available to them.

Patients and family members prefer graphical displays of information. Both dialysis and pre-ESRD patients responded especially well to the graphical displays of quality data. The colored bar graphs for adequacy and anemia in particular seemed to enliven them. They were much less engaged with text-based descriptions. Professionals were better able to absorb text-based information, but most agreed that the graphics make more sense for a website such as DFC that is targeted to patients. It may be that graphics are the best way to encourage patients to become more active in comparing facilities on quality, features, and services.

Diagrams were also recommended frequently by all types of respondents as a way to supplement text-based dialysis and kidney disease information materials. For example, diagrams could be used to illustrate how an arteriovenous fistula is constructed, as a lead-in to describing its benefits in comparison to synthetic grafts or catheters for vascular access. Alternatively, DFC could provide more links to other sites with diagrams or graphics used to illustrate points for dialysis patient education.

Internet access for patients and family members was less of a problem than expected. Many patients reported having family, friends, or local libraries that could provide them Internet access. In one city, Phoenix, we found that most patients indicated they had Internet access, a finding confirmed by dialysis professionals interviewed in that city. Across all four cities we found that most family member respondents indicated they had Internet access, either at home or at work.

In the future, Internet access will be steadily expanding across the country. It may be that Internet access per se will not be as much of a barrier to DFC website use, as some have suggested, but rather the key will be to ensure that patients and family members feel they can gain tangible benefits from using the Internet and the DFC website. That could motivate them to more actively seek ways to gain Internet access through public facilities or their social networks.

Public reporting of quality data was perceived by both professionals and patients to have value for quality improvement. We were surprised to hear a range of different professionals, in several different cities, supporting the notion that the quality data provided to patients and family members on the DFC website could have a positive impact on quality of care. We expected them to challenge that idea. In contrast, many indicated that just knowing that the data are available for public viewing will make them and their professional colleagues work harder to improve patient care. In addition, many patient and family member respondents indicated they would use the quality data to monitor performance of the dialysis facilities they use.

Dialysis family members and peritoneal dialysis patients were less satisfied with the current DFC website. These groups saw the resources currently on the website as responding less to their needs. Family members wanted more information to inform them about the disease and about ways they could enhance their roles to best help the patient. Peritoneal dialysis patients viewed the website as oriented too much toward hemodialysis patients, repeating a pattern they had experienced previously in their dialysis facilities and among professionals. As a result, the DFC was reinforcing a sore point that made it hard for them to focus on the benefits of DFC. Adding data and materials to the DFC to better respond to the needs of these groups should not be too difficult, however. They indicated a number of ways the DFC could be improved to be more relevant to their needs.

DFC has the potential to be a source of information and education for pre-ESRD patients and family members who have less knowledge of kidney disease, dialysis, or dialysis facilities. We found pre-ESRD patients and family members to have very little knowledge of kidney disease, dialysis, or dialysis facilities, especially in comparison with dialysis patients and family members. This was striking, since we recruited pre-ESRD respondents through pre-ESRD educators, who referred patients who had completed their pre-ESRD education programs. We expected these patients would be more knowledgeable due to the education they had received. Dialysis professionals also reported that patients generally have very little understanding of the disease or its treatment when they begin dialysis.

While psychological avoidance or denial may play a part in this situation, it was still surprising that people with such a severe chronic disease had not taken steps to learn more about it and its treatment. This is especially serious given the recent evidence that a range of early interventions – in the pre-ESRD phase of the disease – can have many positive impacts in terms of slowing progression to ESRD, reducing complications and comorbidities, and providing for a smoother transition to dialysis. However, this situation also means that the Internet could potentially have a large role in providing a source of ongoing information and education that could be accessed directly by pre-ESRD patients and family members themselves.

Pre-ESRD educational programs are still in their early stages of development. Most pre-ESRD professionals reported providing a two-hour class to participants on a group or one-on-one basis. We were surprised by how limited these pre-ESRD programs were, and the educators agreed that they would like to be able to provide more extensive programs. A single two-hour class seems very short given the many issues that need to be covered regarding pre-ESRD care, methods for patient self-management, modality choice, placement of vascular access, the transplant option, the transition to dialysis, and others. Funding is an issue that typically limits the scope of the classes, but this may indicate that there is a need for alternate educational vehicles that patients or family members can access on their own, such as the DFC website. It also points to the potential role the DFC website could play as a resource for pre-ESRD educators, as a resource for their curriculums and to show patients where they can go for additional information.

Pre-ESRD educators were aware of the limitations of their programs, so they might be willing to consider ways of supplementing them with Internet resources, including the DFC website and others. The goals of increasing patient self-management and involvement in decision making may be best achieved by involving patients early on in the disease process, in the pre-ESRD stage. In that way, the expectations and habit of active involvement in their care and treatment decisions could start early and be more easily sustained after the transition to dialysis. A number of dialysis professionals also commented on the need for better pre-ESRD patient preparation.

MCOs and DMOs saw potential business applications for DFC. They indicated that the DFC may have potential benefits beyond its primary audience of patients and family members. Representatives from disease management firms indicated they could use DFC information as a tool for exploring local markets. This could be beneficial as they expand their operations into new regions. They could also use DFC as a way of reviewing their breadth of coverage in their existing markets, and for oversight of affiliated facilities. Similarly, MCOs saw the DFC as a way to identify alternate facilities in their existing markets and conduct initial screening of facilities applying to join their networks.

Detailed Findings and Recommendations

Our detailed findings and recommendations for revising the DFC website are presented below in four categories: website presentation and navigation; facility characteristics; quality measures; and dialysis and kidney disease information. Each section includes findings and recommendations on several topics.

The recommendations were developed from the respondents' recommendations, our assessment of the respondent recommendations, our own analysis of the strengths and weaknesses of the DFC website, and our experience with other projects on related topics. We also presented and discussed earlier versions of these recommendations with the DFC Consumer Workgroup, a panel of outside experts on dialysis and kidney disease, and with CMS staff.

Website Presentation and Navigation

Explaining the Benefits of DFC. The current version of the website does a good job of explaining the mechanics of selecting dialysis facilities and viewing their facility characteristic and quality measures. However, a number of participants indicated that the context of DFC, and the benefits it can provide, are not clearly explained for users at the outset. They wanted to know more about why to use DFC, not just about how to use it. Our recommendation is:

- ***Include explanations of the context, goals, intended uses, and benefits of DFC on the first page that opens when a link to DFC is clicked by a user. Consider alternate ways of presenting this information.***

Readability. Both patient and professional participants frequently commented that the reading level of many of the text passages in DFC was too high. For example, both groups indicated that too many technical words are used in the website. Terms such as "ESRD" and "erythropoietin" will be unfamiliar to many dialysis patients and family members. As noted, pre-ESRD patients are even less likely to understand these terms.

We conducted Flesch-Kincaid reading grade level analyses for the "Read This" paragraph, several of the text explanations for the quality measures and several glossary definitions for the quality measures. In each case, the reading level was found to be at the 12th grade level. That is much too high for a website targeted at dialysis patients, who are often from lower socioeconomic backgrounds. Our recommendation:

- ***Reduce the reading grade level of text in the DFC website to 7th-9th grade.***

Another readability issue was font size. Both patients and professionals commented that the size of the type used in the website would be too small for some patients who had vision problems. Providing users a way to increase the font size was one recommended solution that has already been implemented in some Next Generation Compare websites on Medicare.gov, such as Home Health Compare. Our recommendation:

- ***Provide a button on DFC labeled "Use Larger Font" like the one on Home Health Compare.***

Density of Text. In our research, we found that patients and family members skipped over the long, dense paragraphs of text often used in DFC. For example, they would not concentrate on the text explanations of the quality measures unless they were read to them by our staff. One of the basic principles of web design is to break long text sections into more manageable pieces, a technique known as "chunking." Following this principle, our recommendations are:

- ***Use shorter sentences and paragraphs in DFC.***
- ***Include bulleted lists when possible.***
- ***Add columns to limit the line length to 30-50 characters where possible.***
- ***Add more subheadings to break up long paragraphs.***

Spanish. Recommendations for creating a Spanish-language version of DFC came from all types of respondents. There were no dissenting voices on this issue. Fortunately, a Medicare.gov model for developing a Spanish website exists in the Nursing Home Compare website. It includes a toggle button enabling users to switch each web page from English to Spanish and back again. The button reads "Vea en Espanol" on each page in English, and "View in English" on each page in Spanish. Our recommendation:

- ***Create a Spanish language version of DFC using the Nursing Home Compare model.***

Non-Text Content. Patients, family members, and professionals all commented on the relative lack of non-text content in DFC, compared to other websites they had seen. It was quite apparent that both dialysis and pre-ESRD patients and family members all became much more interested in the website when the colored bar graphs for the quality measures were presented. In the focus groups and triads it was evident in both their comments and body language. They "lit up" when those non-text elements came on the screen, especially following a number of pages of text-oriented content.

We reviewed a number of other government websites, and found that many make substantially more use of non-text elements than DFC. In particular, the Centers for Disease Control and Food and Drug Administration websites make more use of graphics, diagrams, and even animation. The professional Medicare website, www.cms.hhs.gov, makes good use of photographs as well. It contains a series of 10 photographs that the home page cycles though each time it is opened. Our recommendation:

- ***Increase use of non-text content on DFC, including graphics, photographs, diagrams, and cartoons.***
- ***Add a mapping function for users seeking dialysis facilities, with the ability to "zoom" into particular locations (like MapQuest.com).***

Other types of non-text content could also be considered, such as animation, audio clips, and video clips. They may have to wait until future upgrades of DFC, however, as they require features that not all computers may have.

There are some ongoing concerns with non-text content as well, that we have discussed with CMS web staff. They include Section 508 requirements for accessibility for visually impaired beneficiaries and the load time required for some types of non-text content. We believe that these concerns can be resolved with careful planning. The examples on the CDC and FDA websites indicate that more intensive use of non-text content is possible for government websites.

Scrolling. On the current DFC, users must scroll through several pages of graphs and text to view all of the quality measures information, without any initial summary of the type of data they can expect to view. A number of participants indicated to us that this could be confusing to some users, who may not be aware of how far they have to scroll to see all of the quality results. Headings that serve as introductory hyperlinks can alleviate this problem by allowing users to select from a list of titles at the top of the page that direct them to the specific portion of text on that topic.

The current DFC site does not make much use of headers with links to information below. The exception is a hyperlink on the first page that allows users to jump directly to begin DFC searching instead of having to scroll down to the search function. However, for the majority of the site, users must scroll down through the pages to view all of the information presented.

Another effective way to organize the website content is to use tabs. Like headings, tabs can be used to prevent a lot of scrolling and potentially missed information by prompting users to the type of information available on a site. Several of the participants in our focus groups and interviews with dialysis professionals suggested adding tabs to make the website easier to navigate and more user-friendly. CMS web staff have indicated that tabs will be a feature of the Next Generation Compare sites. Standard tabs are included, such as those about the site and resources, but there is room for additional tabs or sub-tabs.

Our recommendations:

- ***Add headings that also function as hyperlinks for the quality measures and resources pages of DFC.***
- ***Tabs or sub-tabs should also be added to DFC for this purpose.***

Special Populations. As noted, peritoneal dialysis patients and family members were less satisfied with the DFC website. That reflected their concerns that the DFC is currently too oriented toward hemodialysis patients. Parents of pediatric dialysis patients were also less satisfied for similar reasons. Other special populations also deserve particular attention, such as pre-ESRD patients due to their general lack of knowledge regarding dialysis and kidney disease issues. Headings with hyperlinks or tabs could be used in DFC to highlight the needs of these groups, and the resources that the website does provide for them. Our recommendation is:

- ***Hyperlinks or tabs should be added to DFC to highlight the benefits of the website for special populations such as pre-ESRD patients, PD patients, family members, and pediatric patients and their parents.***

Facility Characteristics Table. Most participants were impressed with the range of data available in the Facility Characteristics portion of the DFC. However, when comparing more than two facilities it is currently necessary to scroll down to look at data for the additional ones. Participants often indicated a preference to view more than two facilities at once, as that would make comparisons across a range of characteristics easier. Our recommendation:

- ***Enable the facility characteristics table to show 4-6 facilities. Reduce the font size if needed, with an option to switch back to the larger font.***

Facility Characteristics

All types of participants suggested numerous additional facility characteristics that could be added to the DFC website. They covered a wide range of topics, including patients' concerns, staffing issues, organizational factors, and facility policy issues. In our recommendations for additions to DFC, we focus on those that seemed most salient and most easily implemented. However, we also recognize that the DFC website may not be able to contain facility-level data on all of the potentially beneficial variables. As a result we also recommend a complementary approach:

- ***Checklists should be added to DFC so that patients and family members will have guidance on what questions to ask, about factors not included in the DFC facility characteristics data, when they are visiting dialysis facilities they are considering for future treatment, assessing their current facility, or discuss facilities with doctors or other providers.***

- ***Checklists should also address issues related to quality measures and dialysis and kidney disease information. Further research should be conducted on what topics and items to include in the checklists.***

Peritoneal Dialysis Information. As noted, PD patients felt the DFC was oriented too much toward the information needs and concerns of HD patients. We believe that this could be mitigated by adding some facility characteristics data to DFC that is oriented toward PD issues. Our recommendations:

- ***List the number of PD patients treated at the facility. (And those treated using the other main modalities: in-center HD and home HD.)***
- ***List the number of PD staff working at the facility.***
- ***Add a staffing ratio: PD patients per FTE PD nurse.***
- ***Indicate if PD training is available at the facility.***
- ***What types of PD supplies and equipment are available (Baxter, Fresenius, or both)?***

Amenities. Since most patients spend a great deal of time at dialysis facilities each week, amenities are a more important factor than in other types of health care services. Patients and professionals alike cited many different types of amenities data that users would find beneficial. Patient checklists could help them inquire about some amenities, since DFC probably cannot include data on all those of interest. For additional facility characteristics data to be added to DFC, our recommendations are:

- ***Provide information on visitor policies.***

- ***Indicate if support groups are available, for patients and for family members.***

- ***Indicate if individual televisions are provided to patients, with cable TV and VCRs.***

- ***Indicate if data ports are available for patients bringing laptop computers.***

Staffing. Information on the staff providing care at dialysis facilities was one of the most common recommendations from study participants. Staffing ratios were a particular concern. Many patients felt that their facilities were understaffed, and professionals also indicated concerns regarding this issue. Technicians were a particular point of contention. Many patients felt they were not receiving high quality care from the technicians at their facilities, and that they were treated disrespectfully as by them as well. This is another area where providing patients with checklists could also be quite beneficial if staffing data prove difficult to collect for DFC. Our recommendations:

- ***Include staffing ratios for all types of patient care staff (nurses, dietitians, social workers, and technicians).***

- ***Provide data on the certification or training of technicians.***

- ***List the number of staff on site.***

- ***Indicate clinical staff availability, such as the days and hours in the week that dietitians are on-site.***

Shift times. The current DFC includes information about whether shifts are available at a facility after 5:00pm. This aids patients who may want to work during the day. However, many participants suggested adding data on other shifts, such as early morning or overnight shifts. Our recommendation is:

- ***Include information on all days and hours of operation, and all shift starting times.***

State Surveys and Inspections. Patients and family members frequently expressed interest in knowing the results of inspections or accreditation site visits. DFC provides the date of original Medicare certification, but patients also wanted to know the date of the most recent certification. They were also interested in whether facilities had any history of citations, deficiencies, or violations listed by state survey inspectors. This information is currently provided by Medicare for nursing homes, on the Nursing Home Compare website. While the inspection system is different for dialysis facilities, CMS should consider adding some of these data to DFC as well. This information could also be considered a quality measure, but we include it under facility characteristics since that is the location of the Medicare certification data in DFC currently. Our recommendations:

- ***Add the date of the most recent Medicare certification.***

- ***Add the date of the most recent state inspection.***

- ***List any recorded deficiencies, violations, or citations the facility has received.***

Quality Measures

In this section we first review findings and recommendations for the existing quality measures. Adequacy and anemia are cussed jointly, since our findings were similar for those two measures. We next discuss the patient survival measure separately. We then present recommendations for new types of quality measures that could be added to DFC, and new ways to present the quality measures data to users.

Adequacy and Anemia. Participants found the presentation of results for these measures to be very appealing. As noted, their colored bar graphs caused participants to "perk up" noticeably in the focus groups, in comparison to the discussion of text-based content. The comparisons to national and state averages and multiple facility comparisons were also well received. Participants appreciated the opportunity to see how each facility was doing compared to the others and to the broader averages. Facilities with higher scores were viewed much more favorably by most respondents.

Professionals had several concerns about the data. First, they indicated a preference for Kt/V data for adequacy, and hemoglobin for anemia, as opposed to the URR and hematocrit data currently used in DFC. They indicted that most dialysis facilities already collect Kt/V and hemoglobin data, and those data would also make DFC consistent with Medicare's Clinical Performance Measures (CPM) program. Most indicated that URR and hematocrit data are acceptable performance measures until the other data become available, however.

Professionals also had concerns about casemix effects. For example, if some facilities had higher percentages of patients on catheters for vascular access (versus fistulas or grafts) or higher percentages of patients signing off early from dialysis, then their adequacy outcomes would likely be lower. Again, however, most indicated they still viewed the existing DFC data as useful.

The age of the quality measures data was also a concern for professionals. In contrast, most patients and family members were not concerned about it, even when it was pointed out to them by the group moderator or interviewer. All respondents expressed a preference for data one year old or less, however, when that option was presented to them.

All groups of respondents were concerned about facilities that showed quality data as "Not Available" in the bar graphs. Despite reference to the explanatory footnotes, participants generally believed that those facilities were "hiding something."

As noted, most respondents had negative responses to the dense and complicated text explanations of the quality measures above the bar graphs and in the glossary. Patients and family members usually just skipped over it unless group moderators or interviewers read it to them.

Our recommendations for the adequacy and anemia measures are limited, since they generally got a positive response. They are:

- ***Replace the "Not Available" results in the bar graphs with the specific reasons the data were not available.***

- ***Simplify the text explanations, reducing the density and reading grade level of the text, as also recommended above.***

- ***Switch the adequacy and an anemia measures to Kt/V and hemoglobin once those data are available from all dialysis facilities.***

Patient Survival. Participants generally found the statistical language used to present the patient survival data hard to understand. The concepts of "better than expected" or "worse than expected" were viewed as especially complex for patients and family members. In addition, patients and family members expressed a preference for the bar graphs used to present the adequacy and anemia results, over the check marks used in the results table for patient survival. The explanation of the results table was also viewed as hard to understand. Nonetheless, patients and family members were consistent in their desire to have access to the patient survival data.

Professionals again expressed concern about casemix effects. Some understood the existing casemix adjustments made to the patient survival data (age, race, gender, and diabetes status), but many missed them. They suggested that facilities with higher percentages of elderly patients, nursing home residents, patients with comorbidities, or non-compliant patients would appear worse in these data.

Respondents generally preferred the FAQs provided for patient survival to the text explanations included with the results table. The FAQs seemed to present the methods in a fashion that was clearer to users. Our recommendations:

- ***As with adequacy and anemia, replace "Not Available" in the patient survival results table with the specific reasons the data were not available.***

- ***Simplify the text explanations, reducing the density and reading grade level of the text, adding more links to the FAQs, and adding more FAQs for the more technical, statistical issues.***

- ***Switch to bar graphs, or another graphical reporting method, to present the patient survival data.***

Patient Satisfaction. Measures of patient satisfaction, or experience of care, was a new type of quality measure strongly requested for DFC by most patients and family members. They indicated they would like to hear more about dialysis and dialysis facilities from fellow patients, and not learn about them exclusively from professionals as they have up to now. Patients seemed to feel that their "voice" was not being heard. Professionals also supported the idea of adding patient satisfaction data to the DFC website, noting that most of the dialysis chains already collect these data and report them back to professionals working in their facilities.

Moreover, patient satisfaction data could capture performance information in a number of hard to measure, yet important areas, such as technician quality and the cleanliness of facilities.

This would also fit with Medicare's current initiative to develop an ESRD CAHPS survey instrument. CMS staff have indicated to us that there is an ongoing discussion over whether ESRD CAHPS data should be reported publicly or not. Our research showed that dialysis patients have a strong preference for public reporting of those data, so that they can have access to them. Our recommendation:

- ***Add a new quality measure to DFC that is based on dialysis patient satisfaction (experience of care) survey data.***

Vascular Access. Another topic recommended by many respondents for quality measurement on DFC was vascular access. This was suggested mainly by professionals, although a number of patients and family members also supported this idea. A vascular access measure would be consistent with Medicare's national quality improvement initiative in this area and with the CPM measures that evaluate the percentages of patients using catheters and fistulas and patients routinely checked for stenosis. Data could include catheter or fistula use, vascular access procedures, or infections at access sites. The last two may be hard to measure, however. Our recommendation:

- ***Add a new quality measure to DFC that includes data on the percentages of patients using catheters and fistulas for vascular access.***

Transplant Information. Many patients and family members requested that a range of additional information be made available on DFC on kidney transplants. They knew that transplants provided better quality of life for most ESRD patients, but felt that their understanding was limited in many areas, including the procedure, the necessary preparation and application process, and its implications for their lives. They requested patient education materials, but also data on the numbers of patients being transplanted at each facility and the numbers of patients on the transplant waiting list. We view the opportunity to receive a transplant as less under the control of the dialysis facility than completing the necessary preparation to gain membership on the transplant waiting list. Our recommendation:

- ***Add a new quality measure to DFC that includes data on the number of patients and the percentages of patients on the transplant waiting list.***

Peritoneal Dialysis Quality. As noted, many peritoneal dialysis patients indicated dissatisfaction with DFC due to its emphasis on hemodialysis issues. Quality measures were one area where this was especially noted. Both PD patients and professionals suggested adding quality measures specific to PD to those currently reported on DFC. The anemia and patient survival measures include both hemodialysis and peritoneal dialysis patients at present, but PD patients believed those numbers would not be meaningful for them, since there are many more hemodialysis patients included in the calculations. The adequacy measure on DFC currently includes only HD patients.

PD-specific quality measures recommended included PD-specific adequacy (only measured through Kt/V), serum albumin levels (more important for PD than for HD patients), and peritonitis rates for PD patients. Albumin levels are measured in the CPM, but their levels have proven hard to change. Peritonitis data may be hard to collect, although several professionals reported that the dialysis chains are actively tracking those data for PD patients. Our recommendation is:

- ***Add a new quality measure to DFC that includes Kt/V data to assess adequacy of dialysis for PD patients.***

Presenting Quality Measures as Trends. DFC currently reports quality measures as data for a single time period. Several professionals noted that quality reports they receive make frequent use of trends to track goals for quality improvement. As DFC data are reported by dialysis facilities over time, it should be possible to add trend graphics to the performance reports. This would be consistent with the preference of patients and family members for graphical performance reports. Several professionals also noted that trends remove some concerns regarding casemix differences between dialysis facilities. Even if a facility is starting from a lower level due to unfavorable casemix, it can still demonstrate improvement over time to show positive performance. Implementing this recommendation may require some lead time to build up a historical data base, but we believe it is an important goal for DFC. Our recommendation is:

- ***DFC should add trend graphics to its performance reports as multi-period data on the quality measures become available.***

Dialysis and Kidney Disease Information and Links

DFC currently provides some patient information resources through links to on-line publications and links to related websites. However, patients and family members expressed strong preferences for increasing the amount of educational materials available through DFC. Professionals also supported this idea, often viewing DFC as a potential tool to aid them in their patient education efforts. A selection of the topics requested by patient and family member respondents include:

- The patient's experience of treatment. For example, "What is it like to be on peritoneal dialysis?"
- More detailed descriptions of the modalities and methods used in dialysis treatments.
- The underlying causes of renal disease, its anatomy and physiology, and its long-term implications.
- Dialysis-related self-care priorities (e.g., nutrition, vascular access), techniques patients should use, and potential problems if they are neglected.
- A range of information on kidney transplantation.
- A good source for explanations of medical terms (e.g., "necrotic").

- Meanings of the lab results patients receive. What are their links to quality measures?
- The implications of patient non-adherence to dialysis treatment. What happens if patients skip treatments or sign off early?
- Information on health topics related to dialysis and its common comorbidities (e.g., diabetes, cardiovascular disease).
- What are the rights and responsibilities of dialysis patients?

We do not believe that DFC should become a website that contains patient education materials that are also available elsewhere, but rather that it should promote increased access to information through expanding the range of its links to other websites that contain them. This would also further the underlying goal of DFC to promote patient self-management and involvement in treatment decision-making. Our recommendations are:

- ***Add more website links to DFC that provide access to dialysis-related information for patients and family members. Links could include renal organizations, dialysis patient education sites, other governmental resources, and commercial sites.***
- ***Add website links to DFC that focus on the needs of special dialysis populations:***
    - ***Pre-ESRD (CKD) patients***
    - ***Peritoneal dialysis patients***
    - ***Family members***
    - ***Pediatric patients and their parents***
    - ***Non-English-speaking patients***

Conclusions

The wide range of information presented in this report illustrates the active level of participation we found among patient, family, and professional respondents across the focus groups, triads and interviews conducted for this study. It is clear that they found DFC to have the potential to be very useful, although it was also clear that a number of enhancements to the DFC's data and presentation are needed. Respondents had a keen interest in the continuing development of the DFC website, and in its potential to serve their needs for information about dialysis and dialysis facilities.

In line with its objectives, patients and family members saw the DFC as having the potential to aid them in better understanding and managing the care they receive, in being more knowledgeable consumers of dialysis services, and in being more effective collaborators with their clinical providers. However, the website needs to be improved in a number of ways to make it more useful and more appealing.

CHAPTER 1
INTRODUCTION AND METHODS

The Centers for Medicare & Medicaid Services (CMS), the largest payer for dialysis services, initiated end stage renal disease (ESRD) quality measurement and improvement efforts in the 1990s. Dialysis quality indicators have been developed, and CMS is now routinely reporting several of them at the facility level through the Dialysis Facility Compare (DFC) website. DFC was launched in January 2001. DFC also includes other types of information on dialysis facility characteristics, dialysis and kidney disease publications, and links to other renal disease websites.

The DFC website is intended to provide information for patients and family members to use in making choices about dialysis care. Its goal is to promote broader roles for patients and their families in understanding and managing their own care, greater participation by patients and family members in care planning and treatment decisions, and better collaboration between patients, family members, and the range of professionals providing dialysis treatment. However, it is still in its early stages of development. As a result, this evaluation tested the extent to which the current DFC website promotes broader roles for patients and family members, and how it can be modified to better achieve that goal.

This report presents our findings and recommendations based on data collected from patients, family members, and professionals as part of the Dialysis Facility Compare (DFC) website evaluation. It is being conducted for CMS by Research Triangle Institute (RTI) and the Medical Education Institute (MEI). It began in September 2002 and is scheduled to conclude in November 2004. The study has four general objectives, to:

- Gain feedback on current DFC content and features from patients, family members, and professionals;
- Identify who uses, processes, or retrieves information on DFC;
- Study the information needs of potential DFC users; and
- Identify ways to improve the DFC.

We selected qualitative research methods for this study since the research objectives are aimed mainly at subjective and exploratory issues. As a result, our data collection methods included focus groups, triads, and individual interviews. Some interviews were conducted in-person and some by telephone.

Qualitative methods provide opportunities for interaction between respondents – and between respondents and researchers – that can illuminate the range of reactions to a topic and the reasoning behind people's viewpoints or opinions. They enable researchers to gauge respondents' degrees of understanding – and intensity of emotional responses – to the topic under discussion or to the webpage being viewed. They enable us to better understand the context and intentions from which participants' responses and ways of understanding and utilizing website information are generated. They also enable studies to explore new possibilities, such as new types of information that would be useful for patients on the DFC website.

However, with small samples of respondents, the results of qualitative research are not intended to be interpreted quantitatively or generalized to the population under study. They are instead intended to generate more depth of insight into a topic, that can be especially useful in guiding development or enhancement of services such as the DFC website.

This chapter includes nine sections. The first section describes the methods used for the focus groups, triads, and in-person interviews conducted for this project. The second section describes the methods used for telephone interviews. The third through eighth sections describe the data collection activities conducted for each of the six types of respondents included in this study and the characteristics of those participants (dialysis patients and family members; dialysis professionals and technicians; pre-ESRD (chronic kidney disease) patients and family members; pre-ESRD professionals; representatives of dialysis chains, disease management organizations, and managed care organizations, and representatives of national renal organizations). The ninth section describes the organization of the remainder of this report.

1.1 Methods for Focus Groups, Triads, and In-Person Interviews

During the period from December 2002 through May 2003, we conducted four site visits, of approximately one week each, in four cities in different regions of the country (Washington, D.C., Atlanta, Chicago, and Phoenix). Respondents included dialysis patients and family members, dialysis professionals, pre-ESRD patients and family members, and pre-ESRD professionals. Data collection at each site included focus groups, triads (small focus groups), and in-person interviews. The triads were intended to include three participants each (as the name implies); however, given the complexities of recruiting and attrition, they included a range of two to six participants in practice.

Each site visit was preceded by a process for recruiting and scheduling participants. That process included contacting and gaining the assistance of a number of provider organizations, renal care stakeholder organizations, dialysis chains, and dialysis facilities. We worked with pre-ESRD educators to recruit pre-ESRD patients and family members. Most of those participants had attended a pre-ESRD education class or had received one-on-one education.

On-site data collection in each city involved a three- or four-member site visit team. The focus groups and triads were conducted in commercial focus group facilities located in each city. Interviews were conducted at patients' and family members' workplaces, in their homes, and in the focus group facilities.

We used semi-structured protocols as a basis for data collection in the focus groups, triads, and interviews. The protocols were prepared in consultation with CMS staff, and were designed to cover the range of key topics and issues necessary for a thorough evaluation of the DFC website. The Institutional Review Board at RTI also reviewed and approved each protocol. Copies of the protocols are available from the authors or from CMS upon request.

For the focus groups and triads, we generally used one skilled moderator with one notetaker in the focus group room. Sometimes we used two notetakers, with one in the observation room, depending on the schedule for other data collection activities. All of the focus groups and triads were recorded on both videotape and audiotape.

We analyzed each focus group and triad using a structured debriefing form. It contained a series of analytic categories developed from our research questions. We then combined and summarized the analyses for each analytic category across focus groups and triads.

For the interviews we generally used one experienced interviewer and one notetaker. In a few instances the schedule for other data collection activities required that interviews be conducted solely by the interviewer. In those cases we audiotaped the interviews.

We analyzed the interviews using NVivo qualitative analysis software. Each participant's responses were recorded as text passages and then coded using analytic categories similar to those used in the focus group and triad debriefer. The text passages were then grouped by code across interviews and combined. We integrated those results with the results from the focus groups and triads for analysis.

In addition, where possible, we identified variations in responses based on the different types of participants, including breakdowns by site (city), patient versus family member, type of professional, interviews versus group discussions (focus groups and triads), and hemodialysis (HD) versus peritoneal dialysis (PD) providers. Those variations were assessed for each of the analytic categories, although significant variations were not always identified.

1.2 Methods for Telephone Interviews

During the period from April through June 2003, we conducted 18 telephone interviews with representatives from dialysis chains, disease management firms, and managed care organizations to gain an understanding of how these organizations might use DFC in their business activities. This business perspective was intended to complement the perspective from patients and providers gleaned in our site visits around the United States.

We selected three of each type of organization, drawing on CMS, RTI, and MEI knowledge of the dialysis field to ensure that prominent organizations were included. In selecting dialysis facility chains, we sought representation from both nonprofit and for-profit chains. We interviewed two people in leadership positions from each organization: one clinical leader (e.g., medical director) and one business leader (e.g., marketing or contracting).

In addition, during June and July 2003, we conducted telephone interviews with representatives from six national renal organizations. We selected these organizations because they are leaders in the field.

RTI and MEI collaborated to recruit participants. MEI made the initial contact, usually by telephone and occasionally by e-mail. Once the individual agreed to participate in the study, RTI staff followed up by telephone to schedule the interview. Interviews were conducted at the convenience of the participants. We asked all participants to visit the website before the scheduled interview, although prior use of the website was not required.

We used a semi-structured interview protocol to guide the telephone interviews. The protocols were prepared in consultation with CMS staff and were designed to cover key topics with high-level respondents in a 30-minute interview. Copies of the protocols are available from the authors or from CMS upon request.

Senior RTI project staff members conducted the interviews. We had intended for the same staff member to conduct all interviews; however, because of scheduling difficulties, one interview was conducted by a different senior staff member.

With consent from the chain, DMO, and MCO participants, these interviews were audiotaped, and the tapes were transcribed for analysis. We analyzed those interviews using NVivo qualitative analysis software. Each participant's responses were recorded as text passages and then coded using analytic categories similar to those used in previous analyses and reports on this project. The text passages were then grouped by code across interviews and combined. This approach enabled us to capture every instance where a respondent spoke to a particular issue, even when such comments were offered in response to a question about a different issue.

In addition, we identified variations in responses based on the different types of participants, including breakdowns by organizational type and role. Those variations were assessed for each of the analytic categories, although significant variations were not always identified.

The interviews with national renal organizations were fewer in number, so we did not use analytic software. Instead, we created analytic matrices, in which the rows corresponded to topic areas and each responding organization's comments had a dedicated column. Each participant's responses were coded and assigned into the topic areas, using analytic categories similar to those used in previous analyses and reports on this project. This manual approach enabled us to capture each instance where a respondent spoke about a particular issue, even when such comments were offered in response to a question about a different issue. In addition, in our analysis we examined differences in patterns of responses between organizations representing patients and those representing dialysis professionals.

1.3 Dialysis Patients and Family Members: Data Collection and Characteristics of Participants

Table 1 summarizes the data collection activities conducted with dialysis patients and family members during each of the site visits. A total of 8 focus groups, 5 triads, and 7 in-person interviews were conducted with those participants for this project.

Table 1
Dialysis patient and family member data collection activities by site visit

Method of data collection	Washington	Atlanta	Chicago	Phoenix	Total
Focus groups	2	2	2	2	8
Triads	0	2	1	2	5
Interviews	3	3	0	1	7
Total	5	7	3	5	20

Table 2 presents the number of dialysis patient and family members participating in each of the four site visits. The Washington, DC site visit included 18 participants; Atlanta had 27; Chicago had 23; and Phoenix had 30. Overall, there were 98 patient and family member participants in the focus groups, triads, and in-person interviews conducted for this project.

Table 2
Dialysis patient and family member participants by site visit

Method of data collection	Washington	Atlanta	Chicago	Phoenix	Total
Focus groups	15	14	17	18	64
Triads	0	10	6	11	27
Interviews	3	3	0	1	7
Total	18	27	23	30	98

Table 3 indicates that 75 (77%) of the 98 participants were patients and 23 (23%) were family members. This represents the positive result of our efforts to boost participation by family members in the last three site visits, in response to concerns regarding the low level of family member participation in the Washington, D.C. site visit. (Only one family member participated in Washington.) In Atlanta we conducted two triads with only dialysis family member participants. In both Chicago and Phoenix we conducted one triad with only dialysis family member participants. We found that limiting the triads to family members was useful for focusing our recruitment efforts, gaining active participation by family members, and for ensuring that their comments and concerns could be clearly distinguished from those of the patients.

Table 3
Patient or family member status of participants

Patient or family member	Study participants	Percent
Patient	75	77%
Family member	23	23%
Total	98	100%

The next six tables (Tables 4-9) present analysis of the patient-level data (n=75). For selected variables, information on the patient participants is compared with data on the national distribution of dialysis patients.

Table 4 indicates that patient participants were primarily middle-aged, with the largest group falling into the age 45-64 category. Only two participants were 75 or older, although another two were 74, falling just below the cut-off for that category. The limited participation in the 75+ category probably reflects the challenges inherent in the need for patients to travel to attend the focus groups. Three patients did not indicate their ages.

These data can be compared with national data on the age of dialysis patients, which are presented in the Appendix. Study participants were somewhat younger than the national distribution. Both populations have the largest group in the age 45-64 category. However, 28% of the study participants were in the age 20-44 category, versus 17% for the national population. In the national population, 20% were in the age 75+ category, while 3% of the study participants fell into that category. We did not recruit pediatric patients for this study, and the national distribution shows that only 1% of dialysis patients are less than age 20.

Table 4
Age distribution of patient participants

Age	Patient participants	Percent
0-19	0	0%
20-44	21	28%
45-64	43	57%
65-74	6	8%
75 +	2	3%
Unknown	3	4%
Total	75	100%

Table 5 indicates that patient participants were somewhat more likely to be males. However, study participants are reasonably similar to the national dialysis patient population in terms of gender. The national data show 53% males and 47% females.

Table 5
Gender distribution of patient participants

Gender	Study participants	Percent
Male	49	65%
Female	26	35%
Total	75	100%

Table 6 shows that most of the patient participants (57%) were black. However, 33% were white, 4% were Latino, and 5% were Native American. This differs somewhat from the national data shown in the Appendix, which indicate that 55% of dialysis patient are white. Nonetheless, these data represent the positive results of our efforts to boost participation by whites and non-black minorities in the last two site visits (Chicago and Phoenix). Twenty-one of the 25 whites in our study were participants in those last two site visits. Moreover, 2 of the 3 Latinos and all 4 of the Native Americans participated in those site visits.

The differences between the site visits may reflect differences in the racial composition of the dialysis patient populations in Washington, D.C. and Atlanta, compared to Chicago and Phoenix, or they may reflect the urban focus of the first two site visits more generally. We focused the last two site visits on suburban locations known to have higher proportions of white residents. In addition, all 4 of the Native Americans participated in the Phoenix site visit, reflecting the higher proportion of Native Americans in that city.

Table 6
Racial distribution of patient participants

Race	Patient participants	Percent
Black	43	57%
White	25	33%
Latino	3	4%
Native American	4	5%
Total	75	100%

Table 7 indicates that 12 of the patient participants (16%) were peritoneal dialysis (PD) patients. This compares with the national distribution in the Appendix showing 9% PD patients. The study data reflect the positive results of special recruiting efforts we undertook for PD patients during the last two site visits (Chicago and Phoenix). In the first two site visits, only one PD patient participated. For the Phoenix site visit we also conducted a triad and an interview only for PD patients.

We found that when the HD and PD patients were mixed together in the same focus groups, in the Chicago site visit, the unique issues faced by PD patients were not actively expressed. That seemed to be due to the fact that the PD patients were a minority of patients in the focus groups, so the discussion tended to focus on HD issues. By having some data collection activities focused solely on PD patients in Phoenix, we were able to focus those discussions on PD issues.

Table 7
Dialysis modalities of patient participants

Dialysis Modality	Study Participants	Percent
Hemodialysis	63	84%
Peritoneal dialysis	12	16%
TOTAL	75	100%

Table 8 presents the educational experience of the study participants. Eight of the 75 patients (11%) had not finished high school. The largest group (39%) reported some college studies, but had not completed college. Only 3 (4%) had any post graduate training. Comparative national data for dialysis patients are not available for this variable.

These data suggest that the participants were a relatively educated group, which we view as positive in some ways for purposes of this study. This was reflected in the relatively active levels of discussion we found in all of the patient and family member focus groups, triads, and interviews. Nonetheless, we will take steps to ensure the DFC website does not assume educational levels that are too high in its content and presentation. It will be important to avoid creating barriers to its use for patients with lower education levels.

Table 8
Highest educational experience of patient participants

Education	Study Participants	Percent
Some high school	8	11%
Completed high school	15	20%
Some college	29	39%
Completed college	17	23%
Post graduate	3	4%
Unknown	3	4%
TOTAL	75	100%

Table 9 illustrates that the participants were, on average, a group of patients with relatively long experience on dialysis. National data indicate that only 29% of patients survive longer than 5 years on dialysis. The average for our participants was just over 5 years on dialysis, with the range reaching up to 24 years. The median was somewhat below the mean at 3 years.

We view these data as positive for purposes of this study. We often found that patients with longer experience had many useful comments and perspectives to contribute in the focus groups, triads, and interviews.

Table 9
Years on dialysis of patient participants

Years On Dialysis (N = 75)	
Range	0.1 - 24 YEARS
Median	3 YEARS
Mean	5.16 YEARS
Standard deviation	5.20 YEARS

1.4 Dialysis Professionals and Technicians: Data Collection and Characteristics of Participants

Table 10 summarizes the data collection activities conducted with dialysis professionals and technicians during each of the site visits. A total of 8 focus groups, 6 triads, and 16 in-person interviews were conducted with those participants for this project.

Table 10
Dialysis professional and technician data collection activities by site visit

Method of Data Collection	Washington	Atlanta	Chicago	Phoenix	TOTAL
Focus Groups	2	2	2	2	8
Triads	0	2	1	3	6
Interviews	6	5	2	3	16
TOTAL	8	9	5	8	30

Table 11 presents the number of dialysis professionals and technicians participating in each of the four site visits. The Washington, DC site visit included 22 participants; Atlanta had 26; Chicago had 21; and Phoenix had 29. Overall, there were 98 professional and technician participants in the focus groups, triads, and in-person interviews conducted for this project.

Table 11
Dialysis professional and technician participants by site visit

Method of Data Collection	Washington	Atlanta	Chicago	Phoenix	TOTAL
Focus Groups	16	17	17	15	65
Triads	0	4	2	11	17
Interviews	6	5	2	3	16
TOTAL	22	26	21	29	98

Table 12 indicates the range of professionals and technicians that were involved in the data collection efforts. As expected, the largest numbers of professionals were mid-level providers, including nurses, social workers, and dietitians. Each of the four site visits included data collection with some mid-level providers. Most of them were treating chronic hemodialysis patients, but one nurse was a case manager and two nurses worked in acute care units. One was also a nurse practitioner. In addition, during the Phoenix site visit we conducted two triads with mid-level providers serving peritoneal dialysis patients.

Nephrologist interviews were conducted in each of the four site visit cities. Technician interviews and triads were conducted in Washington, Atlanta, and Phoenix. Renal administrator triads were conducted in Atlanta and Chicago.

Table 12
Distribution of professions among professional and technician participants

Profession	Study Participants	Percent
Nephrologist	9	9%
Nurse	22	22%
Social Worker	29	30%
Dietitian	25	26%
Technician	9	9%
Renal Administrator	4	4%
TOTAL	98	100%

1.5 Pre-ESRD Patients and Family Members: Data Collection and Characteristics of Participants

Table 13 summarizes the data collection activities conducted with pre-ESRD patients and family members. They were studied in the Chicago and Phoenix site visits. A total of 3 focus groups, 2 triads, and 1 interview were conducted.

Table 13
Pre-ESRD patient and family member data collection activities by site visit

Method of Data Collection	Chicago	Phoenix	Total
Focus groups	2	1	3
Triads	1	1	2
Interviews	0	1	1
TOTAL	3	3	6

Table 14 presents the number of pre-ESRD patient and family members participating in each site visit. The Chicago site visit included 25 participants, while Phoenix had 17. Overall, there were 42 pre-ESRD patient and family member participants in the focus groups, triads, and interview conducted for this project.

Table 14
Pre-ESRD patient and family member participants by site visit

Method of Data Collection	Chicago	Phoenix	Total
Focus groups	23	12	35
Triads	2	4	6
Interviews	0	1	1
TOTAL	25	17	42

Table 15 indicates that 25 (60%) of the 42 participants were patients and 17 (40%) were family members. In both Chicago and Phoenix we conducted the focus groups and triads separately, with only patient or only family member participants. We found that limiting the focus groups and triads to only one type of participant at a time was useful for focusing our recruitment efforts and for ensuring that the comments and concerns of each type of participant could be clearly distinguished from the other.

Table 15
Patient or family member status of participants

Patient or Family Member	Study participants	Percent
Patient	25	60%
Family member	17	40%
TOTAL	42	100%

1.6 Pre-ESRD Professionals: Data Collection and Characteristics of Participants

During the period from April to May 2003, we conducted eight interviews with pre-ESRD patient education professionals in Chicago and Phoenix. Seven of them had a clinical background in nephrology nursing. One had a background in nephrology social work.

We chose to interview pre-ESRD professionals to obtain a more in-depth understanding of the factors involved in patients' initial selection of a dialysis center, to help us understand pre-ESRD professionals' perception of the utility of the DFC website to them and to patients, and to gain pre-ESRD professionals' perspectives on how the DFC website might be modified to improve its usefulness to them and their patients. Pre-ESRD professionals were recruited from pre-dialysis education programs in each of the target cities and through contacts with corporate dialysis providers and renal care stakeholder organizations.

1.7 Representatives of Dialysis Chains, Disease Management Organizations, and Managed Care Organizations: Characteristics of Participants

Table 16 summarizes the organizational roles of the telephone interview participants, noting both the type of organization and the various clinical and business leader positions held by participants.

Table 16
Organizational roles of telephone interview participants

Organization type	Clinical leader	Business leader
Dialysis facility chains	Corporate nurse Medical director Clinical research division director	Manager, information technology (IT) systems Business development specialist Director of regulatory affairs
Disease management firms	Clinical director for renal products Medical director Medical director	Renal product director Chief executive officer Vice president of marketing
Managed care organizations	Director of nephrology Managing director for Medicare products ESRD demonstration program manager	Patient education director Provider relations Network contracting specialist for ESRD demonstration project

1.8 Representatives of National Renal Organizations: Characteristics of Participants

Six national renal organizations participated in this portion of the evaluation:

- American Association of Kidney Patients (AAKP)
- National Kidney Foundation (NKF)
- American Society of Nephrology (ASN)
- National Renal Administrators Association (NRAA)
- American Society of Pediatric Nephrologists (ASPN)
- Renal Physicians Association (RPA)

A seventh organization, the American Nephrology Nurses Association, was invited to participate. However, the president of this group was not able to participate, noting that since the Association does not have a position statement on the DFC website, she could not speak on behalf of the organization.

Respondents included executive directors, presidents, members of the organization's executive committee, a director of patient services, and other staff members. Five of the associations had a single representative speaking on their behalf; the RPA offered two leaders who spoke together in a conference call.

1.9 Organization of This Report

Chapter 2 includes discussion of cross-cutting themes that were found in our research across the different types of respondents included in this study. Chapter 3 presents our findings from the research on dialysis patients and family members. Chapter 4 presents our findings from the research on dialysis professionals. Chapter 5 presents our findings from the research on pre-ESRD patients and family members. Chapter 6 presents our findings from the research on pre-ESRD professionals. Chapter 7 presents our findings from the research on representatives from dialysis chains, disease management organizations, and managed care organizations. Chapter 8 presents our findings from the research on representatives from national renal organizations. Chapter 9 includes our recommendations for changes to the DFC. Chapter 10 presents our conclusions.

CHAPTER 2
CROSS-CUTTING THEMES

In reviewing the findings across all of our data collection efforts, we identified 13 themes that cut across the different respondent groups. They are presented in two sections in this chapter. The first section includes nine general themes that cut across most of the respondent types. The second section includes four more specific themes that focus on a narrower range of respondents.

2.1 General Themes

1) After reviewing the DFC website, patients and family members indicated they have a strong interest in its continuing development.

Hemodialysis and pre-ESRD patients were pleased to have access to the data on DFC, and saw it as relevant for their needs, although they wanted access to more data and to have it presented in a more user-friendly fashion. All respondents indicated that they view an enhanced DFC as having the potential to aid them in better understanding and managing the care they receive, in being more knowledgeable consumers of dialysis services, and in becoming more effective collaborators with their clinical providers. The engagement and involvement of participants was evident across all four of the site visits and throughout the telephone interviews.

Many participants also indicated they would use the website as an information source, especially for FAQs and definitions of dialysis and medical terms, although they wanted a range of additional information added to the site. The opportunity to learn more about the process of dialysis and Medicare benefits were also cited as useful features of DFC for patients and family members.

2) Few patients, family members, or professionals are currently using the DFC website.

This finding was expected, since the website was developed just two years before the data collection for this project, and anecdotal evidence had indicated that the DFC website had gotten little use to date from patients or family members. Respondents in our study who had used it were mostly professionals. They often accessed it for exploratory purposes, or to check the accuracy of the data it contained for their facilities. Notably, none of the pre-ESRD educators were using the DFC regularly in their work.

Several of the national renal organizations reported introducing the DFC website to their members, and using it in discussions with them. Most indicated use by patients and family members has been limited up to now, however.

These findings highlight the need for CMS to get the word out about DFC, and to improve the DFC in ways to make it more user-friendly and more responsive to the needs of its intended audience of patients and family members. CMS' plans to implement a "next generation" version of all of its consumer websites, including DFC, are an important step in that direction. The recommendations of this study include many additional ways in which the DFC could be improved in response to the expressed interests and ideas of study respondents.

Improvements to DFC that are developed from this type of consumer-based research should result in improved utilization of the website as knowledge of its potential benefits becomes more widespread among patients and their family members.

3) All types of respondents provided many recommendations for ways to improve the DFC website.

Both the number and range of respondents' recommendations for improvements to the DFC were striking. As expected, dialysis patients and family members and dialysis professionals were the respondents with the most ideas. However, each of these groups presented over 100 recommendations, many more than expected. Pre-ESRD patients had fewer ideas, which was also expected given their more limited knowledge of dialysis issues, but they provided input on most of the same topics as the dialysis groups.

For compatibility across respondent types, we structured the recommendations from these first three groups into a standard set of 15 topics:

- Physicians;
- Dialysis staff;
- Equipment and facility information;
- Amenities;
- Organizational information and policies;
- Clinical policies;
- Patient issues;
- Accreditation and regulations;
- Peritoneal dialysis – facilities;
- Quality measures;
- Dialysis and kidney disease information;
- General health education;
- Medicare information;
- Transplant issues; and
- Peritoneal Dialysis – education.

Dialysis patients and family members and dialysis professionals had multiple recommendations on all of these topics. Pre-ESRD patients had recommendations on all of these topics except two of them, peritoneal dialysis – facilities and clinical policies. The other three groups of respondents also presented several dozen ideas for improving DFC. The fewer numbers of ideas presented by these groups may reflect the fewer numbers of respondents of those types.

In sum, the broad-ranging response we received from all six types of participants indicates the depth of their interest in the DFC as a medium for communication regarding dialysis issues. In particular, it is clear that the target audience for DFC, dialysis patients and family members, view it as having good potential to aid them in better understanding and managing the care they receive, in being more knowledgeable consumers of dialysis services, and in being more effective collaborators with their clinical providers.

4) Medicare is perceived as an honest broker of dialysis, kidney disease, and dialysis facility information.

Many respondents commented on the value of receiving information directly from Medicare. Moreover, none were critical or suspicious of either Medicare or CMS as a source of information. In fact, the few concerns that were raised focused on why Medicare had not gone further, and used the DFC data to provide ratings or rankings of individual facilities.

Other sources of dialysis information were often viewed as somewhat suspect, given respondents' perceptions that the sponsoring organizations may have underlying agendas. These concerns were mainly focused on private sector organizations. Other government agencies also seemed to be viewed a reliable sources of information. For example, patients and family members praised the clarity and value of the definitions and explanatory diagrams contained in the NIDDK dictionary that is linked to DFC.

It appears that Medicare is a powerful and trusted "brand name," that makes it an appropriate sponsor for a website such as DFC, that contains a range of quality of care, service characteristics, and dialysis and kidney disease information. CMS could take advantage of this situation to aid in its promotion of the DFC website. The trust in Medicare that exists among the target audience of patients and family members could be the basis of messages that encourage them to access and use the DFC. That could be another way to boost utilization.

5) The goal of DFC is to provide information to give patients more choices; however, we found that patients' ability to choose dialysis facilities varied by site.

We found significant variation across sites in patients' reported ability to exercise choice among different dialysis facilities. Chicago and Phoenix participants reported more choice available for patients than did participants in Washington, DC and Atlanta. These reports were consistent across patient, family member, and professional respondents in Phoenix, although they were more focused in professionals in Chicago.

Many more patients in Phoenix reported having choice among dialysis facilities even very early on in the process, before the transition to dialysis. Professionals presented a similar assessment, and suggested that may reflect efforts by dialysis chains to build more dialysis facilities in the Phoenix area. That may in turn be motivated by expectations of population and economic growth in Phoenix.

Nephrologists' affiliations with particular dialysis facilities were reported to be looser in Phoenix, which may also provide patients with more facility options if they wanted to avoid switching nephrologists. The need to switch nephrologists was often cited as a barrier to switching dialysis facilities in Washington and Atlanta.

Professionals in Chicago commented that patients have more choices among dialysis facilities than they perceive. This may reflect their broader understanding of the range of facility options in that large metropolitan area. It may also reflect a difference in the balance between supply and demand for dialysis facilities in Chicago versus Washington and Atlanta.

The exact reasons for the differences in options for patient choice were not clear, however, and may warrant further study. Nonetheless, it was clear that patients' ability to make choices between dialysis facilities is not uniform across all cities.

6) At the same time, dialysis patients were perceived to have less choice among facilities when first starting dialysis, but more after they have been on dialysis for a while.

One consistent finding regarding patient choice was that their available options, and ability to exercise choice, increase with more experience on dialysis. Most patients, family members, and professionals agreed on this point. This seemed to be a combination of two factors. First, during the transition to dialysis and the first several months, patients often feel very sick and emotionally distraught. That makes it hard for them to be active participants in managing their care and making treatment choices. At that point they may not know what questions to ask.

Second, patients learn more about the range of facility options they have over time. Hemodialysis patients, who receive treatment three times per week, have many opportunities to talk to providers and to other patients about alternate facilities that are available to them. (They may not be given choices initially.)

Patients may also become less fearful of changing facilities and even nephrologists over time, as they stabilize after the initial transition and learn more about the disease and the treatment options. Some family members reported that they saw their role as facilitating that process, and providing encouragement for patients to change facilities when that seemed the best course of action.

A number of patients and professionals noted potential value of the Internet as a vehicle for promoting patient education regarding facility choice. In Phoenix, several professionals indicated that many of their patients use the Internet to learn more about kidney disease through web sites and talking to other ESRD patients in chat rooms. They indicated the patients then become more confident in their ability to make changes in their treatment due to the information they have gained. Several patients commented that they did not realize that lists of dialysis facilities were available, and that just having the list on the DFC would help encourage them to think more about the possibility of switching facilities.

7) Patients and family members prefer graphical displays of information.

Both dialysis and pre-ESRD patients responded especially well to the graphical displays of quality data on DFC. The colored bar graphs for adequacy and anemia in particular seemed to enliven them. They were much less engaged with text-based descriptions.

The use of graphics, diagrams, and pictures may be especially salient for pre-ESRD patients, since most have not had the chance to visit a dialysis facility or to experience the dialysis process. As one respondent put it, they are often scared at this point in their disease, and diagrams or pictures may provide some reassurance or at least de-mystify the process to some extent.

As expected, professionals were better able to absorb text-based information, but most agreed that the graphics make more sense for a website such as DFC that is targeted to patients. It may be that graphics are the best way to encourage patients to become more active in comparing facilities on quality, features, and services.

Diagrams were also recommended frequently by all types of respondents as a way to supplement text-based dialysis and kidney disease information materials. For example, diagrams could be used to illustrate how an arteriovenous fistula is constructed, as a lead-in to describing its benefits in comparison to synthetic grafts or catheters for vascular access. Alternatively, DFC could provide more links to other sites with diagrams or graphics used to illustrate points for dialysis patient education.

Our discussions with CMS web staff have included review of a number of limitations on the ability of DFC or other Medicare.gov websites to use extensive graphics, diagrams, or photographs. Nonetheless, it seemed that a simplified approach such as the bar graphs for adequacy and anemia was effective, so perhaps other simplified methods could also be applied. Moreover, website graphics are used more extensively by other federal agencies, such as the CDC and FDA. The methods they used should also be applicable for DFC.

We believe that increasing the use of graphics, diagrams, and pictures on the DFC website – to the extent possible – will increase its appeal to patients and family members. Those methods may also increase the ability of DFC to communicate quality and facility information effectively to patients, family members, and other users.

8) Internet access for patients and family members was less of a problem than expected.

Many patients reported having family, friends, or local libraries that could provide them Internet access. In one city, Phoenix, we found that most patients indicated they had Internet access, a finding confirmed by dialysis professionals interviewed in that city. Several professionals in Phoenix indicated that their patients often bring laptop computers to use during dialysis. They use the Internet as a way to pass the time during dialysis and access "chat rooms" to exchange information with other patients. Across all four cities we found that most family member respondents indicated they had Internet access, either at home or at work.

Most pre-ESRD patient and family participants also reported using the Internet themselves or having friends or family who could help them with it. About half reported using it for health, medical, or kidney disease information. The breadth of Internet access reported by these participants is encouraging for future DFC utilization. Psychological issues such as denial will likely remain a barrier to DFC use, but may be mitigated in the future by the expanding national efforts at pre-ESRD education. The recent AAKP initiative entitled, "Kidney Beginnings" and the NIDDK's new National Kidney Disease Education Program are only two examples of the increasing efforts at pre-ESRD education and intervention nationwide.

In the future, Internet access will be steadily expanding across the country. It may be that internet access *per se* will not be as much of a barrier to DFC website use, as some have suggested, but rather the key will be to ensure that dialysis and pre-ESRD patients and family members feel they can gain tangible benefits from using the Internet and the DFC website. That could motivate them to more actively utilize the DFC from their own computers, or seek ways to gain Internet access through public facilities or their social networks.

9) Public reporting of quality data was perceived by both professionals and patients to have value for quality improvement.

We were surprised to hear a range of different professionals, in several different cities, supporting the notion that the quality data provided to patients and family members on the DFC website could have a positive impact on quality of care. We expected them to challenge that idea. In contrast, most indicated that just knowing that the data are available for public viewing will make them and their professional colleagues work harder to improve patient care.

Many professionals indicated they would use the DFC to see how their facility compared to others in their local area. Several suggested that they would work to find ways to compare favorably to their local colleagues, or at least not fall behind.

Many patient and family member respondents indicated they would use the quality data to monitor performance of the dialysis facilities they use. They saw the data as helping them to formulate questions to pose to facility staff, and helping them in decisions about switching facilities or in choosing facilities when traveling or moving.

2.2 Focused Themes

10) Family members and peritoneal dialysis patients were less satisfied with the DFC website.

Family members and PD patients did not see the resources currently on the DFC website as responding well to their needs. They suggested that it needs to be enhanced in a number of ways to provide more meaningful benefits to them.

Dialysis family members wanted more information to inform them about the disease and about ways they could enhance their roles to best help the patient. Many did not feel that the DFC website directly addressed the concerns they have in aiding and caring for their relatives on dialysis. As a result, they tended to have more ideas for additional data elements they would like to have added to the website, such as additional links to sources of dialysis and kidney disease information.

Pre-ESRD family members exhibited very little knowledge of kidney disease, dialysis, and dialysis facilities. They expressed a desire for more guidance on what information they should be seeking. They seemed in many cases to be unclear on the topics under discussion, including dialysis facility characteristics. Several of them also asked about information on the types of roles they could expect to play in support of patients. The current information on the DFC did not seem to be directly addressing their needs.

Peritoneal dialysis patients viewed the website as oriented too much toward hemodialysis patients, repeating a pattern they had experienced previously in their dialysis facilities and among their caregivers. As a result, the DFC was reinforcing a sore point that made it hard for them to focus on the benefits of DFC.

PD professionals indicated similar concerns. They also reported ongoing issues related to the HD emphasis of their facilities and their professions. They suggested that PD patients would be more likely to use the DFC website if it had quality measures, facility characteristics, and other information that was clearly targeted to their needs. As a result, the need for more PD-specific information on the DFC website was a consistent theme.

Adding data and materials to the DFC to better respond to the needs of these groups should not be too difficult, however. A number of recommended additions to the facility characteristics, quality measures, and dialysis information links would provide information useful to those groups. Including special links or tabs in the website to guide members of these groups to those targeted resources would be a way to demonstrate responsiveness to their needs.

11) DFC has the potential to be a source of information and education for pre-ESRD patients and family members, who have less knowledge of kidney disease, dialysis, or dialysis facilities.

This was striking, since we recruited pre-ESRD patient respondents through pre-ESRD educators, who referred patients who had completed their pre-ESRD education programs. We expected these patients would be more knowledgeable due to the education they had received. Dialysis professionals also reported that patients usually have very little understanding of the disease or its treatment when they begin dialysis.

Part of this problem may be due to the limited scope and effectiveness of pre-ESRD education programs. That issue is discussed in the next theme.

However, patients could also be encouraged to access the DFC for pre-ESRD information if they are not involved in formal programs. It is evident that their needs for information are large, and that once pre-ESRD patients see the types of information available on the DFC they may become interested in it, especially if information targeted to pre-ESRD populations is added to the website.

One approach for more targeted information could involve creating a special link or “tab” on the home page of DFC that is labeled as providing information for pre-ESRD patients. Their information needs are different from those of patients already on dialysis, so they probably deserve to have a special series of web pages within DFC that address their issues and concerns.

While psychological avoidance or denial may play a part in the lack of knowledge among pre-ESRD patients, it was still surprising that people with such a severe chronic disease had not taken steps to learn more about it and its treatment. It may also be the case that their physicians did not inform them of the severity of their disease. In any event, this is especially serious given the recent evidence that a range of early interventions – in the pre-ESRD phase of the disease – can have many positive impacts in terms of slowing progression to ESRD, reducing complications and comorbidities, and providing for a smoother transition to dialysis. However, this situation also means that the Internet could potentially have a large role in providing a source of ongoing dialysis and kidney disease information that could be accessed directly by pre-ESRD patients and family members themselves.

12) Pre-ESRD educational programs are still in their early stages of development.

Most pre-ESRD professionals reported providing a two-hour class to participants on a group or one-on-one basis. We were surprised by how limited these pre-ESRD programs were. A single two-hour class seems very short given the many issues that need to be covered regarding pre-ESRD care, methods for patient self-management, modality choice, placement of vascular access, the transplant option, the transition to dialysis, and others. Many dialysis professionals commented on the need for intensive pre-ESRD patient education and preparation to maximize patient outcomes when they reach dialysis.

Moreover, short pre-ESRD classes may have limited effectiveness. Some pre-ESRD patients that were referred to us by pre-ESRD educators did not recall even being in the classes.

Funding is an issue that limits the scope of pre-ESRD classes, but this may indicate that there is a need for alternate educational vehicles that patients or family members can access on their own, such as the DFC website. It also points to the potential role the DFC website could play as a resource for pre-ESRD educators to add to their curriculums and to show patients where they can go for additional information.

The pre-ESRD educators were aware of the limitations of their programs, so they might be willing to consider ways of supplementing them with Internet resources, including the DFC website. The goals of increasing patient self-management and involvement in decision making may be best achieved by involving patients early on in the disease process, in the pre-ESRD stage. In that way, the expectations and habit of active involvement in their care and treatment decisions could start early and be more easily sustained after the transition to dialysis.

One approach could be for CMS to develop DFC-based modules or scenarios for pre-ESRD educators to use in their classes. A module might include pursuing links to educational resources or an exercise for investigating dialysis facilities in a new city to which patients might be moving or traveling. It could also provide patients with an advance "preview" of the facilities in their area, to help them begin the process of considering where they might choose to receive their dialysis treatments in the future.

A more modest approach might be to provide educators with examples for demonstrating some of the capabilities and links provided by the DFC website. Instead of simply including the DFC website in a longer list of resources, the examples could get patients more involved in "hands-on" exploration of the website during or after pre-ESRD classes. In that way, patients would be more likely to return to the website, since they would be familiar with it and its potential benefits.

13) MCOs and DMOs saw potential business applications for DFC.

MCOs and DMOs indicated that the DFC may have potential benefits as a business application, beyond its primary audience of patients and family members. Representatives from disease management firms indicated they could use DFC information as a tool for exploring local markets. This could be beneficial as they expand their operations into new regions. They could also use DFC as a way of reviewing their breadth of coverage in their existing markets, and for oversight of affiliated facilities. Similarly, MCOs saw the DFC as a way to identify alternate facilities in their existing markets and conduct initial screening of facilities applying to join their networks.

While these applications do not directly address the primary audience of patients and family members, they do provide indirect ways to boost the utilization and visibility of the DFC website in the ESRD community. In the long run, this could enhance use by dialysis and pre-ESRD professionals and patients as well.

CHAPTER 3
DIALYSIS PATIENTS & FAMILY MEMBERS

This chapter presents our findings from analysis of the data we collected from dialysis patients and family members. As noted in Chapter 1, a total of 98 patients and family members contributed comments in the focus groups, triads, and interviews conducted with these respondents.

This chapter includes two sections. The first presents detailed issues. It is structured around 19 analytic categories, each including one or more key issues studied through a set of questions presented to the participants. The second section presents more general themes that we identified through analysis of respondent comments. The themes cut across the more detailed issues presented in the first section.

3.1 Detailed Issues

For each of the 19 analytic categories in this section, we provide an overall report based on the responses of dialysis patient and family participants from all four site visits. For the longer categories, we also summarize the key findings at the outset using bullet points.

In addition, where possible, we identify variations in responses based on different types of participants, including breakdowns by site (city), interviews versus group discussions (focus groups and triads), patients versus family members, and HD versus PD patients. These variations were assessed for each of the 19 analytic categories, although significant variations were not always identified.

3.1.1. What a New Patient Needs to Know About Dialysis and Dialysis Facilities

Each focus group and triad started with introductions and brainstorming thoughts about what participants believe a new patient needs to know about dialysis facilities. It is worth noting that although the moderator stressed that participants should share their thoughts about dialysis facilities, many comments had to do with dialysis or ESRD more generally. This is reflected in the summary below, and indicates the importance of those latter issues for the participants. The main points participants emphasized for new patients to know were:

- Educate yourself about dialysis.
- Technicians can be a problem.
- Get to know the staff at your dialysis facility, and ask questions.
- Monitor how your treatment is going.
- Take care of your health and your access.

The importance of gaining knowledge about dialysis was a common theme. Both patients and family members talked about the importance of doing your own research, and not relying on what you are told at the dialysis facility. They stressed that patients need to understand their treatment options (HD, PD, transplant), understand where to go for financial help, and how to get free medications. Several participants suggested a seminar would be helpful for new patients, prior to starting dialysis. The value of patient education more generally was also emphasized.

Understanding the importance of dialysis was also cited as a key issue. As one family member said of her spouse, *"He needs to know how important dialysis is, he thought it was a joke at the start."*

The frequency of problems with technicians was another common theme. Several family members noted that there are not enough technicians in many facilities, and that as a result the patient often needs to wait to get started on dialysis after arriving at the facility. The technicians are sometimes late as well, which can also cause a patient to have to wait.

The quality of care provided by technicians was also reported to be a common problem. A number of patients expressed unhappiness with the job done by their technicians, indicating that it is very important to them that their dialysis is done right, and some technicians just don't care. Participants reported that technicians often spend too much time bickering with each other and with other staff. As one family member said, *"There are two technicians that I won't let mess with my wife."* A patient suggested, *"Keep an eye on what they're doing, because sometimes they don't do what they're supposed to do."*

At the same time, many participants talked about the need to get to know the staff who are providing dialysis care, and to ask questions. It's another way to gain information. Several noted the importance of having someone to provide guidance at the beginning of a person's dialysis treatment, such as a social worker. Some suggested talking to other patients or to technicians who seem knowledgeable. As one patient said, *"You need someone to hold your hand initially, to show you the ropes."* Another described a friend who had *"started dialysis not realizing that it is not a death sentence, that there can be hope."* The general message was for patients to be sure to find out what to expect and to learn what they need to do when they are on dialysis.

Dialysis facility staff will usually respond to questions, but several participants stressed that they will not often volunteer information. One patient warned, *"If you are quiet, you are a victim and not respected."* The importance of understanding your lab results was noted by several patients. Since issues related to the labs are sometimes not explained, patients should be sure to ask.

The importance of monitoring closely how each dialysis treatment is going was also stressed. As one family member put it, *"Don't wait for the alarms, then it is too late."* Suggestions included knowing what the dialysis machine is doing, understanding the mechanics of the machine, and knowing your options.

Participants indicated that new patients need to understand that different facilities have different ways of doing things. Simple things are sometimes important, such as having individual televisions or comfortable chairs. They recommended that new patients get tours of potential new facilities and see what they think of them and their staff. As one said, *"Find a facility that you are comfortable with."*

More generally, participants stressed the need to watch your health and stay clean at the access site. Taking care to maintain your graft was a related comment. Patients should realize that some days they will feel really sick. They should also pay close attention to their weight; they may be cramping unnecessarily if they do not know their target weights. As one patient suggested, *"You need to learn a lot of things. I still have so much to learn about dialysis. We need to discipline ourselves, for one thing, and eat the right foods."*

Transportation issues were cited as a potential problem area for new patients to be aware of. They can cause patients to be late for dialysis.

PD patients stressed the importance of getting to know the PD nurse early on, since their monthly visits with the nurse are their main clinical contacts. Training is also vital, since PD patients provide their own care. So it's especially important that they know what to expect, what problems they might run into. One PD patient said, *"It took me 5 months to get used to the dialysis and the exchanges."* In addition, they suggested that PD patients should understand the cost of PD care to the patient (HD is cheaper), and find out all of the locations for PD care.

3.1.2 Finding a Facility

For this section, we asked participants what they look for to determine whether or not a dialysis facility is a good one. We also asked what they considered to be important issues regarding dialysis facilities when they first started dialysis, and how much choice between facilities they felt they had. To summarize, the main points were:

- Most dialysis patients do not feel they have much choice between facilities when they are first starting dialysis.
- More choice may be possible after patients have been on dialysis for a while.
- Phoenix was different from the other three sites; more patients reported having choices, even early in dialysis.
- When patients make their initial transition to dialysis they feel very sick, overwhelmed, and afraid, so it is hard for them to think about choices.
- Family members or patient support groups could help during that initial transition, both with the adjustment to dialysis and with making choices more possible.
- More training regarding the initial transition period might also help patients adjust and make choices.

Participants in Washington, Atlanta, and Chicago reported that they do not feel they have much choice between dialysis facilities, at least initially. Where they receive dialysis treatment when they first start on dialysis is driven mainly by:

- where their nephrologists practice;
- the distance from their homes and available transportation;
- health insurance coverage; and

- the shortage of dialysis facilities with open stations for new patients.

During the initial transition to dialysis patients usually feel afraid, overwhelmed, and very sick, so they are not thinking about making choices between dialysis facilities. Family members also reported emotional reactions during the initial transition. One said, *"We were all in shock."* Moreover, at the beginning patients do not know what criteria to use to compare dialysis facilities. These problems further restrict patients' ability to exercise choice during the early stages of dialysis treatment.

However, family members might be able to help at that point. Several family members indicated the importance of family support during the first six months or so, when the patient is feeling sick, upset, and depressed about the transition to dialysis.

Several participants suggested that some training to reinforce the message that choice is possible would be helpful at that early stage. Patient support groups could also be especially valuable at that point in the process, during the initial transition.

Transportation problems were cited as limiting choice by some family members in Atlanta, where the metro area spans several counties. Their transportation service is limited to a particular county, so if an alternate facility is located across county lines, they would have to find another way to get there.

The comments on availability of choice were mixed in Phoenix, with some patients and family members reporting that they knew they had options to choose from among different facilities. One patient reported that she was given an opportunity to choose from among 3 facilities when she was first starting dialysis.

Some participants suggested that after they have been on dialysis for a while (about 6-12 months) here is more ability to make choices. That was especially true in Phoenix. At that point patients have settled in to dialysis, feel less sick, and know more about what to look for in other dialysis centers. This issue sparked some debate in a Washington focus group. One patient reported that he had switched centers; others disagreed about how easy that would be for them. In Atlanta, several family members suggested checking out different centers and stressed the importance of not being afraid to switch. However, several patients in Atlanta expressed concern that if they switched facilities they would also have to switch doctors.

Participants noted the need to have access to a list of dialysis facilities to help them understand the choices that are available. As one put it, *"When I was going out of town, that was the first time I found out there was a list."* Several stressed that it would also be helpful for patients to be able to talk to the patients in other facilities directly. Having opportunities to visit another facility was also viewed important, so they could see it and talk to the social worker and other staff there as well. It's also important to see how the staff treat the patients.

For traveling, some patients indicated the importance of finding facilities in other cities from the same dialysis chain. That way, they might have similar treatment procedures.

PD patients indicated they did not have much choice of facilities when first starting out. Their doctors sent them to a PD clinic. What types of insurance were accepted by the facility was also important, as that can cause restrictions.

PD patients did understand that they have a choice between HD and PD, however. Most chose PD due to its convenience, the ability to manage their own care, the ability to set their own schedule, the fewer diet restrictions, and the fact that PD has fewer ups and downs than HD since patients are doing PD every day.

PD patients also suggested there would be value in having a list of facilities that offer PD, to help promote choice. Knowing the specific locations of each one was also important to them, since transportation and convenience are often considerations.

3.1.3 What Defines Good Dialysis Care?

We asked participants what "good quality" dialysis care means to them. We also asked what information on dialysis care they would like to have for choosing dialysis facilities and what information would help them know if they are getting good care.

These questions sparked a wide range of responses, with numerous clinical and amenities issues cited by both patients and family members. The responses are summarized below in nine categories, with the first six categories focused on clinical issues and the last three on amenities. The categories are as follows: staffing issues – clinical; physician issues; patient and family education; equipment and facility issues – clinical; the process of care; the patient's experience of treatment; equipment and facility issues – amenities; staffing issues – patient satisfaction; and administrative issues.

The descriptions of the responses presented below are fairly lengthy. We considered condensing them further, but decided that for this preliminary report it would be better to preserve this level of detail. The detail will enable this report to provide a broader range of input into our future analysis of potential ways to revise the DFC website.

Staffing Issues- Clinical

- The skills and experience of technicians was a concern cited by most participants. This includes several things. For example, the ability to insert needles without causing excessive pain or causing problems with vascular access (this was a frequent comment). Patients believe technicians vary widely in their skills in this area; they avoid certain technicians whenever possible. Two patients stressed the importance of exercising their right to refuse treatment from some technicians. Politeness and encouragement of patients by technicians were related issues also viewed as both important and widely varying among technicians.
- Training and certification of technicians (or lack thereof) was also viewed as important. As one patient commented, *"I've seen some who can't even add the numbers up."*

- Many patients don't like technicians, and don't trust them. They are often viewed as too young. They are sometimes rude, yelling across the room to each other. One patient stated that, *"Techs don't give you the information on why your results are what they are. If you ask questions, they get mad. You have to have a tech who likes you."*
- Most patients prefer to be treated by RNs, as they are viewed as more competent.
- Easy access to dietitians was important to most participants. This was assessed by patients by how often the dietitians would meet and talk to them.
- Access to social workers was also viewed as important. They should be knowledgeable and able to tie patients into useful programs, such as pharmacy assistance programs.
- A low patient to staff ratio was stressed by the participants. Ratios of patients to technicians and nurses were most often cited, although dietitians and social workers were also mentioned. (This was a frequent comment.)
- Low staff turnover was also emphasized. As one patient put it, *"It tells you something if they can't keep their employees."*
- PD patients indicated they want continuity in their PD nurses. They do not want to switch nurses very often.
- Timeliness of staff was another key issue. This includes rapid start-up of dialysis treatments, ensuring patients do not have to wait too long for their shifts to begin, and ensuring patients do not have their dialysis time cut short due to scheduling problems on earlier shifts.
- Responding quickly when the machine "beeps" is a related issue. The "beeps" mean the machine has stopped, and if the staff do not respond quickly, it can result in reduced dialysis time.
- Good communication between staff members was viewed as important. As one patient stated, "Good communication gets good results."

Physician Issues

- Easy access to doctors was a key issue for patients. This was expressed in several ways, but with a common theme of having "face-to-face" time with doctors on a routine basis, and especially when needed to resolve problems, without excessive delays. Patients believe doctors should come into the facility on a regular basis.
- Politeness and encouragement of patients by doctors were also viewed as important, and as factors that vary widely among doctors.
- Doctors should be proactive versus reactive. Some patients believed that their doctors were not doing enough for them.

Patient and Family Education

- The need for good patient education was a frequent comment. That includes being taught about diet, the importance of taking medicines, and not skipping dialysis sessions. Lab test results should be reviewed on a monthly basis with patients, with guidance on how to improve the results. The lab results should be timely and well explained by dialysis staff. A PD patient stated that *"One of the things that annoys me is that if my levels go down, like potassium. They want to prescribe you pills instead of just eating a couple of bananas. Help me change my diet, don't give me more pills."*
- One family group emphasized the idea that, *"one size doesn't fit all."* So patients should question everything – different patients have different needs for information and education.
- Family members stressed the importance of training and education for family members as well as for patients. Family members need to know what to expect and how they can help the patients. In addition, providers should meet with family members to find out what is going on with the patient at home. One family group talked about the importance of four-way communication, between the family, patient, staff, and doctor.

Equipment and Facility Issues - Clinical

- The importance of modern equipment, such as new dialysis machines was a frequent comment. Concerns about the age of the dialysis equipment were often cited. A patient from Phoenix who visited another center while traveling stressed this point, *"I went to one center in DC and their equipment was antique."*
- Re-use of dialyzers or other dialysis equipment was a practice in some facilities that raised concerns for participants. Some suggested patients should get a new dialyzer every time they receive dialysis treatment.
- Proximity to a hospital was viewed as vital if emergencies arise during treatment. A related concern was whether the facility is affiliated with a good hospital or a bad one.
- Infection control practices were cited as a key issue. They include washing hands, changing gloves between patients and not setting dialysis machines up the night before, but rather just before the patient goes on the machine.
- No infections was viewed as an important goal. Several participants suggested that a facility's statistics on infections are a good indicator of quality of care.
- Getting good clearance in dialysis sessions was important to many participants. This includes ensuring the dialysis machine settings are adjusted correctly for each patient.
- For PD patients, easier access to PD nurses outside of scheduled visits is important. That way, if there is a problem they do not have to go to the emergency room.
- One PD patient stressed the importance of using Baxter PD equipment instead of Fresenius, believing Baxter to be superior for PD.

The Patient's Experience of Treatment

- Patients indicated that they would prefer a facility that is recommended by other patients. (This was a frequent comment.)
- How they feel when they get off the machine was important to patients. Is the patient happy at the end of the treatment?
- Several patients stressed that they should not get hurt; there should not be bruising or infiltrations.

Equipment and Facilities Issues - Amenities

- Cleanliness of the facility was important to patients. (This was a frequent comment.) One patient noted that, *"Some chairs still have blood on them."*
- Another issue was the size of the facility. Several participants said the larger facilities make you feel like a number.
- Many patients emphasized the importance of comfortable chairs. (This was a frequent comment.)
- Patients believed television should be provided for all. Individual TVs were considered important, rather than group ones. Cable TV was also cited as important. (These were frequent comments.)
- Access to dialysis facilities should be ensured for people with disabilities.
- Good parking was a priority for some participants.
- The need for a cheerful looking facility was emphasized by several participants, since they spend so much time there. As one said, *"Some of them are depressing."*

Staffing Issues – Patient Satisfaction

- Staff should be friendly, have a positive attitude, and have compassion and respect for patients. They should take time to explain things. They should not be detached. One patient who had moved from another city said that, *"In New Orleans, they treat people like cattle."* In a related metaphor, a patient in a different city said staff attitudes can vary widely, *"Are you a customer or a piece of beef?"* To show a contrast, another patient stated, *"In [a certain] clinic, they treat you like family."* Others also used the *"family"* metaphor to describe how they should be treated by dialysis staff. As one patient commented, *"I've been to 7 or 8 different places. The ones that stood out to me were the ones that treated you like you were somebody. There's a couple of techs that I can remember from about 6 years ago that would ask, 'are you alright?' And before you could answer they were across the room."*
- Technicians should also understand the patient's perspective. As one put it, *"I want to suggest that it's mandatory that the techs, before they can ever come into the unit and do anything, sit in our seats for at least a week. So that they can understand. Cause, like, some things like, there's this one guy, and I'm trying to sit up and gather*

my strength to hold my sites. 'Sit back!' [he says]. And I don't want to sit back, but he don't understand that, because he's never been where I am."

- The presence of a patient advocate would be helpful to many participants. Some patients said they are afraid to voice concerns; they are afraid of retaliation from staff.
- Many patients would like eating to be permitted either during or after treatment. Some described facilities that provide snacks for patients after they complete their treatment.

Administrative Issues

- Access to background information about the dialysis facility would be valuable, including who is the administrator and what are the rules and regulations.
- When patients call the facility on the telephone, staff should not put them on hold. Family members indicated they want to be sure that if they leave a message for a patient, he or she will get it in a timely manner. PD patients noted that it is especially important for staff to return their phone calls quickly, since PD patients only visit their facility about once per month and they could be calling about some type of problem. If they have questions or problems they should be able to talk directly to someone, and not have the call go to voicemail.
- Many patients indicated they would like to have the ability to change shifts when needed.
- Interviews often provided more detailed information on these quality of care issues than the focus groups or triads. The additional time available during interviews to discuss them appeared to be the reason for this difference.

3.1.4 Information Sources

We asked participants about the sources they use for information about dialysis care or dialysis facilities. We probed especially regarding Internet use, whether for dialysis issues or for other uses. To summarize, the main points were:

- Most patients and family members cited providers, other patients, and written materials as key information sources.
- Some patients and most family members reported having Internet access. More patients in Phoenix reported having access than in the other cities.
- Among patients without Internet access, family and friends were cited by some as possible sources of access.

Most patients cited providers (doctors, nurses, social workers, or dietitians) or other patients as key information sources regarding dialysis. Some attend kidney disease support groups, and some get written materials such as kidney disease newspapers or newsletters from

NKF, DaVita, or other sources. Some family members cited other family members as information sources.

Patients viewed other patients as especially valuable information sources. For example, one described how other patients had helped, *"So you can learn about the needles, the machine, cramping, dizziness…the doctor can only tell you so much. But we're the ones on the machine."*

Internet use varied by location. Most patient participants in Washington did not use the Internet. No one from the focus groups and only two interview participants used it regularly.

Notably, the sole family member participating in the Washington, D.C. site visit (an interview) used the Internet regularly at work. Providing Internet access may be a possible role for family members. Several patients in Washington also noted that while they do not use the Internet themselves, they do have friends or family members who could look things up for them. Several others reported that they have access through work or the library.

Interviewees in general were more likely to be Internet users than focus group or triad participants. Overall, 5 of the 7 dialysis patients interviewed for this study use it.

In Atlanta some patients reported using the Internet. In one focus group 2 of 7 patients use the Internet themselves. Among Atlanta family members, 6 of 10 reported being Internet users. Chicago was similar, with about half of patients and family members reporting either being Internet users or having friends or family members who could help them with it.

Phoenix seemed to have more Internet users among the study participants, with more than half the patients and all of the family members reporting Internet access for their own use or through family or friends.

Websites cited by participants as helpful for dialysis-related issues included the following:

- WebMD;
- dukeandthedoctor.com;
- Medline;
- nephron.com;
- askjeeves.com;
- msn.com and yahoo.com for searches;
- the Medicare and Social Security sites;
- ikidney.com;
- the Cleveland Clinic website;
- the NKF website;
- the Arizona Kidney website; and

- the PKD foundation website.

3.1.5 Exploring the DFC Website: Expectations

We asked participants what they would expect from a website called “Dialysis Facility Compare.” Several participants said they did not like the name. It did not make them want to use the website. No participants indicated that they like the name, although not all addressed this question directly. One said, *“The name is vague – is this a resource?”* Another said she was *“not overwhelmed by it.”* Several said the name sounds too long or too wordy.

Two patients had used the DFC website before this study. The others had mixed opinions about what they would expect to find there. Some seemed to base their responses on the name (parsing it); other responses seemed to reflect what participants would like to find there.

Most expected to see lists of dialysis facilities and comparisons between facilities on the website. For example, the equipment and dialyzers used in each facility, the number of seats, which facilities have TV, if they accept new or transient patients, the number of nurses, and the number of patients getting transplants, the doctors, and the types of treatments offered.

Some expected ratings of facilities. Several thought Federal guidelines would be presented on the site, so patients could check up on their facilities.

A few thought the website would have information for family members, so they could better understand what patients go through. Some others expected information about dialysis and ESRD, what Medicare covers, and information about medical benefits and financial information.

3.1.6 Exploring the DFC Website: Facility Characteristics

We showed participants the DFC website live on the Internet, on a computer for the interviews and several smaller triads, and on a screen using a projection device for the focus groups and for most triads. On the overview page, we showed them the list of facility characteristics and asked how they thought that information would be useful.

The current range of data elements on facility characteristics were viewed as useful and interesting by most patients and family members, but most participants – across focus groups, triads, and interviews – also felt that many other facility characteristics need to be added to the list. That is reflected in the lengthy list of specific recommendations for additional data elements presented below.

Patients and family members liked knowing the date of Medicare certification. They seemed to value knowing that a facility had been in operation for a number of years.

The ownership indicator sparked several lively discussions. Several patients said they prefer non-profit centers, as they believe those centers will focus more on care versus financial results. Others said they thought the non-profits would be cheaper. Some were not sure if one type would be better than the other.

The basic data on the name, address, and number of stations were viewed as useful. As one put it, those data *"give you some place to start."* Several indicated this would be useful for travel.

3.1.7 Exploring the DFC Website: The "Read This" Paragraph

We showed participants the "Read This" paragraph on the overview page of the DFC website, and read it to them aloud. We then asked for their reactions, which can be summarized as follows:

- Participants liked the idea of visiting facilities before selecting one.
- They agreed that the data on the DFC website should be one of several considerations in choosing a dialysis facility.
- Some suggested they should also talk to patients as well when visiting a facility, not just to providers as suggested in the paragraph.
- Some suggested that the DFC website should also include a series of common questions to ask when visiting a dialysis facility, since many patients do not know what to ask.

The text of the "Read This" paragraph is as follows:

READ THIS: The information in Dialysis Facility Compare should be looked at carefully. Use it with the other information you gather about dialysis facilities as you decide where to get dialysis. You should visit any facility in which you are interested and talk with the dialysis facility staff. You may also want to contact your doctor, local ESRD Network or State Survey Agency for more information before you choose a dialysis facility. The telephone number for local ESRD Network and State Survey Agency can be found in the Helpful Contacts section of this website.

Most participants agreed with the content of the "Read This" paragraph, and stated that they like it and it made sense. The idea of visiting facilities before being treated at them was appealing. Both patients and family members agreed that decisions about treatment in dialysis facilities should not be made solely on the basis of the data on the DFC website, and that they need to do additional research, ask questions, and take responsibility (or be "proactive") in their search for a facility.

As one patient put it, *"The part where it says visit is the important part. I've changed facilities after going there one time. The only way you can really know is to go there and see them."*

However, some indicated that new dialysis patients may be too sick to consult with providers, and may need family members to help with that process. For choosing a second facility this may make more sense, as one put it, *"because the first facility was assigned to you."*

Participants also stressed the importance of talking to other patients. They did not want to talk only with providers, as emphasized in the "Read This" paragraph. Several suggested the role of the social worker could be important in helping patients explore different facility options.

Some pointed out that patients often don't know what questions to ask when visiting a dialysis facility. They suggested that the website could include a set of common questions that patients and family members could ask staff and patients when visiting a facility. As one put it, *"If you don't know what you're looking for, there should be some questions to help you know what you're looking for."*

Several participants in Washington indicated this advice would be more useful if more genuine choices between dialysis facilities were available. Atlanta patients had similar comments, and indicated that whether they can "shop around" as this paragraph suggests depends a lot on whether their doctor is affiliated with more than one dialysis facility. And if other facilities will accept their health insurance. One said she *"feels stuck in her facility."*

Some of the language in this paragraph was found to be too complicated or obscure. For example, many participants did not know what an "ESRD Network" is.

A few found the paragraph disconcerting, indicating it sounds like a *"standard disclaimer"* or *"the fine print on a contract."*

The interviewees seemed to focus in more detail on this paragraph than participants in the focus groups and triads. This may be a better issue for the individual interviews where more time is available and the questions can be more personalized.

3.1.8 Exploring the DFC Website: Quality Measures

We showed participants the list of quality measures on the overview page of the DFC website, and asked how many had heard about them. We also asked if they had discussed those measures with a provider and what each of the quality measures means to them. The responses can be summarized as follows:

- Most had heard of the urea reduction ratio (URR) and hematocrit measures, and had discussed them with providers.
- Many patients get routine "report cards" with these and other clinical measures from their facility.
- The patient survival measure was less familiar to the participants, harder to understand, and scary to some.

Almost all participants had heard of the quality measures, and most knew the general meanings of those terms.

Most had experienced one or more providers discussing their own numbers with them on the URR and hematocrit measures. The specific provider involved varied among doctors, nurses, and dietitians. Some participants had specific targets they could cite, such as a goal of 70 or 75 for URR, depending on the facility.

The PD patients noted that the adequacy measure for their mode of dialysis is Kt/V. The DFC website currently does not have any data on that, only on URR for the HD patients.

Many patients get routine, monthly "report cards" with their scores on these clinical measures and several others. Most of those patients had talked with their doctor, nurse or dietitian about the report cards, and how to improve their numbers.

Participants had talked about the measures in general if they did not get report cards. However, fewer family members reported knowing about these quality measures or talking to providers about them.

Most were clear on the differences between facility-level averages for these quality measures and their individual numbers, but some were not.

Patient survival was very interesting to the participants, presumably because of the severity of their illness and the ongoing threat of death most dialysis patients feel. As one patient said, *"Patient survival scares you to death."* Two patients in Atlanta talked about their experiences of seeing other patients die right in front of them in their dialysis facility.

However, the data presented on patient survival are couched in statistical terms (e.g., "worse than expected") on the website and as a result were less well understood. As one put it, *"what do you mean by that?"*

Several noted that survival is related to other patient- or doctor-related factors, not just to the facility. Some suggested that URR and hematocrit are better measures of quality, since they are more related to the performance of the facility. Another suggested infection rates would be more related to the facility's performance than patient survival.

An extra question was included in the interviews regarding the Glossary definition for the adequacy measure. Most found it too busy and confusing, and several contrasted it with the definition in the National Institute of Diabetes & Digestive & Kidney Diseases (NIDDK) dictionary, which was viewed as much simpler and easier to read. Another patient, who also happens to be a provider, understood the Glossary definition, but also felt it was not clear enough.

Some found the descriptions of the quality measures on the main website pages hard to understand. As one stated, *"For myself, it's about half and half. Its understandable, but for someone who's just starting with this, it's like legalese."* Several also suggested using some pictures and diagrams to help explain the quality measures, instead of relying only on text.

In general, participants viewed the quality measures as useful, if not necessarily comprehensive or perfect.

3.1.9 Exploring the DFC Website: Links of Interest

In the Washington focus groups and all of the interviews we showed participants the links on the overview page of the DFC website and asked which ones they would like to explore. We then clicked on one or two links and reviewed the content with the participants. During the site visits after Washington, we showed focus group and triad participants examples of links, but did not explore them in detail due to time constraints.

The NIDDK dictionary was the most popular link. Its short definitions of dialysis terms were found to be much more readable than the longer paragraphs in the DFC website. Its diagrams showing how dialysis procedures work in the body, such as how PD works, were deemed quite helpful.

Other links mentioned as potentially interesting included: helpful contacts; glossary; dialysis publications and related sites; download dialysis facility compare database, and select a geographic area.

3.1.10 Exploring the DFC Website: How Is The Information Useful?

In reviewing the overview page of the DFC website, we also asked participants how the information would be useful to them. Most said that the information would be useful. They also suggested the DFC information would be better understood, and hence more useful, after a patient has been on dialysis for a while and can better understand the value of the information.

Participants said the DFC would be especially valuable for patients who were traveling or moving to another city. As one put it, *"Just to know how many dialysis units there are in that area is useful. And to know that I don't have to have someone else look, I could look myself."*

A number of patients said the DFC information would be helpful to them in general, but seemed to have a hard time addressing this issue. They seemed a bit unclear about usefulness at this point in the focus groups, triads, and interviews, before they had seen the specific examples of applications of DFC information in the moving to Florida scenario (discussed below in Sections 11 and 12).

Several participants suggested the DFC information would also be useful in the pre-ESRD phase of kidney disease, to help patients prepare for dialysis. This will be especially true if they know well in advance that they will need dialysis, so they have time to prepare by using the DFC website and other information sources.

3.1.11 Scenario of Moving to a City in Florida: Facility Characteristics

We presented participants with a scenario in which they would be moving to a city in Florida, and needed to choose a dialysis facility in that city. We walked participants through the process of identifying the dialysis facilities available in that city using the DFC website. We selected four facilities in that city and showed participants their facility characteristics data using the website. (We pre-selected the four facilities to ensure they varied on several characteristics, including size, ownership status, availability of evening shifts, and chain membership.) We asked participants what the information told them about these facilities.

Overall, patients and family members were pleased to have the facility characteristics available to them. They viewed some of the specific characteristics as particularly useful. Those data elements included the locations of the dialysis facilities (addresses), the contact information (telephone number), the presence of evening shifts, the number of dialysis stations, nonprofit/for-profit status, and chain membership.

Here again, however, participants felt additional information was needed; a list of their recommendations is included below in Section 18.

The number of dialysis stations seemed interesting to many patients, especially for the facility with 45 stations in the scenario. Several commented that that facility sounded awfully large.

As before, some thought they would get better treatment at nonprofit facilities. Others were not sure of the meaning of nonprofit/for-profit status.

Chain membership was viewed as useful by some participants, who liked being part of a large organization and the idea of continuity within the same chain if they moved or switched centers. As one Fresenius patient who had switched facilities put it, *"my unit is under the same management."* Several others commented that they like knowing the chain name since they believe *"some have better reputations than the others."*

Several family members in Atlanta commented that this web page seemed a bit too wordy. They suggested that the type in this section should be bigger and bolder.

The PD patients noted that the information in this section is oriented to HD patients. For example, the number of stations is for HD, but there are no similar data on the capacity for serving PD patients.

3.1.12 Scenario of Moving to a City in Florida: Quality Measures

Continuing the moving to Florida scenario, we showed participants data on each of the three quality measures for those same four facilities. (The facilities were also pre-selected to ensure they varied on the quality measures, including adequacy, anemia, and patient survival.) We compared the results for those four facilities with the national and state average data also available on the DFC website for each of the quality measures. One facility (Facility A) was selected since it was much higher than the others – and higher than the national and state averages – on both adequacy and anemia. Another (Facility D) was selected since it was significantly lower than the others on patient survival. A third, (Facility C) was selected since its results showed all of the quality measures as "Not Available."

We asked participants what the information on the quality measures told them about those four facilities. Their responses can be summarized as follows:

- Participants were impressed with the favorable results for Facility A on the adequacy and anemia measures.
- The colored bar graphs used to display the adequacy and anemia data made the results easy for patients to understand and more interesting to them.
- Participants were much less interested in the text descriptions of the quality measures placed under the graphs.
- The patient survival measure and its results were harder for them to understand.
- The lower patient survival results for Facility D raised a lot of concern.

- The “Not Available” results for Facility C also raised concern. Participants thought that facility was hiding something.

All of the patients and family members could easily see that Facility A had better adequacy and anemia results. Most were very favorably impressed, as the graphs showed Facility A as much higher on both measures than any of the other facilities. Several noted that it beat both the state and national averages as well. One called the graphs an *“eye-opener.”* Several suggested that the results meant that Facility A was being more proactive and better managing the care of its patients. Most indicated the results would make them lean toward going to that facility, or at least lead them to check it out further. As one put it, *“Facility A is doing their job.”*

The graphical displays of the data comparing the different facilities, and the use of color in the graphs to highlight them, seemed to make the data easy for patients to understand. They responded much better to the graphs than to the text explanations under the graphs for the quality indicators (or to the earlier discussions listing and describing the quality indicators, presented above). However, once pointed to them, most participants thought the explanations of dialysis adequacy and anemia below the graphs were clear.

Some participants asked about the sources of the data. After going back to the website’s link for reviewing the data sources, they seemed satisfied.

Several suggested that other factors may affect adequacy results, and that the facilities may not be completely responsible for them. For example, several knew that patients with catheters for vascular access have a harder time getting adequate dialysis. Some commented that older or sicker patients might do worse on the anemia and patient survival measures. Others suggested that the doctor may affect the quality measures more than the facility. But most felt the numbers and graphs presented on the DFC website at least provide a good starting point for questions to ask facility staff and physicians.

The patient survival data were reassuring to those who interpreted the survival categories and associated check marks correctly. Some indicated they would not go to Facility D, however, since it was rated “worse than expected.” Others said they would not take the Facility D results at face value, but seemed concerned nonetheless.

Many were confused by what the survival data meant. The text explanations of the survival data were unclear to most. For example, some asked what the data presented for the facilities mean about the expected survival of an individual dialysis patient. One described the patient survival data as *“loosey goosey.”*

In contrast, the Frequently Asked Questions (FAQs) for survival were found to be interesting. Participants seemed to be looking for ways to predict or improve their own survival. The risk factors highlighted in the FAQs were viewed as helpful, since patients felt they could apply to themselves.

Several participants noted that patient survival depends on a lot of factors. However, the statistical methods and covariates used in the expected survival predictions were not well understood.

It is interesting to see how engaged the participants were in discussing the FAQs and factors affecting survival. Despite being somewhat afraid of this topic, they also saw the potential value in learning more. It may be useful to add some additional FAQs on this topic.

The "Not Available" results for Facility C raised a lot of concern. Despite the explanatory footnotes that were pointed out by the group facilitators and interviewers, participants were suspicious that Facility C was hiding something in not releasing its data. It seemed that few, if any, participants would consider being treated at that facility.

One problem several participants noted was the placement of the headings for the graphs. They wanted the headings to be right above the graphs, not above two graphs at once, where sometimes they cannot be easily seen when all four facilities' graphs are being viewed at the same time.

PD patients again noted that the adequacy measure is just for HD.

The interview guide contained additional questions focused on the explanatory paragraphs for the quality measures. The paragraphs were not well received. They were considered too long and too dense. However, most participants saw their value when pushed to read them, or when the paragraphs were read to them. Several suggested summarizing them in bullet points or shortening them.

3.1.13 Most & Least Important Information

We asked all participants what they thought was the most important information on the DFC website. In the Washington site visit, we also asked what they thought was least important.

Answers to these questions were varied but fairly limited. Opinions about the "most important" information included: facility characteristics, address and phone numbers for the facilities, phone numbers for networks, adequacy and anemia bar graphs with percentages, patient survival information, quality measures, the ratings, profit vs. non-profit status, which company is involved, locations, and treatment modalities offered. Facility characteristics were mentioned most frequently, but generally without a lot of conviction.

Family members in Atlanta and Chicago seemed less pleased with the DFC website and more often willing to say not much was relevant to them. Some said it's mainly for traveling, or it's just a starting point to give patients and family members some idea of what's available. Several said, *"I just ask my doctor."*

In Phoenix, family members were more mixed in their responses. Nonetheless, in general, family members were less enthusiastic about the website than patients. It seemed as though family members were looking for other types of information from the website that they did not feel they were getting. As a result, the family members tended to have longer lists of additional data elements they would like added to the website.

Survival was mentioned as being "least important" by several participants in Washington. They were the ones who believed that too many other factors affect survival rates to hold facilities accountable. Nothing else was described as least important. However, many participants did not respond to that question.

Most participants seemed unable to answer these questions effectively, perhaps because they were just seeing this information for the first time in the DFC website format. Some said all the data are important, but seemingly without really considering the question. As one put it, *"it was all kind of relevant – I wouldn't take anything out."*

3.1.14 Does the DFC Website Meet Participants' Expectations?

We next asked participants to think back to before we showed them the DFC website, when we asked what information they expected it would provide. We then asked to what extent the website had met their expectations.

Most indicated the website met their expectations, although once again they also indicated it needs additional information added. Some had initially said they thought the website would have performance rankings of facilities, but still expressed satisfaction even though that expectation was not completely realized. They may have found the relative quality comparisons in the moving to Florida scenario to provide some useful comparisons, if not rankings.

Others pointed out a number of things they had listed at the start of their group as important issues (presented in Section 1 above), but were not yet in the website. They included staffing, staff skills and certification, and staff experience.

Some said the website had more information than they expected. As one put it, *"it had more than I thought it would."* Another said, *"It's a good start."*

Patients tended to be more satisfied. They seemed to feel empowered by having access to information they had not had before. As one put it, "This is the most information that I've seen in [over 10] years on dialysis."

Once again, it was the family members that were more dissatisfied. Several said it just does not give them much information. Others said it does provide some useful information, but overall they had fewer positive responses than the patients.

3.1.15 Content of the DFC Website – How Would Participants Use It and Recommend It?

We asked participants how likely they would be to use the DFC website, what information they would use, and how they would use it. We inquired about potential barriers to its use. We also asked under what circumstances they would recommend the website to others.

Most indicated they would use the website and would recommend it to others, especially others about to start dialysis. None were strongly negative on these questions, although some did not respond.

Travel or moving to other cities were most often cited as reasons to use the website. This included both for themselves and to recommend to others who were traveling or moving.

Several indicated the website would help them to be more self-reliant in searching for facilities in other cities, and not need to rely on their social worker so much.

Some participants also indicated they would use the website as an information source, especially for FAQs and definitions of medical terms. Several said they would use the website to learn more about dialysis, about their Medicare benefits, to gather information about their own facility and others, and to see how their unit measures up compared to others in their area. Several said they would use the phone numbers to call other facilities and find out more about them.

Several suggested the website would be good for patients about to go on dialysis or their family members. It could help them know how to prepare and what to do.

Only a few mentioned lack of computers, Internet access, or computer literacy as a barrier to use of the DFC website. Those issues did not seem to be major concerns. Some said they could use computers at the library. Several suggested that the dialysis facilities should have computers available for patients to use for things like the DFC website.

Some PD patients again said the website seemed too focused on HD, so they might not use it. Other PD patients said they still might use it for facility comparisons, and they would recommend it to others who were just starting dialysis.

3.1.16 Content of the DFC – Is It Complete?

We asked participants how complete the DFC website seemed to them. There was limited response to this question. Participants seemed hesitant to make a judgment on "completeness," since virtually all were seeing it for the first time.

Some said that the website has a lot of information, but needs more. As one put it, *"It's a starting point."* Several participants in one patient group in Chicago argued that the website is not very complete and needs more information on facility characteristics. A family member group in Atlanta made similar arguments.

The PD patients again pointed out the need for more PD-related information.

Several patients suggested that the website needs more graphics or even videos. They said that there is too much text, especially compared to other websites they had used. As one put it, *"Diagrams are better for explaining things as you can visualize it in your head. Hearing words is not as helpful."*

A number of suggestions were made at this point regarding additional data elements that could be added to the website. They are included in Section 18 below.

3.1.17 Content of the DFC – Is It Up To Date?

We asked participants how up to date the DFC website seemed to them. Patients in Washington were not concerned with the age of the data, although their responses were limited. Most did not notice that the quality measures data were old. Those who did notice, or had it pointed out to them, still seemed satisfied. However, documenting the age of the data was considered important. Periodic updates of the data were also considered important, at least once per year.

Some patients and family members in Atlanta, Chicago, and Phoenix seemed more concerned with the age of the data, although others were satisfied. Several said the data were not new enough, and would be better if they were only one year old. Family members made this point more frequently. They also wanted updates at least annually.

3.1.18 Other Information Participants Would Like To See on the DFC Website

As part of the moving to Florida scenario, we asked participants what additional information they would like to have on facility characteristics and quality measures for the four facilities they were comparing. We also asked again, at a later point in the group or interview, what other information they would like to see on the DFC website, including information about dialysis facilities, kidney disease, or how to better manage their own care. As noted, participants also volunteered suggestions for additional information that could be added to the website in response to other questions. We combined all of those recommendations into this section.

One frequent suggestion was to have more information in Spanish throughout the DFC website. Or possibly a Spanish language version of the entire website.

Numerous suggestions were made for additional data elements to be added to the website, including additional data on facility characteristics, quality measures, and additional dialysis or health-related information. The specific recommendations are listed below in 15 categories. The first nine categories include recommendations on facility characteristics. The tenth includes recommendations on quality measures. The last five categories include recommendations on additional dialysis or health-related information.

These lists of recommendations are lengthy. We considered condensing them further, but decided that it would be useful to preserve this level of detail to give readers a better feel for the scope of recommendations made by these dialysis patient and family respondents. The recommendations are as follows:

Physicians

- The number of doctors practicing at the facility, their credentials and academic ranks.
- The frequency that doctors see patients in the dialysis facility. (This was a frequent recommendation.)
- How many patients per doctor.
- What are the options for changing doctors?
- Are doctors on site? What days and times? For all shifts? (This was a frequent recommendation.)

- Are doctors on staff?
- Provide some type of doctor ratings.

Dialysis Staff

- Are social workers available in the evenings?
- When are the social workers and dietitians actually at the facility, the days and hours.
- Are the social workers and dietitians full-time or part-time?
- The numbers of clinical staff of all types.
- Ratios of patients to technicians, nurses, social workers, and dietitians. (This was a frequent recommendation.)
- Are monthly meetings with dietitians possible?
- Can patients pick their own nurse and technician?
- What are staff turnover rates.
- Indicate what the ratios of patients to technicians, nurses, social workers, and dietitians should be.
- Provide Medicare's rules about ratios of patients to staff.
- Some measures of staff experience with dialysis.
- Some measures of staff education and training.
- Indicate what the qualifications, training, experience of those staff should be.
- What are the academic affiliations of the facility and staff?
- Are the technicians at the facility certified?
- Provide staff biographies.
- What languages are spoken by staff?

Equipment and Facility Information

- When was the dialysis equipment last updated?
- Indicate the type of equipment – the type and age of the dialysis machines
- Indicate what the age and types of equipment should be. How old is too old for dialysis equipment?
- How many isolation chairs are available?
- Provide information on parking and handicapped access.
- What types of transportation are available?

Amenities

- Are blankets available?
- Is TV available?
- Is cable TV available?
- Can patients have radios?

Organizational Information and Policies

- Add the complete schedule for dialysis, the days and shifts the facility is open. (This was a frequent recommendation.)
- What are the holiday hours and shifts?
- Provide the email address of the facility.
- How many of the facility's stations are for inpatient versus outpatient care?
- When was the information on the website last updated?
- Provide patient testimonials.
- Provide pictures of the facility on the website.
- Provide a virtual tour of the facility on the website.
- Does the facility have its own website? If so, provide a link to it.
- Indicate the layout of chairs in the facility.
- What's in the area – like restaurants?
- Indicate the types of access used by patients at that facility.
- Provide maps & directions to the facility.
- Provide some kind of mapping feature on the website, like MapQuest.
- What is the cost of treatment, if you have to travel?
- Show facility ratings on cleanliness.
- List the amenities the facility offers patients.
- Does the facility allow visitors?
- Who owns the facility?
- Is the doctor getting a percent of the facility's profits?
- What are the hours for phone contacts?
- Does the facility allow patients to eat during dialysis treatments?
- Provide the rules and regulations of the dialysis facility.

- Provide the history of the facility, including the date opened.
- What insurance plans are accepted?

Clinical Policies

- What is the emergency system, when people get sick while on hemodialysis?
- What is the proximity to a hospital? As one patient put it, *"If my blood pressure drops and I pass out and need medical attention, I'd like to know it's close by."*
- What is the connection between the facility and the hospital?
- What mental health care is provided for dialysis patients? Do staff check for depression?
- What is the policy on re-use of dialyzers or other medical devices?
- Can you stick yourself?

Patient Issues

- Indicate the number of visiting or transient patients per day.
- What is required to be a transient patient at this facility? (This was a frequent recommendation of family members.)
- Describe the requirements for new patients. One patient said, *"I went to a unit where they required an HIV test – and they wanted me to pay for it. I didn't happen to have an extra $200-300 for a test. So they should say that."*
- Indicate how to contact patients already at the facility, to talk to them about their impressions. (This was a frequent recommendation.)
- What is the average number of years on dialysis for patients at that facility?
- Provide an age breakdown of patients at the facility.
- How many patients are working?
- Does the facility have a waiting list?
- Is family member education available? (This was a frequent recommendation of family members.)
- What is the patient transfer rate to other facilities?
- Are support groups or networks for patients available? (This was a frequent recommendation.)
- Are support groups or networks for family members available? (This was a frequent recommendation of family members.)
- The number of patients receiving transplants, and compared to the state average per facility.

- The number of patients on a transplant waiting list.
- Accreditation and Regulation
- Is the facility on probation from regulators?
- Date of facility's last inspection.
- When was their Medicare certification last updated? Any time since the date of original certification? (This was a frequent recommendation.)
- Have a rating for each facility. As one put it, *"In California, they rate fast food restaurants from A to F and they have to post it right in the front window. Maybe they should do that for dialysis!"* Another suggested, *"Have a rating like hotel or AAA by inspection. Just say, this unit here has a four star rating…based on an average of everything."*
- Did the inspectors find any problems?
- Has the facility ever received reprimands?

Peritoneal Dialysis

- Is PD training offered at the facility (in addition PD care)?
- When is PD care offered?
- Are both types of PD supplies and equipment supported (Baxter and Fresenius)?
- Indicate the numbers of PD patients and HD patients.
- What insurance is taken for PD?

Quality Measures

- Add data on vascular access and graft problems.
- Indicate the numbers of patients on catheters for vascular access.
- Add Kt/V data to complement URR data.
- Add patient satisfaction data. (This was a frequent recommendation.)
- Add data on the facility's infection rate.
- Provide quality goals for pediatric patients.
- Provide more information on survival rates.
- Add data on PD adequacy, with graphs.
- Add data for PD anemia only – separate from HD anemia.
- Add survival data for PD only.

- Are “report cards” with key lab values and other outcome data provided to patients on a periodic basis?
- Are there opportunities to discuss the “report cards” with doctors, nurses, or dietitians?
- Break down quality measures by rates for people in different demographic or other categories.

Dialysis and Kidney Disease Information (This topic was a frequent concern of family members.)

- Provide more information on what to expect in dialysis treatment. (This was a frequent recommendation.)
- Provide information on what to expect when starting dialysis for the first time. (This was a frequent recommendation.)
- Include some information on how long patients can live on dialysis. One patient said, *“My doctor said that the longer your treatment, the longer you can live. I go 5 hours.”*
- Indicate where to go for financial help
- Provide medical updates, reports on new medications, and new procedures
- Provide links to pharmaceutical websites for drugs that are commonly used.
- Add information on frequent dialysis. One patient said, *“Shorter treatments on more days acts more like a normal kidney. You go every morning for 5 days. I think we ought to know how much these contracts are. Our unit has a list of prices you pay.”*
- Provide a list of questions to ask a dietitian.
- Provide a list of questions to ask a nephrologist.
- Provide a bibliography on dialysis and kidney disease.
- Provide vascular access information, such as how often grafts will clot and how patients can help prevent that from happening.
- Provide practical information on fluid equivalents, for meal planning, such as 1 cup = “x” oz.
- Explain what happens when patients skip dialysis sessions.
- Include educational pictures and videos, such as the anatomy of the kidney, and the process of peritoneal dialysis.
- Discuss current topics under debate in the dialysis and ESRD community, such as the number and length of hemodialysis treatments recommended per week.
- Provide a source for definitions of general medical terms, e.g., “necrotic.”
- Provide a source for pre-ESRD information.

- Describe the symptoms of kidney failure, so patients can know about it earlier.
- Set up a chat room, for talking with other patients.
- Set up a chat room for on-line advice from doctors or nurses (like at Kaiser).
- Provide more FAQs targeted at family members and other in-home caregivers. Explain what they should expect, what they should think about. (This was a frequent recommendation of family members.)
- Add information on mental health issues and mental care for dialysis patients.
- Provide information on alternative medicine and treatment for dialysis.
- Provide a way to request that dialysis and kidney disease information be mailed.
- Provide information on how to take care of yourself after leaving the dialysis facility.
- Provide useful links to other websites: NIDDK, kidney.com, NKF, websites with information on medicine, links to good and bad things to do on dialysis, links to networks for the state.
- Clarify that patients have the right to refuse treatment by particular technicians and nurses.
- Clarify that technicians and nurses have to stick to doctors' orders.
- Provide a place on the website where patients can ask questions about dialysis and about their facilities.
- Provide guidance on how to find nephrologists.
- Include information about the option to be treated at home.
- Provide information about what to do to improve rehabilitation and quality of life for patients on dialysis.
- Include links to information on pediatric dialysis.
- Provide resources for children on dialysis – for example, where can they go swimming?
- If dialysis is not adequate, what does that mean?
- Add "fun stuff" – like information on dialysis cruises and international travel.

General Health Education

- Patient education materials could be available on the website. For example, "What I can do to help myself stay healthy and to improve my quality of life."
- Provide information on what to eat and what happens if you eat the wrong things.
- Provide links to the medical literature (such as PubMed), and clinicaltrials.nih.gov.
- Provide information on common medications and their cost.

- Provide links to drug company brochures to explain medications.
- Include special health information for the elderly.
- Include links to health insurance sites.
- Provide helpful hints – like the importance of exercise.

Medicare Information

- Explain how to sign up for Medicare.
- Include more information on patients' Medicare benefits
- Describe any costs that Medicare does not pay.
- Provide some way to give feedback to Medicare.
- What are the extra fees when patients travel out of state? As on patient put it, *"The extra 20%."*
- Another patient suggested the following, *"Explain that Medicare only pays for half the drugs you need when you get a transplant."*

Transplant Issues

- Discuss transplants as an option for treatment.
- Include links to transplant information, for the success rate, how well it does for the patient, what patients have to do to avoid rejection (the importance of taking the medications).
- Describe the pro's and con's of transplants to dispel rumors like, *"You need to take 100 pills a day."*
- Describe the side effects to expect from the drugs used with transplants.
- Explain that patients have to have a financial plan for all of the payments before they can get a transplant.
- Explain what to expect with a transplant.
- Provide information on how organs are donated.

Peritoneal Dialysis Issues

- Provide education on what to expect in PD, and what the process of adjustment to it is like (not just a brief description).
- Provide call-in line to PD nurse, 24 hours a day, like United Health.
- Describe the different types of PD supplies (Baxter is not the only one.)

In general, the participants providing the most ideas for additional data elements were patients in interviews and family members in triads. Extra time to discuss these issues seemed to help interviewees generate more ideas.

As noted, the family members seemed more dissatisfied with the information on the website, so they presented more ideas for additional information. The unique ideas from family members related to issues specific to them, such as the presence of family member support groups. Their other ideas tended to be covered in other groups at some point, but they had longer overall lists of ideas generated from their individual triads.

Family member also expressed stronger interest in issues of dialysis and kidney disease education. They seemed concerned about how to be better caregivers and how to provide support to the patients without neglecting their own needs. They wanted to have access to much more information about treatments, what to expect physically and emotionally from patients, how to improve clinical outcomes, rehabilitation, quality of life, pharmaceuticals, and many other topics. Many seemed to find their caregiver role stressful.

3.1.19 How Medicare Could Let Dialysis Patients & Family Know About the DFC Website

We asked participants about the best ways for Medicare to tell other dialysis patients and family members about the DFC website. A number of suggestions were made for "getting the word out":

- Provide pamphlets and posters on the DFC website for dialysis units and nephrologists' offices.
- Provide pamphlets in Social Security Administration offices.
- Provide inserts in Medicare mailings or bills.
- Provide pamphlets during patients' initial Medicare interviews.
- Send a letter to patients. One patient suggested that, *"If you have to go through the unit you'll never get it – it will get lost in the shuffle, not a priority."*
- Have parties for patients and family members with a video and pamphlets about the DFC website.
- Advertise on AOL.com and the NKF website.
- Set up links from pharmaceutical websites
- Social workers could provide DFC information as part of the package of information they provide patients when they start dialysis.
- Promote the website through social workers in other ways.
- Have a computer in the lobby of each dialysis facility.
- Get the word out through patient support groups.
- Advertise in magazines, newspapers, or on television.

- Have the Phil Donahue show do a segment on the DFC.
- Several patients suggested that materials advertising the DFC website should also include Medicare's suggestions for places patients could go for computer and Internet access.

3.2 General Themes

The focus groups, triads, and interview we conducted with dialysis patients and family members also included three more general themes. As noted, they cut across the more detailed issues presented in the last section.

3.2.1 Dialysis Patients and Family Members Prefer Graphical Displays of Information

Patients responded especially well to the tabular displays of the facility characteristics information and to the graphical displays of the quality data. The colored graphs, comparing multiple facilities, in particular seemed to enliven them. They were much less engaged with the text-based descriptions. It may be that graphics are the best way to engage patients actively in quality issues and facility comparison.

Diagrams were also mentioned a number of times as a way to supplement text-based patient education materials. For example, diagrams could be used to illustrate how an arteriovenous fistula is constructed, as a lead-in to its benefits in comparison to synthetic grafts and catheters for vascular access. Alternatively, DFC could provide more links to other sites with diagrams or graphics used to illustrate points for patient education.

Pictures of dialysis patients, dialysis machines, or dialysis facilities could also be used as a way to more actively engage patients in the DFC site. For example, the www.cms.hhs.gov website has a series of 10 photographs that cycle into its home page as a user clicks on that page, to other pages, and back to the home page. That type of approach could also be used on the DFC site to enliven its content.

Our discussions with CMS web staff have included review of a number of limitations on the ability of DFC or other medicare.gov websites to use extensive graphics, diagrams, or photographs. Nonetheless, it seemed that a simplified approach such as the bar graphs for the DFC quality measures was effective, so perhaps other simplified methods could also be applied. We believe that increasing the use of graphics, diagrams, and pictures on the DFC website – to the extent possible – will increase its appeal to patients and family members, and its ability to communicate effectively with them.

3.2.2 The Phoenix Site Visit Had Several Unique Results

The Phoenix site visit had some results that were different from the other three (Washington, Atlanta, and Chicago). Patients in Phoenix believed they have more choices among dialysis facilities than patients in the other cities. (This viewpoint was also borne out in our data collection with dialysis professionals in Phoenix, as presented in a companion report.) Moreover, Internet access was more widespread among patient and family participants in

Phoenix. Most indicated they either had their own access or could gain access through family or friends.

The differences in Internet access are not easy to explain. They could be due to greater use of computers and the Internet generally in the Phoenix area, but that question would need further study. In the future, Internet access will be steadily expanding across the country. It may be that Internet access per se will not be as much of a barrier to DFC website use as some have suggested, but rather the key will be to ensure that dialysis patients and family members feel they have something to gain by using the Internet and the DFC website. That could motivate them to more actively seek ways to gain Internet access through public facilities or their social networks.

The wider range of facility choice reported in Phoenix may have been due to the economic and population growth in that city. Several professionals indicated to us that a number of new dialysis facilities were being constructed. They could have provided for a wider range of choice. Nephrologists also seemed to be more willing for their dialysis patients to be treated at facilities with which they did not have formal affiliation agreements. That type of practice pattern seemed different from those found in the other cities.

3.2.3 Peritoneal Dialysis Patients Want More PD-Specific Information

PD patients were quite vocal about the HD emphasis of the current DFC website. They pointed out that the data on facility characteristics present information on capacity (number of stations) for HD, but no measure of PD utilization or capacity. They also expressed interest in having quality measures focused on PD adequacy and PD-specific measures for anemia and patient survival.

Several PD participants indicated that the lack PD-specific information made them much less likely to use the DFC website in its current form. They seemed to be especially sensitive to this issue from other experiences. Several noted that the dialysis community is more slanted toward HD issues and HD patients in a number of ways.

PD professionals participating in data collection for a companion report indicated similar concerns. They also reported ongoing issues related to the HD emphasis of their facilities and their professions. As a result, the need for more PD-specific information on the DFC website was a consistent theme.

Several data elements for facility characteristics were suggested for DFC, such as the numbers of PD patients treated at each facility and the types of PD supplies supported. Some of the suggestions were more complex, such as adding quality indicators for albumin levels and Kt/V measures of dialysis adequacy for PD. Nonetheless, it appears that the DFC website does need to make some effort to accommodate these recommendations if PD patients are a desired audience.

CHAPTER 4:
DIALYSIS PROFESSIONALS AND TECHNICIANS

This chapter presents our findings from analysis of the data we collected from dialysis professionals and technicians. As noted in Chapter 1, a total of 98 professionals and technicians contributed comments in the focus groups, triads, and interviews conducted with these respondents.

This chapter includes two sections. The first presents detailed issues. It is structured around 19 analytic categories, each including one or more key issues studied through a set of questions presented to the participants. The second section presents more general themes that we identified through analysis of respondent comments. The themes cut across the more detailed issues presented in the first section.

4.1 Detailed Issues

For each of the 19 analytic categories in this section we provide an overall report based on responses of participants from all four site visits. For the longer categories we summarize the key findings at the outset using bullet points.

In addition, where possible, we identified variations in responses based on the different types of participants, including breakdowns by site (city), type of professional, interviews versus group discussions (focus groups and triads), and HD versus PD providers. Those variations were assessed for each of the analytic categories, although significant variations were not always identified.

4.1.1 What a New Patient Needs to Know About Dialysis and Dialysis Facilities

Each focus group and triad started with introductions and brainstorming thoughts about what participants believe a new patient needs to know about dialysis facilities. It is worth noting that although the moderator stressed that participants should share their thoughts about dialysis facilities, many comments had to do with dialysis or ESRD more generally. This was similar to the results we found from the patient and family members. The main points the professional and technician participants emphasized for new patients to know were:

- Dialysis is a lifelong process (absent transplant).
- Patients can have a life outside of dialysis.
- Patient education is key for both HD and PD, but especially for PD patients, since they administer their own treatments. Patients should ask a lot of questions as part of their learning process.
- Patient compliance is important for both HD and PD.
- Patients need to understand the physiology and mechanics of dialysis, and the different modalities that are possible.
- Dialysis facilities are ***not*** all created equal. Patients should learn about dialysis facilities in their area.

- PD is an ongoing option, even if a patient starts out on HD.

Many of the professionals' comments indicated that they often encounter patients who start dialysis with minimal understanding of ESRD, their treatment options, and dialysis. A social worker pointed out that all of this new information is often hard for patients to absorb at the start.

Several suggested that patients need to understand that dialysis is a lifelong process. They need to organize themselves to ensure their treatment is as effective as possible. It needs to be a lifestyle. A nurse said, *"They're not told that recovery of their renal function is unlikely. So they enter the unit thinking, 'How long do I need to come here?'"*

At the same time, patients need to know that they can still continue with activities outside of dialysis. A dietitian said, *"I was going to add that it's not the end of the world. They can continue to travel, they can continue to work. They can continue to have a life."*

For successful dialysis, patient education is key. For example, patients need to know what they can and cannot eat. Diet is often a challenge for patients.

Several professionals noted that patients have access to a wide range of services, so they should feel free to ask questions. They should understand the range of staff resources available – physicians, nurses, social workers, and dietitians. Patients should be clear on the roles of all of those members of their interdisciplinary team. And patients should know that they are also part of the team. For example, they need to take care of their vascular access.

But patients should also be clear on the difference between what the doctor can provide and what the dialysis facility can provide. The facility can't provide all of their medical needs, especially those unrelated to dialysis or involving comorbidities such as cardiac problems.

Patients often are suffering from denial or emotional distress during the initial transition to dialysis. This makes patient education difficult. As a social worker put it, *"And they're so overwhelmed when they come in that they're not really hearing."*

Professionals of all types agreed that patients should learn about the different modalities of dialysis as well as the different options for reuse. Patients should fully understand the physiology behind dialysis, and what the machine is doing. They need to know that their blood will go out of their body and through the machine. They should understand how long dialysis will last, how to be comfortable, that their bodies will fluctuate in temperature, and that they will feel badly at first, but they will get better. This should all be included in pre-ESRD education, so they are not so overwhelmed at first, and can do what they need to do as well to stay healthy. As a renal administrator said, *"Patients need to understand how dialysis works, and what they are responsible for."*

Compliance is an issue that was stressed by all types of professionals and technicians. For example, the renal administrators said that patients sometimes sign off dialysis too early. Patients also need to know about what happens if they miss a treatment. Both can affect clinical outcomes and how the patient feels. As a renal administrator suggested, *"Emphasize that the* *patient is the number one person responsible for his or her own health. We provide the tools for it."*

Patients need to learn about dialysis facilities in their area. For example, what are their shifts and hours, what are the layouts of the facilities? How close are the facilities to the patient's home or work? What are the transportation options? They should talk to other patients about dialysis facilities. Are they satisfied? As a social worker said, *"I think patients should know that dialysis centers are not created equal. One way they're not equal is staffing ratios, another way is patient and family satisfaction with the facility, and thirdly that patients have a choice about what facility to go to. Once the smoke clears, it's important that they have a choice."*

Technicians' answers varied from those of the professionals in response to this question. Several stressed that patients should understand that things don't always work according to plan that sometimes technicians have to use their judgment.

PD providers stressed the importance of understanding the time requirements of doing dialysis at home. Also, while patients only have to be seen at the PD clinic once per month they also have to get to know their clinic, and check it out before starting.

PD providers stressed the importance of patient education and patient compliance even more strongly HD providers. They indicated that PD patients need to be especially vigilant regarding both monthly clinic visits and following the training in doing exchanges. PD patients do not see providers as often as HD patients, so the patients have an even greater responsibility to care of themselves. They also need to learn how to triage themselves; to learn what to call the PD nurse about and when not to call.

PD providers suggested that patients are referred less often for PD, for a variety of reasons, but that could change if providers and patients knew more about PD as an option and if demand for dialysis services continues to increase rapidly, while the number of available HD stations increases more slowly. It is interesting to note that staff from one dialysis chain indicated they are now actively recruiting HD patients to switch over to PD, due to a shortage of HD nurses.

A final point regarding PD was that some patients feel so sick at first that even though they may have heard about PD they will just start on HD as it seems easier. Then, after they have settled down and made the initial transition to dialysis over several months, they may be more willing to try PD. They need to understand that PD is a continuing option.

4.1.2 Finding a Facility

For this section, we asked participants what they look for to determine whether or not a dialysis facility is a good one, and what they think is most important to patients in finding a dialysis facility. We also asked how much choice patients have between facilities when they are first starting on dialysis and, later, when they may consider switching facilities.

For the Chicago and Phoenix site visits, we asked what information would be provided to a patient or family member calling their facility to learn more about it. We also asked how their facility would respond if someone asked to come in for a tour of the facility.

To summarize this section, the main points were:

- Professionals and technicians look for staffing (quantity and quality), outcomes, and some facility characteristics to identify good dialysis facilities.
- Professionals and technicians believe that patients look for staff attitudes, amenities, comfort, and other facility characteristics to identify preferred dialysis facilities.
- Patients have less choice of facilities when they start dialysis, but potentially have more of a choice later on. This varied by site, with Chicago and Phoenix professionals indicating patients have more choice than they think they do at all stages.
- Professionals and technicians indicated that inquiries from potential patients are welcomed and tours are given routinely in their dialysis facilities.

Professionals and technicians believe that they are more concerned with staffing and dialysis outcomes in selecting facilities than are patients. As a social worker put it, *"patients don't look at outcomes."* Professionals and technicians said the types of things they look for in a good dialysis facility are:

- Ratios of patients to nurses and other staff.
- The quality of the staff.
- The attitudes of the staff, including both professionalism and friendliness.
- The location of the facility in relation to patients' homes and workplaces.
- The transplant rates for the facility.
- The hospital that is nearby.
- The mortality rates for the facility.
- The number of chairs the facility has for HD treatment.
- The infection rates at the facility.
- The shifts and times that are available to patients.
- The quality of the physicians affiliated with the facility.
- How frequently the doctors will see patients.
- An opportunity to tour the facility and talk to patients, to see if they are getting good care.
- Whether or not PD is offered.
- The cleanliness of the facility

- Whether or not the facility has ever been sanctioned or had complaints lodged against it.

Professionals and technicians indicated the things they think ***patients*** look for in a facility are:

- The location – is it close to home or work?
- The availability of physicians.
- Staff attitudes – are they friendly, empathetic, and professional? As one technician said, *"They want to see pleasantness."* Another technician said, *"Some people just make you feel good and comfortable. You just want to be with them."*
- Whether or not alarms on the dialysis machines are answered quickly by staff.
- The staff turnover rates.
- The types of insurance that are accepted.
- The cleanliness of the facility
- Whether or not television is available separately for each patient.
- The comfort level of the facility for patients.
- Whether or not vending machines are available.
- The different shifts that are available, to accommodate patients' schedules.
- Is the facility one that their doctor likes?
- The temperature in the facility.
- Whether or not they can see their doctor frequently.
- PD patients have fewer chances to socialize with other patients, so they look for facilities with support groups they can attend to have more opportunities to talk with other patients.

Most professionals indicated that patients don't usually have much choice when first starting out on dialysis, as they are overwhelmed, feel poorly and don't want to ask a lot of questions. Or, they may not know what questions to ask. They usually go where their doctor recommends, and where their insurance allows. Some said that patients with good pre-ESRD education have more choice between facilities since they know more about their options and are better prepared to make choices about their treatment. Those who start dialysis with little notice will rely more on their doctors' recommendations.

Professionals and technicians in Washington and Atlanta also indicated that the limited supply of dialysis facilities means more limited choices. That was less true in Chicago and Phoenix.

Most professionals and technicians agreed, however, that patients do have more choice after they have been on dialysis for a while. They talk to other patients since they have a lot of time together, and learn a lot that way. They also talk to staff and learn from them as well. They become more aware of their choices. Some may switch facilities to find a doctor or staff more to their liking. But some stay where they are since they don't want to rock the boat with their doctor.

One Phoenix social worker reported that about 80% of her patients use the Internet. She indicated that many bring laptop computers in with them when come in for dialysis. They use them to go into chat rooms on dialysis and kidney disease issues, and report to her that they learn a lot from other patients that way.

Doctors sometimes do offer choices among facilities. Professionals also noted, however, that patients may have more choices between facilities if they are willing to change nephrologists. And if they are willing to change dialysis facility staff as well (sometimes they get very attached to their staff). More educated patients usually know they have more choices. As a technician said, how much choice is available depends on the patient, *"Some are very adamant, some are passive, but they have the last word."*

In Chicago, participants in one focus group of nurses, dietitians and social workers suggested that although patients may think they have minimal choice, they potentially have a lot of choice and just don't know it. Too often, these participants said, patients just do what the doctors tell them to do. Staff from one chain said their chain's policy is to tell patients they have a choice up front. Sometimes staff in that chain will tell the patient about facilities closer to where they live. The renal administrators in Chicago agreed, indicating similarly that patients have a lot of options, but they just don't realize it.

A Phoenix social worker echoed those comments, *"The doctor tells them where to go. I'll have patients come in who say, 'My doctor said I have to go here.' And I'll say, 'but there are several other units that are closer to where you live.'"* A Phoenix technician also concurred, saying, *"A lot of doctors try to force the patients to go to the unit where the doctor is, even though it is 10 miles out of the way."*

In Phoenix, professionals said social workers generally talk to patients at the hospital, so the patients know about choices. Some patients may have to start dialysis at a different facility while they wait until a chair opens up in their preferred facility, but at least they know they have choices.

PD professionals reported that there may be less choice among PD facilities available to patients since there are fewer facilities providing PD than providing HD. If patients wanted to switch clinics they would have to travel further. However, PD patients don't have to be seen in the clinic as often, so travel is less of a burden and hence less of a barrier to switching. Insurance can also be a barrier to choice for PD patients, apparently due to differences in benefits or coverage for PD versus HD in some insurance plans.

In general, PD professionals indicated that HD gets the majority of attention from providers and patients. Many expressed concern that PD issues and the PD option very often are neglected. As a nurse put it, in PD they are the *"stepchildren of dialysis."* A social worker said PD patients and staff are the *"sixth toe on the fourth foot."*

As noted we also asked the professional participants in two sites about how they would respond to prospective patients and family members who call to request information or facility tours. In Chicago, professionals in one group indicated that if patients call for information, who they talk to will depend on when they call and who is available. In another group participants said most questions about the facility go to the social worker. Visiting facilities is encouraged according to both groups, but tours may be limited due to privacy issues.

Social workers give most tours according to Chicago participants, but receptionists also give some. Staff are available to speak with visitors, but only one participant reported allowing visitors to speak to patients. Most are concerned about patients' rights and confidentiality. They reported tours being given about twice a month. One facility was on a bottom floor with a doctor's office upstairs, so they would get a lot of walk-ins with no advance call.

The Chicago renal administrators reported about 3-10 telephone inquiries a month from prospective patients, and about 1-2 tours provided each month. Both indicated they accept traveling or transient patients on a regular basis.

The Phoenix technicians reported that tours were given frequently by many different types of staff. In contrast to the reports from Chicago, they encourage visitors to talk to the patients. They give tours once or twice every week.

PD staff reported giving frequent tours, especially at one facility where the tours were associated with a pre-ESRD patient education class. The classes are held at the PD facility, so the PD clinic is used to introduce the CKD patients to the PD option.

4.1.3 What Defines Good Dialysis Care?

We asked participants what "high quality" dialysis care means to them. We also asked how they know if patients are getting good care.

These questions generated a wide range of responses, with numerous clinical and amenities issues cited by participants from all of the different professional and technician groups. The responses are summarized below in nine categories, with the first six categories focused on clinical issues and the last three on amenities. These are the same categories used in the last chapter on patient and family member participants. We decided to retain the same categories to facilitate comparisons between the responses from the two different types of respondents. The categories are as follows:

- staffing issues – clinical;
- physician issues;
- patient and family education;
- equipment and facility issues – clinical;
- the process of care;
- the patient's experience of treatment;

- equipment and facility issues – amenities;
- staffing issues – patient satisfaction; and
- administrative issues.

As in the companion report on patient and family respondents, the descriptions of professionals' and technicians' views on what defines good dialysis care are lengthy. We considered condensing them further, but decided again that for this type of preliminary report it would be better to preserve this level of detail. The detail will enable this report to provide a broader range of input into our future analysis of potential ways to revise the DFC website.

Staffing Issues - Clinical

- Well trained, experienced staff who genuinely care about patients' well-being. (This was a frequent comment.)
- A relatively low ratio of patients to nurses and other staff. (This was a frequent comment.)
- A relatively low level of staff turnover. (This was a frequent comment.) A renal administrator noted that this is a common problem, *"There is a high turnover rate – that can affect quality of care. Turnover is not a reflection on the facility – it's because there is a serious nursing shortage."*
- Interdisciplinary staff working together as a team, including the physicians, nurses, dietitians, social workers, technicians, and the patient and family as well. (This was a frequent comment.) A renal administrator commented, *"It's a team effort – patient, nephrologist, dietitian, social worker, nursing staff – everybody has to play their part."*

Physician Issues

- The quality of the physicians affiliated with the clinic.
- The presence of good basic internal medicine care for patients, as well as dialysis care.
- The identity and objectives of the medical director
- How often doctors go on rounds in the dialysis facility, to see patients. (This was a comment made by several nurses.)

Patient and Family Education

- Patients who are involved in their care.
- Effective patient education provided at the facility.
- A good support system for the patients. A family that is involved with the patient.
- PD professionals noted that patient education and training is especially crucial in PD.

Equipment and Facility Issues - Clinical

- Up-to-date technology (This was a comment made more frequently by nurses.)
- Dialysis machines that function well and do not "cut off" frequently.
- Adequate floor space.
- Cleanliness of the facility.

The Process of Care

- Direct patient and family member involvement.
- Staff who have good technique when inserting needles into patients. For example, are needles typically inserted into patients with little pain or bleeding?
- Staff who pay attention to vascular access problems
- Staff who take time to answer questions.
- Staff who take time to talk to patients and to other staff.
- A rehabilitation program at the facility.
- Timeliness of the staff. As a social worker said, *"Sticking to the schedule, getting people on and off when they are supposed to."*
- A staff with cultural competence for treating patients from a range of backgrounds.
- A caring atmosphere. (This was a frequent comment. It was made more often by nurses and technicians.) As one nurse said, *"It's a matter of developing trust with the patients so they can learn."* A technician said, *"...staff show concern and make the effort to do the small things. Make sure they are comfortable, pay attention, always there, showing honest interest in the patient's well being."*
- Presence of an active continuous quality improvement (CQI) program. Quality improvement and quality assurance programs in participants' facilities include measurement of Kt/V, URR, hematocrit, iron saturation, phosphorous, calcium, albumin. They indicated that the best approach is to look at trends over time, not at numbers at one point in time.
- Does the facility follow the Kidney Disease Outcomes Quality Initiative (K/DOQI) clinical guidelines?
- Staff that follow infection control procedures. A technician said, *"I had a patient yesterday say he was counting how many of the staff were not wearing aprons."*
- How are emergency situations handled? (This was a comment made more frequently by nurses.)

The Outcomes of Care

- Facilities should have low rates of complications, infections, access problems, hospitalizations, and mortality. (These were frequent comments.)
- Patients should be functioning well.
- PD patients should have low rates of peritonitis.

- Patients should have good lab results, including URR, hemoglobin/hematocrit, nutrition, and bone management.
- The transplant rate should be high.

The Patient's Experience of Treatment

- What is the patient's attitude? It often comes from the care they receive from facility staff. For example, do the patients believe they have control over many factors that affect their health and do they feel positive about their efforts at self-care?
- Patients should say they feel good. (This was a frequent comment.)
- What do they say about the staff?
- What activities are patients involved in outside of dialysis? Are they able to do the activities they liked before going on dialysis?
- Privacy issues are important; are patients treated with discretion?

Equipment and Facilities Issues - Amenities

- Is the facility accessible for disabled patients?
- Is there adequate parking for patients?
- Is the facility located near patients' homes?
- Does the facility have shifts that are available when patients need them?

Staffing Issues – Patient Satisfaction

- The presence of "customer service" is important. As one social worker said, *"I hear how patients are treated, or not treated. That they're ignored. I think it varies from company to company and unit to unit."* Another social worker said patients are concerned about, *"Are they nice to me? Do I get my treatment on time?"*
- Patients should reasonably adhere to diet, weight, lab results, and dialysis treatments. If the patients are compliant, the staff is doing its job.

Administrative Issues

- Do staff and patients have easy access to the facility administrator?
- Do managers treat staff well?
- Has the facility been cited for accreditation or inspection violations?
- Is there adequate information technology support for clinical staff and for managing patient processes and outcomes?
- Is the facility open to a range of physicians or is it a "closed facility" that only works with a limited number of physicians.

4.1.4 Information Sources

We asked participants about the sources they use for information about dialysis care or dialysis facilities. We probed especially regarding Internet use, whether for finding dialysis facilities, other dialysis or kidney disease issues, or other applications. In the interviews, we also asked participant what their role has been in helping patients find new dialysis facilities.

Professionals use the Internet quite actively to get information about dialysis, other medical issues, and for personal use. However, only a few had used the DFC website. Websites cited by participants as helpful for dialysis-related issues are listed below in alphabetical order in two categories, those most frequently cited and those also cited.

Most frequently cited websites:

- Dialysisfinder.com
- HDCN.com
- ikidney.com
- Nephron.com
- NKF.org
- Search engines (Google mentioned most often)

Other Websites Cited:

- AAKP's website
- ASN website
- Arizona Kidney Foundation website
- Culinary Kidney Cooks website
- DaVita.com
- Dialysis Clinical Nephrology
- Dialysis Facility Compare website
- ESRD.com
- ESRD Networks' websites
- Gambro's website
- Globaldialysis.com
- Kidney.com
- Kidney.org
- kidneydirections.com (Baxter)
- Kidneyschool.org

- Kidneytools.com
- lifeoptions.org
- MapQuest.com
- Mdconsult.com
- Medicare.gov
- Medline
- National Center for Health Statistics website
- RCG locator website
- SSA.gov
- Therenalnetwork.com
- transweb.com (University of Michigan)
- TRI
- Uptodate.com
- WebMD

When searching for dialysis facilities for patients, professionals often use nephron.com and dialysisfinder.com. They also use those websites to investigate other dialysis facilities when job hunting for themselves.

HDCN.com was cited by nephrologists as an impressive website. It is a "one-stop shop" for clinical guidelines, U.S. Renal Data System (USRDS) data, continuing education talks for providers (including slides), and many other things.

Other information sources for professionals include doctors, staff colleagues ("word of mouth"), in-service training, training manuals, NKF, local dialysis professional meetings, industry sales reps, journals, newsletters, kidney disease and dialysis textbooks. Some indicated they use "The List" to locate dialysis facilities in other cities. It is an annual issue of Dialysis and Transplantation that lists dialysis facilities.

Nephrologists indicated that they sometimes played a role in providing information to patients about potential new dialysis facilities, but the majority stated that the social worker was more of a resource. Social workers reported using the Internet more than other professionals to search for dialysis facilities for patients who were traveling or moving. That is usually considered part of their job.

4.1.5 Exploring the DFC Website: Expectations

We asked participants what they would expect from a website called "Dialysis Facility Compare." We also asked if they were aware of the DFC website before this study and if they had ever used it before this study.

Most professionals had not heard of the DFC website prior to this study. However, all of the renal administrators had heard of it and most had used it before, primarily to check out the data listed for their centers.

In addition, more professionals in Chicago had heard of the DFC website or used it than in the other cities. In one Chicago focus group 4 of 9 participants were aware of the site, and 3 had used it to check out information on their own clinic. In the other Chicago focus group 4 of 8 had heard of it and 3 had used it to look at how their facilities ranked against others. Two indicated they shared the comparisons with colleagues.

The main expectations for the DFC were that it would have ratings or rankings of facilities (a frequent comment), recommended facilities, and comparisons of facilities across a range of data (most frequently cited, probably from the name). A technician commented that it sounds like the website will show, *"the good, bad, and ugly."* Or, as a nephrologist stated, *"Dialysis Facility Compare implies pick a winner."*

Another nephrologist stressed that we need all of the dialysis units we can get. So, instead of trying to identify good and bad units, why not switch to a CQI focus on improving the quality of care in all of the facilities?

Other expectations for the website were that it would have locations of facilities, phone numbers, assurances of the safety of facilities, staffing, the name of the medical director, affiliations, hours the facility is open, patient satisfaction surveys, outcome data, Medicare information, insurance accepted, number of chairs, number of shifts, cleanliness, information about whether the facility had been in "trouble" with state regulators, and what additional services the facility offered. On the last point, a social worker commented, *"I saw an ad for a center in Florida that offered Internet access and Bingo!"*

Some thought that having "Medicare" in the name of the website was a good idea, that it makes the website sound more official. However, others said the name is too long or too bland, and that it needs something more short and snappy.

4.1.6 Exploring the DFC Website: Facility Characteristics

We showed participants the DFC website live on the Internet, on a computer for the interviews and several smaller triads, and on a screen using a projection device for the focus groups and most triads. On the overview page, we showed them the list of facility characteristics and asked how they thought that information would be useful to patients who had to go to a different dialysis facility.

Professionals generally liked what they saw in the facility characteristics. As one said, *"There is a lot in there."* They indicated that how long the facility has been in business is important for showing its experience. The size is good, since the larger units can get *"crazy."* Addresses and phone numbers are useful for helping patients find facilities. The types of dialysis are important for showing what treatments are available. Availability of evening shifts is good for indicating the choices patients will have. Ownership status data were important to some. As a participant from a non-profit facility said, *"We are proud of our non-profit status and like the patients to know that."*

But, at the same time, most professionals said that other facility characteristics need to be added to the website. That is reflected in their lengthy lists of recommendations for additional facility characteristics to be added to the website. They are included in section 18 below.

4.1.7 Exploring the DFC Website: The "Read This" Paragraph

We showed participants the "Read This" paragraph on the overview page of the DFC website, and read it to them aloud. We then asked for their reactions. (A copy of the paragraph is included in Chapter 3.)

Professionals liked the paragraph very much, across sites and across professions. They liked the message that patients should visit facilities and talk to staff before making a decision about which facility to go to, and not just rely on data from the DFC website. They also liked that it emphasizes patients becoming more proactive, getting more involved in their care. As a nurse said, *"It encourages them to be active. I think it's great!"* A technician commented that it tells patients to, *"Visit a clinic and talk to the staff – the patient care techs, nurses, social workers – to get a good feel for the clinic to see if it fits your particular needs."*

Some recommended that this section should be made more prominent in the website. It should stand out more, or be highlighted. It should be at the top of the overview page. It could also be presented in bold letters or caps, or perhaps in a different color.

A social worker cautioned that, *"Some of the words are probably larger than many patients could read."* Several participants noted that patients might not know the meaning of some of the terms used in the paragraph, such as "ESRD" or "ESRD Network". A renal administrator commented that this paragraph seems to be more for their *"highly motivated patient – the informed consumer."* She suggested that many patients don't have enough insight to know there is *"more to the picture."* The website designers need to understand the learning readiness of the patient.

Several nephrologists added that this paragraph should provide more information to patients in order for them to be able to make important decisions such as choosing dialysis facilities. Also, it should stress the need for constructive dialogue between patients and providers more strongly. Several thought it sounded too much like a way for Medicare to protect itself.

4.1.8 Exploring the DFC Website: Quality Measures

We showed participants the descriptions of the three quality measures (for adequacy, anemia, and patient survival) on the overview page of the DFC website, and asked how many had heard about them. We also asked if they had discussed those measures with patients, and how that information would be useful to patients who were looking for a new dialysis facility.

All of the professionals were familiar with the three quality measures. As a renal administrator put it, *"you're beat over the head with it all the time."* Professionals liked the adequacy and anemia measures. Some use the anemia measure as a way to educate patients. Several noted that, in response to concerns about that outcome, many units now have anemia managers. Most reported discussing adequacy, anemia, and other lab values with their patients every month. They tell patients their results for each measure, and how to get their levels into the normal range if they are outside of it.

Some explain to patients that better labs are linked to better survival and quality of life. They also use lab results to explain why it's important to show up for treatment. Several said they tell patients that lab results are not just for the patient's benefit, that they are also a reflection on the staff. A nurse said*, "I tell them it's a reflection on me, so they better get on the stick!"*

A number of the professionals reported that compliance is an ongoing problem with some patients, and that affects these quality measures. Patients may sign off early, or skip sessions altogether. As a dietitian said, *"If they feel doomed from the start, why be compliant?"* A social worker stressed the importance of patient education, *"We would have less problems with people signing off early if they understood [the consequences]."* A renal administrator commented that it is, *"difficult for some patients to understand it is a team effort, and that patients need to be part of the team."*

PD professionals noted that the adequacy measures for PD patients are Kt/V and creatinine clearance. So they were less sanguine about the way that quality measure was presented only for the URR on the DFC website.

Professionals were mixed in their opinions of the patient survival measure. Patient survival may be harder for patients to interpret. The populations of different clinics may vary. Clinics with evening shifts may have a younger, healthier population, for example. Facilities with larger nursing home populations probably have worse outcomes on patient survival. Some indicated this measure is still useful, but others disagreed. A nurse argued that, *"You are comparing apples to oranges."* One renal administrator was skeptical about all of the measures, saying, *"Medicare needs to take these quality measures off the site because it is unfair to facilities because there are so many other factors involved."*

Participants indicated they will tell patients it is possible to live for many years on dialysis. One said she tells patients that, *"...some live 24 years. But to get there, you have to do X, Y, and Z."*

Participants recommended a number of additional quality measures they would like to see added to the website. They are included below.

4.1.9 Exploring the DFC Website: Links of Interest

In the Washington focus groups and all of the interviews we showed participants the links on the overview page of the website and asked which ones they would like to explore. We then clicked on one or two links they selected and reviewed the content with them. During the site visits after Washington, we showed focus group and triad participants examples of links, but did not explore them in detail due to time constraints.

Several links were selected more frequently by the participants. The NIDDK dictionary was considered very good by all who looked at it. Its definitions were seen as *"short and* *sweet,"* so patients are more likely to read them. The Helpful Contacts and Dialysis Publications and Related sites were also viewed as useful and interesting.

The Glossary was viewed as useful by some, but as hard to read by most. The interview guide contained an additional question focused on the Glossary definition of adequacy of dialysis, so that was a section interview participants considered in more detail. Most thought that definition was poorly written. Several suggested that it needs to be written at a much lower reading level, perhaps as low as the 5th grade level. Several said that it describes what the URR is, but not why patients should care about it. Several nephrologists argued that the definitions would not be understood by patients, especially inner city and elderly patients who need to understand them the most, so they would not really be useful.

The time available to explore the links was limited; however, so many participants did not provide detailed comments.

4.1.10 Exploring the DFC Website: How Is The Information Useful?

After reviewing the overview page of the DFC website, we asked participants how the information would be useful to a patient who had to go to a different dialysis facility.

Participants agreed that the facility characteristics would be useful to patients. They thought those data would be especially helpful for transient patients.

Most agreed that the quality measures are useful for comparing facilities. As a dietitian put it, *"If patients have good URRs and hematocrits, patients are well managed and somebody really cares."* A technician said, that if these numbers are good, then it tells you, *"that a facility is running very well, the staffing is great – techs and nurses working toward patients' well-being."*

A renal administrator said she, *"would use [the DFC website] to compare her facility to another facility."*

However, many participants noted that there may be other factors that affect the quality results besides the performance of facility staff. For example, the number of patients with catheters for vascular access, and the number of patients who sign off early or skip sessions can affect the URRs.

At this point, participants once again recommended a number of additional facility characteristics and quality measures that could be added to the website. They are included in Section 18 below.

4.1.11 Scenario of Moving to a City in Florida: Facility Characteristics

We presented participants with a scenario in which a patient would be moving to a city in Florida, and needed to choose a dialysis facility in that city. We walked participants through the process of identifying the dialysis facilities available in that city using the DFC website. We selected four facilities and showed participants their facility characteristics using the website. (We pre-selected the four facilities to ensure they varied on several characteristics, including size, ownership status, availability of evening shifts, and chain membership.) We asked participants what the information told them about those four facilities.

The professionals liked the detailed information on the website regarding facility characteristics, especially the modalities, ownership, number of chairs, evening shifts, and how long the facility has been Medicare certified. Most indicated the information would help a patient or family member focus their search. One said, *"It's telling me a lot."*

Several commented that they liked knowing which facilities are non-profit. They said that in their experience the staffing ratios of for-profits are not as good. However, others disagreed and some were not sure of the impact of this factor.

Many were concerned about the overall size of dialysis facilities, and liked having that information. One facility in the scenario had 45 chairs, and several noted that that sounded awfully large. One technician said, *"For me to help a patient, I'd prefer a smaller clinic with more one-on-one attention. Twenty-four stations is pretty decent. You can get overwhelmed with a larger facility – patients can start just being a number."*

Some commented that patients would probably need input from professionals to better interpret the facility characteristics.

Since there was general agreement that the data currently available on the website are valuable, much of the discussion in several groups focused on what additional facility characteristics would also be useful. Many additional recommendations were made and they are included below.

Several participants noted that the DFC has more information than the dialysisfinder.com website, which only has some basic information on each facility. It does give the distance to the facility, however, which participants viewed as quite useful. Nephron.com also provides limited information but does have the clinic director, which was viewed as important.

4.1.12 Scenario of Moving to a City in Florida: Quality Measures

Continuing the moving to Florida scenario, we showed participants data on each of the three quality measures for those same four facilities. (The facilities were also pre-selected to ensure they varied on the quality measures.) We compared the results for the four facilities with the national and state average data also available on the DFC website for each of the quality measures. One facility (Facility A) was selected for the scenario since it was much higher than the others – and higher than the national and state averages – on both adequacy and anemia. Another (Facility D) was selected since it was significantly lower than the others on patient survival. A third, (Facility C) was selected since its results showed all of the quality measures as "Not Available."

We asked participants what the information on the quality measures told them about those four facilities, and what they would say to patients about the quality measures.

Most professionals and technicians liked the first two quality measures, on adequacy and anemia, but had some reservations about how to interpret the results. They were impressed with the numbers achieved by Facility A on both of these measures. However, some were concerned that the information could be misleading, depending on the composition of the underlying patient population. For example, different facilities could have different percentages of non-compliant or elderly patients, different numbers of Medicare patients (used to calculate the quality measures), or different rates of fistulas.

One group of renal administrators (in Atlanta) made this point more than the others. They saw the numbers as being used to blame the clinic, when poor results could actually be due to non-compliant patients. The other triad of renal administrators (in Chicago) were less concerned. One of them said, *"[Facility A] looks like they run a tight ship."* They stressed that they would not be comfortable recommending one particular facility based on the DFC quality measures, however. They would prefer to present the data to the patients and their family members and then encourage them to make the choice.

Other professional groups were more convinced by the adequacy and anemia numbers. They noted that Facility A was above both the other facilities and the national and state averages on those measures, while the others were, *"pathetically below."* Several suggested that Facility D, with 45 chairs, was probably too large for staff to keep up with the needs of all of their patients, and that might explain some of their low numbers. One nurse said patients should, *"run to [Facility A]."*

PD professionals noted again that the URR measure of adequacy does not apply to PD. They explained that evaluating adequacy for PD is different than evaluating the adequacy of hemodialysis. Different values are used. Many participants noted that they use hemoglobin to measure anemia, not hematocrit. They explained that hematocrit levels can be affected by factors unrelated to anemia, such as the patient's fluid status. They agreed that the hematocrit data were useful, however.

Several participants thought the explanation of the anemia data underneath the graph was too advanced for most patients. As a dietitian said, *"The sentence about the hormone that tells your body to make red blood cells is too much. Keep it simple and concise."* Most agreed that the explanation of adequacy under that graph was a good one, however, especially for patients who have been on dialysis for a while and will be familiar with adequacy numbers and issues. Several interviewees stated that it was clearer than the explanation of adequacy in the Glossary that they had reviewed earlier. Several suggested both should be written at a lower reading level, however, no higher then the 7th grade level.

Some participants noted that the better anemia results at Facility A may reflect the facility staff's work more than the better URR numbers, since the URR is more affected by patient compliance. Staff affect anemia more through their work; they have to watch it closely. As one put it, *"It's a lot of work to get good [anemia] numbers… the EPO dose should be changed every two weeks."* Some noted that anemia could be affected by whether a facility has a dietitian on staff, and the extent and effectiveness of patient education.

Several participants noted that anemia treatment is not only about Epogen any more, so the wording of the explanation of the quality measure should be changed.

Most participants thought the patient survival measure depended on a range of factors, with many outside the facility's control. For example, they argued that nutrition and albumin levels, which affect survival, are more under the patient's control. Nonetheless, most participants still said that the survival data indicate that patients should not go to Facility D. The impact of its "worse than expected" rating seemed to be very powerful. As one nurse put it, *"Stay away from [Facility D]."*

Some found the presentation of the survival data confusing. They suggested that patients might not understand the statistical calculations underlying those data. As a dietitian said, *"What are expected deaths?"* One suggestion was to have bar graphs for the patient survival data, like the adequacy and anemia indicators. A dietitian argued, *"[The bar graphs] are more user-friendly, and it seems strange to change formats now."* A technician said, *"'As expected?' They don't have a number?"*

In contrast, the FAQs on patient survival were viewed as very good. Participants especially liked "What Affects Patient Survival?"

Participants were initially concerned that all of the information was "Not Available" for Facility C. However, after the group moderator or interviewer pointed out the explanatory footnote about missing data, they were more willing to withhold judgment. As one technician put it, *"I would not just give up on them."* This contrasted with the results from the patient and family member participants (discussed in the companion report); they generally remained suspicious about the data listed as "Not Available" even after reading the footnote. However, none of the professional respondents noticed the footnote without having it pointed out to them.

Most participants agreed that they would say to patients that they should look at the quality data. Again, most were impressed with Facility A's results, and even those skeptical of the quality measures said patients should at least check it out to see if it really is as good as it looks in the quality data. As a dietitian put it, *"I would say to patients that it's a good idea to go an extra few miles to at least check out [Facility A]. If I was choosing I probably would choose [Facility A], but I fully understand the implications [that there could be other factors affecting their results]."*

Participants agreed that patients should call or visit facilities to find out more information, and talk to patients if possible. They thought that patients should see the quality measures, especially if they are used as opportunities for patient education, but that they should also be educated about the possible range of their meaning.

Several participants indicated that trend data would be better than one-time percentages. That would show if the facility is improving or not.

The age of the quality data was a concern to many participants. They argued that if the data were only 6-12 months old, they would be more useful. Several noted that the ESRD Networks have data that recent.

Participants again recommended a number of additional quality measures that could be added to the website. They are described below.

4.1.13 Most & Least Important Information

We asked all participants what they thought was the most important information on the DFC website. In the Washington site visit, we also asked what they thought was least important. The responses to these questions were limited and quite varied. It seemed that participants had a hard time answering them since most were seeing the website for the first time.

Some thought the survival data were the most important information. The "worse than expected" results for Facility D really stood out for them. Others thought all of the quality measures were important.

The group of renal administrators that distrusted the quality measures said the facility characteristics were most important. In contrast, the other renal administrator group indicated that all three quality measures, considered together, were the most important information.

A number of other participants indicated that selected elements of the facility characteristics were most important. Several suggested that location is most important to the patients, since the convenience of the facility is key for them. Others thought the number of stations was most important.

Some were not willing to make a judgment, indicating that what is most important is for the patients to determine. Others said that the information in the website was too technical for patients, that it is better for professionals.

Both PD professional triads liked the facility characteristics more than the quality measures. They suggested the quality measures are more for professionals than patients.

There was limited response to the question regarding what information was considered least important. Items mentioned included patient survival, profit versus non-profit status, date of certification, and anemia.

4.1.14 Does the DFC Website Meet Participants' Expectations?

We next asked participants to think back to before we showed them the DFC website, when we asked what information they expected it would provide. We then asked to what extent the website had met their expectations.

Most said the website either met or exceeded their expectations. One technician said she was, *"Highly surprised and very impressed."* Another technician said that she was now, *"Less afraid of what the site must show."* Technicians sounded as though they had been afraid of being overwhelmed by the site, but now felt they could navigate through it and understand the data and the other information.

The mid-level staff (nurses, dietitians, and social workers), renal administrators, and nephrologists seemed more familiar with using the Internet and websites and were not at all concerned about understanding the information. They were more concerned about its value to patients and family members. A renal administrator said it, *"matched her expectations."*

However, most participants also indicated there were many other things they would like added to the website. Several said again they were concerned with the age of the quality data and the need for better explanations of the range of factors that affect those results.

Several said the word “Compare” in the name promises rankings of facilities, that the website does not deliver. Another commented that the quality data should include all patients, not just those on Medicare.

Others commented at this point on the need to improve the presentation of the website. Several indicated that it did not seem very user-friendly, especially for a new patient. For example, the wording seemed too sophisticated.

A nurse suggested, *“Make it more entertaining.”* Ideas included using more bullet points and adding more visuals to break up the text.

PD professionals again qualified their comments by saying it would be a better website for their patients if it had more PD-specific information. The emphasis on HD issues was clearly something they had encountered before in other venues. As a social worker said, *“We are the stepchild [of dialysis].”*

4.1.15 Content of the DFC Website – How Would Participants Use It and Recommend It?

We asked participants how likely they would be to use the DFC website in their everyday practice, and what they would use it for. We also asked under what circumstances they would recommend the website to other professionals and under what circumstances they would recommend it to patients and family members. Most agreed they would use it in their everyday practice.

Nurses and dietitians said they would be less likely to use the website than social workers. The social workers agreed that it is more relevant to their job, since they are the ones who usually help patients who are traveling or moving. Nurses and dietitians indicated they would use it for job hunting or to see how their facility measures up to others, although they may at times also use it to help patients. Several also said they could use it for patient education.

Technicians said they would use the website to show patients data on other facilities they may be considering for their treatment. The technicians noted that social workers do not always have the time to investigate all of the options for patients who are traveling or moving. Technicians would also use it to compare their facility to others. Its potential for job hunting was again mentioned.

Renal administrators said they would use the website to compare their facility to others. They also indicated they would monitor the DFC website to check on the accuracy of the data listed on it for their facilities.

The professionals would recommend the website to their colleagues, especially since most of their colleagues would like to see how their facilities compare to other facilities. As one put it, dialysis professionals are often, *“a bit competitive.”*

Most professionals would also recommend the website to patients, especially patients who have not yet started dialysis, who were traveling or moving, who were forced to switch facilities due to insurance changes or changes in insurance contracts with facilities, or those who were not happy with their facility. A few professionals were again concerned that the website could be misleading to patients, who might not understand the range of factors that can affect the quality measures, or for whom the information could be overwhelming.

4.1.16 Content of the DFC Website – Is It Complete?

We asked participants how complete the DFC website seemed to them. There was limited response to this question. Some participants seemed hesitant to make a global judgment on "completeness," since most were seeing it for the first time.

Responses to this question were varied. Some said the website seemed reasonably complete, given their expectations. As one put it, *"Considering how health care is regulated, it's about as good as you will get."*

Others disagreed, again arguing that additional data elements need to be added to the website, that more recent data is needed for the quality measures, that more information or links on self-care, nutrition, and rehabilitation should be added, and that additional explanations of the range of factors that can affect the quality measures should be included. As one said, *"It's a good start."* Most of the PD professionals said that more PD information is needed to make the website complete.

A number of suggestions were again made at this point regarding additional data elements that could be added to the website. They are included in Section 18 below.

4.1.17 Content of the DFC Website – Is It Up To Date?

We asked participants how up to date the DFC website seemed to them. As noted, many of the professionals were concerned with the age of the data. Most wanted more recent data to be used for the quality measures. They suggested that one year old data would be much better than the 2-3 year old data they saw on the website. In addition, they suggested that it should be updated every 3-6 months. As one put it, *"A lot can happen in two years."*

Some suggested data for quality measures should be no older than 6 months. A dietitian said, *"I think this could be very deceiving. A lot of units have really turned around, either for good or bad."* A social worker in the same group said, *"It should be 2002, as recent as possible."* As a dietitian said, *"I'm an RD. I'm into numbers. I like current numbers."*

Several noted that Medicare gets data on URRs and hematocrits every month. Others again noted that the Networks have more recent data, especially Networks 9 and 10. The dialysis chains were viewed as having more recent data as well.

Several again suggested it would be better to track the data over time as well. Trends could show if the facilities were making improvements.

All agreed that the DFC data were useful, however. Patients can follow up with the facilities or with the Networks for the more recent figures. As a social worker said, *"It's still educational.*

4.1.18 Other Information Participants Would Like To See on the DFC Website

As part of the Moving to Florida scenario, we asked participants what additional information they would like to have on facility characteristics and quality measures for the four dialysis facilities they were comparing. We also asked again, at a later point in the group or interview, what other information they would like to see on the DFC website, including information about dialysis facilities, kidney disease, or links to other websites. As noted, participants also volunteered suggestions for additional information that could be added to the website in response to other questions. We combined all of those recommendations into this section.

One frequent general suggestion was to have more information in Spanish throughout the DFC website, or, alternatively, to have a Spanish language version of the entire website. Other general suggestions were to have a "Help" function on the website and to use more "bullet" points in the explanations instead of longer paragraphs.

Numerous specific suggestions were made for additional data elements to be added to the website, including facility characteristics, quality measures, and additional dialysis or health-related information. The specific recommendations are listed below in 15 categories. The first nine categories include recommendations on facility characteristics. The tenth includes recommendations on quality measures. The last five categories include recommendations on additional dialysis or health-related information. The categories used here are the same ones used in Chapter 3 for patient and family respondents, to enable comparisons with the data collected from the professionals.

These lists of recommendations for additional data elements are lengthy. As in the patient and family report, we considered condensing them further, but decided that it would be useful to preserve this level of detail to provide readers with a better feel for the scope of recommendations made by participants. The recommendations were as follows:

Physicians

- Background on the physicians practicing at the facility and their training.
- List the doctors practicing at the facility, their credentials and academic ranks.
- Describe the frequency that doctors see patients in the dialysis facility. (This was a frequent recommendation.)
- Who is the Medical Director?
- Is the Medical Director on site?

Dialysis Staff

- Provide ratios of patients to the different types of staff, and the ratio of patients to the total number of direct caregivers (including both nurses and techs). (This was a frequent recommendation.) As one social worker said, *"If I was going to pick a unit, I would want to know what they're staffing is."*

- Include the government regulations regarding ratios of staff to patients
- Are there RDs and SWs at the facility every day? Or only certain days of the week?
- List the numbers of staff of all types working at the facility.
- What languages are spoken by staff? As one social worker said, *"If we have a staff member who is out sick and we have a large proportion of Spanish speaking patients, we ask the bilingual patients if they would mind sitting next to the Spanish speaking ones so they can translate."*
- Provide data on staff experience with dialysis.
- Provide data on staff education and training.
- Are the technicians certified?
- Do all of the staff speak English well?
- At how many different facilities do the staff work?
- Include the turnover rate of staff. (This was a frequent recommendation.)
- Who is the nurse administrator?
- Who is the social worker?
- Include the number of staff working on PD.
- Is there a full-time PD nurse?
- Provide the ratio of PD patients per nurse. (This was a frequent recommendation.) (Several participants indicated it should not be greater than 25:1.)
- Is there a PD nurse on call in evenings and weekends?
- Provide data on ***staff*** satisfaction.

Equipment and Facility Information

- Provide maps and driving directions. (This was a frequent recommendation.)
- Include a map search function.
- Maps should show how far a facility is from location "x" (like mapquest.com does).
- Are there extra stations for travelers or transients?
- Describe the parking situation
- Describe all of the transportation options.
- List all of the days and hours of operation for regular patients. (This was a frequent recommendation.)
- List all of the days and hours of operation for transient patients.
- What are the holiday schedules?

- Are the facility's stations full?
- Describe accessibility of the facility for handicapped patients.
- Is the facility freestanding or located in a hospital?
- What is the nearest hospital, and how far away is it?
- Does the facility have isolation chairs for hepatitis patients? (This was a frequent recommendation.)
- How many isolation chairs are available?
- What kind of isolation method is used - a rope, a room?
- Does the facility accept hepatitis patients?
- What types of dialysis machines are used and what are their ages? (This was a frequent recommendation.) As one nurse said, *"I really think patients are interested in that."*
- Is cable TV available?
- Do patients get individual TVs or shared ones?
- Are VCRs available?
- Does the facility have heated chairs?
- Does the facility provide anything else for patients, like ice or blankets?

Organizational Information and Policies

- Add transplant program statistics, including the number of patients on a transplant waiting list, and the number of patients receiving transplants at each facility. (This was a frequent recommendation.) A social worker noted that, *"Dialysis centers are measured on their transplant referral rates."*
- Describe the facility's policies on visitors.
- Describe the facility's policies on eating.
- Describe the facility's policies on cell phones.
- List a contact person for the facility.
- What is close by – grocery stores, bus stops, restaurants?
- Include pictures of the dialysis facility. A social worker said, *"[patients] will say, if I could have seen a picture I would never have gone there."* Another social worker said, *"Is there room for a photo or something to break up all this text?"*
- List the clinic director's name.
- What insurance plans are accepted? (This was a frequent comment.)
- What county is the facility is located in?
- Can patients bring in laptop computers and hook them up?

- Are data ports for laptop computers available in the dialysis chairs for patients to use?
- Is the unit an open one or a closed one (i.e., is the facility required to accept any patient regardless of which doctor is treating the patient, or are only certain doctors permitted to admit patients to the facility).
- Include the clinic's fax number.
- Include the e-mail address for the facility.
- Add tabular columns on the website to make it more easy to navigate and more user-friendly.
- Provide a link to the facility's own website.
- Does the facility accept transient patients?
- Does the facility accept new patients?
- Provide a phone number to call for more information at the corporate level for facilities that are owned by chains. As a participant indicated, *"Since that is where decision-making occurs."*

Clinical Policies

- What is the clinic's policy on reuse?
- How long can patients dialyze at this facility per session?
- Does the facility have special programs, like support groups or exercise programs (This was a frequent recommendation.)
- Is daily dialysis offered?

Patient Issues

- List the number of patients being treated at the facility.
- List the number of Medicare patients being treated at the facility.
- List the number of patients working or in vocational rehabilitation.
- Include the distribution of years on dialysis for patients being treated at the facility.
- Describe the age distribution of patients being treated at the facility.
- Provide testimonials from current or former patients.

Accreditation and Regulation

- Has the facility ever been in trouble with regulators or inspectors?
- Has the facility ever been cited by accreditation agencies for any deficiencies?
- When was the facility last inspected and when was it last accredited?
- Describe any complaints or sanctions that have been lodged against the facility. A social worker commented, *"Some sites about nursing homes have that information, and it's great because you can really compare."*

- What was the date of the facility's last Medicare certification? Did the facility get a 1 year or a 2 year certification from Medicare?

Peritoneal Dialysis - facilities

- When is PD care available – what days and hours? What is the holiday schedule? (This was a frequent recommendation from the PD professionals.)
- For PD, are there any emergency numbers to call for patients who are traveling and need supplies or medical attention?
- What types of PD machines are supported – quantum (one exchange per night) versus continuous cycler.
- What types of PD supplies are carried – Baxter or Fresenius, or both?
- Does the facility provide home peritonitis kits (antibiotics to get treatment started early to try to avoid ER visits or hospitalization?
- What is the number of PD patients at the facility? (This was a frequent recommendation from the PD professionals.)
- What is the percentage of PD patients at the facility?
- Are both CAPD and CCPD available?
- How many patients are on CAPD and how many on CCPD?
- Do nephrologists see patients at the PD clinic?
- Is the PD clinic freestanding or attached to an HD facility?

Quality Measures

- Add trends over time for the data for all quality measures, not just, *"One year, frozen in time."*
- Add patient satisfaction data. (This was a frequent recommendation.) Participants noted that most facilities already measure it. Staff from one dialysis chain reported that they conduct a patient satisfaction survey once a year for all patients, including both HD and PD. Staff are then given goals to reach for this measure for the next year. This has led them to take a number of concrete steps to improve patient satisfaction. For example, they changed the parking arrangements at their facility in response to patient complaints.
- Provide data on vascular access and graft problems. (This was a frequent recommendation.)
- Include data on the numbers and percent of patients with catheters for vascular access, and the numbers and percent with fistulas. (This was a frequent recommendation.)
- Provide some types of psychosocial measures.

- Provide lab data on phosphorous levels.
- Provide incident reports.
- Include data on renal osteodystrophy.
- Provide data on serum calcium levels.
- Provide descriptions of CQI programs and use of clinical pathways at the facility.
- Provide data on patients' average time on dialysis during treatment sessions.
- Add data on patients' blood iron stores.
- What is the percent of patients vaccinated against hepatitis B?
- Add serum albumin and other nutrition data. As a dietitian said, *"25% are malnourished."*
- Include hospitalization data. (This was a frequent recommendation.)
- Add data on the facility's infection rate.
- Add data on the facility's hepatitis C transmission rate.
- Add lab data on serum phosphorus and parathyroid levels.
- Provide data on vascular access infiltrations.
- Include some quality measures just for peritoneal dialysis patients as well as some just for hemodialysis. (This was a frequent recommendation by the PD professionals.)
- For PD, include peritonitis rates (or number of months or days between peritonitis cases per 100 patient years – one chain tracks that measure). (This was a frequent recommendation by the PD professionals.)
- For PD, include albumin levels. (This was a frequent recommendation by the PD professionals.) Participants indicated this is more important for PD versus HD as patients lose protein in dialysis, gain weight with PD, and feel full on PD. They also consider albumin more important for PD patients than adequacy. Albumin issues are *"drilled into them monthly, with reminders and testing."* Albumin should be at least 3.5 for PD, and 3.7 for HD. One chain sets the standard at 4.0.
- For PD, add Kt/V data for adequacy.
- Include anemia and patient survival data just for PD patients.
- Include the number of hospitalizations for PD patients for all causes. (This was a frequent recommendation by the PD professionals.)
- Include the number of hospitalizations for peritonitis for PD patients.
- For PD, include data on exit site infections.

Dialysis and Kidney Disease Information

- Provide information on how to care for vascular access. (This was a frequent recommendation.)
- Provide information on the different types of dialysis.
- Add descriptions of the importance of dialysis (for survival) and what it does to remove toxins.
- Describe the jobs of each person on the dialysis treatment team.
- Include financial assistance options related to kidney disease, especially for drugs.
- Add information about the main medications used by dialysis patients.
- Add links to ikidney.com, NIH, NIDDK, and NKF websites.
- Add links to the different dialysis chain corporation websites.
- Describe what to expect on dialysis – for example that patients won't urinate.
- Provide lessons on the importance of compliance – why patients should not sign off early and why they need to be there 3 times per week.
- Provide lessons on why patients need to *"Know your numbers."*
- Include videos showing the different vascular access options, and explaining why a fistula is best and a catheter is worst. As a technician put it, *"They don't really understand that catheters are temporary, and are associated with more infections and poorer clearance."*
- Use cartoons for the patient education lessons. They are better for getting and keeping patients' attention.
- Reduce the technical jargon in the DFC website. For example, some patients may not know what a Medicare "beneficiary" is.
- Provide more pre-ESRD information – to get the information to patients as soon as they have a CKD diagnosis. (This was a frequent recommendation.)
- Provide detailed information about the underlying disease entities *"in layman's terms."*
- Describe the transportation issues faced by many patients and options for dealing with them.
- Provide patient education materials, including recommendations for how patients can increase their life spans. (This was a frequent recommendation.)
- Include more FAQs, and provide a list of them.
- Provide vocational rehabilitation information and lists of local agencies.
- Describe how to interpret lab results.
- Provide general information about the kidney, how it functions.

- Include more pictures. (This was a frequent recommendation.) For example, pictures of blood going through a dialysis filter. Another participant suggested this might work best, *"If it could be animated, showing the little PacMan eating up all of the wastes."*
- Add a sidebar with tabs for options to make navigation through the website easier.
- Include a way for patients to e-mail questions and get answers.
- Provide specific self-care information, such as *"What do I do if my URR is <65?"* (This was a frequent recommendation.) And similar advice related to key threshold levels for other clinical measures, such as phosphorous, anemia, etc.
- Provide lists of questions that patients should ask doctors and dialysis facilities. (This was a frequent recommendation.)
- Explain practical things that are important to patients. For example, that most patients feel cold much of the time.
- Provide information on bone disease.
- Add information on how patients can improve their lab levels.

General Health Education

- Provide general information on nutrition.
- Describe financial programs for other health issues (e.g., dental care) that the patients may have access to.
- Provide information on prescription drug assistance programs, including links to websites such as NeedyMeds.com and LillyCares.com. (This was a frequent recommendation.)
- Add general information on medications.
- Add information on diabetes care and diet recommendations.
- Add links to anemia information.
- Describe the rights and responsibilities of patients.

Medicare Information

- Provide an explanation of Medicare payments.
- Include information on the range of benefits available to patients from Medicare.
- List what services are covered by Medicare and Medicaid.
- Add a list of FAQs, including what Medicare and Medicaid will cover.

Transplant Issues

- Explain how to get on a transplant waiting list, and what factors increase your chances of being on one.
- Different types of transplant donors.

Peritoneal Dialysis - education

- Describe how to prevent peritonitis.

4.1.19 How Medicare Could Let Dialysis Patients & Family Know About the DFC Website

We asked participants about the best ways for Medicare to tell dialysis patients and family members and other professionals about the DFC website. Suggestions for “getting the word out” to these groups are presented in two categories below:

Dialysis Patients and Family Members

- Distribute flyers in dialysis facilities and doctors’ offices.
- Conduct mass mailings.
- Put up bright posters in the lobbies of dialysis facilities and doctors’ offices.
- Include information about the DFC website in new dialysis patient packets provided by the Networks.
- Give out refrigerator magnets for the DFC website to patients.
- Include information about the DFC in the Medicare & You publication.
- Advertise in the AAKP magazine.
- Arrange for pre-ESRD educators to hand out information on the DFC website to their clients.
- Arrange for pre-ESRD educators to use the DFC website as one of the materials in their curriculum, with hands-on training on the website for CKD patients.

Dialysis Professionals

- Notify professionals about the DFC website through a social work listserv on the Internet.
- Send letters and flyers to social workers at dialysis facilities and ask them to post the flyers on facility bulletin boards.
- Send letters to professionals.
- Send e-mails to professionals.
- Provide links to the DFC from the NKF website and other websites.
- Provide “sponsored links” in Web search engines such as Google, to ensure the DFC is listed on the first page whenever anyone conducts a Web search using certain key words, such as dialysis, kidney failure, renal disease, etc.
- Advertise in professional publications (Nephrology News & Issues, Dialysis & Transplantation) and journals.

- Contact the NKF, all of the Networks, and professional associations (RPA, ANNA, CNSW, etc.) and ask them to publicize the DFC in newsletters they send to their members.
- Conduct presentations at Network meetings and professional conferences.
- Provide flyers on the DFC at Network meetings and professional conferences.
- Make the website more worthwhile for professionals. If they use it more they will spread the word to patients and other professionals.

4.2 General Themes

The focus groups, triads, and interview we conducted with dialysis professionals also included four more general themes. As noted, they cut across the more detailed issues presented in the last section.

4.2.1 Participants recommended a wide range of additional types of information they would like to see added to the DFC website.

The lengthy lists of participants' recommended data elements in the last section are noteworthy. Ideas and recommendations covered all aspects of the DFC website, including facility characteristics, quality measures, and other types of information on kidney disease, dialysis care, and patient education. Suggestions were made at many points during the focus groups, triads, and interviews, indicating the intensity of interest among participants in finding ways to improve the DFC website.

We found these professional and technician participants to be generally positive regarding the potential of the DFC to provide useful information to patients and their family members. They seemed to believe that adding a range of additional data elements would significantly enhance the ability of the DFC to provide those benefits.

The challenge facing us for the next phase of this project will be to set priorities from among the many recommendations provided by these participants (and those contributed by the other types of respondents as well). The dialysis professional and technical participants had the largest number of recommendations for new data elements, but dialysis patients and family members, and other respondents also had a large number of suggestions. Fortunately, the recommendations overlap in many cases. That will reinforce the strength of some recommendations, since they were repeated independently by two or more types of participants.

4.2.2 Differences were observed in perspectives regarding DFC across the different types of participants involved in the study.

A wide range of dialysis professionals was included in this evaluation. As a result, we expected to find some differences in perspectives among the different groups. There was some variation in responses across different categories of participants, although it was somewhat less than we had expected.

One group included the mid-level providers – nurses, dietitians, and social workers. We saw few differences in perspective within that group. That may reflect the interdisciplinary approach applied in dialysis facilities, which supports a shared understanding of issues among these mid-level providers. They were generally favorable toward the website, with their main concerns focusing on the age of the data used for the quality measures and the range of non-facility factors that may affect them.

Nephrologists were more favorable toward the DFC website. They acknowledged the shortcomings highlighted by the mid-level providers but seemed to focus more on the potential benefits of the data on the website, both for patient education and for tracking the performance of their affiliated facilities. Their more positive outlooks seemed to be related to their looser association with the facilities than the other participants.

Renal administrators were very interested in the content of the DFC website, but were more cautious than the other groups. They viewed the DFC as reflecting directly on their own facilities and hence their own personal performance. This made one quite defensive and rather strident in her attacks on the quality of the data in the website. The others were more even-handed, however, and seemed willing to accept the website and the need to manage carefully to improve the performance of their facilities so that they would be reflected favorably on the website.

Technicians seemed somewhat less confident in their views compared to the other groups, about both the content of the website and, at least initially, about web applications for distributing information regarding dialysis. This probably reflected their lower levels of training and experience relative to the other types of participants.

4.2.3 The Chicago and Phoenix site visits had some results that were different from the other two (Washington and Atlanta).

Participants in Chicago and Phoenix believed that patients have more choices among dialysis facilities than the professionals in the other cities. While patients may not clearly understand the range of choices they have, they suggested that patients could be educated about their ability to more actively investigate a range of different facilities and choose the one best suited to them.

We developed several hypotheses regarding the factors behind these differences. In Chicago, a number of professionals indicated that patients had more choices among facilities than they often realized. This may reflect a different relationship between supply and demand for dialysis services in that city.

A supporting factor in Phoenix seemed to be that patients were more able to receive treatment at dialysis facilities that did not have affiliations with the patient's nephrologist. This opened up more options – and choices – for many patients since more dialysis facilities were available to them. Another factor seemed to be the population growth experienced by Phoenix. Several professionals reported that this had led the large dialysis chains to more actively build new dialysis facilities in the Phoenix area.

It is interesting to note that patients in Phoenix also reported that they saw more choices among dialysis facilities than patients in the other three cities. This finding is included in our companion report on data collection with dialysis patients and family members. It is consistent with the findings here from professionals, and reinforces the view that Phoenix has a different environment for dialysis services that promotes greater choice for patients.

4.2.4 PD professionals were quite vocal about the HD emphasis of the current DFC website.

PD professionals commented frequently that the DFC website is too focused on HD issues and HD data. They indicated that this tendency is endemic in the dialysis community, which seemed to make them especially sensitive on this issue.

They pointed out that the data on facility characteristics need to be supplemented with PD information in a number of ways. They also expressed interest in having quality measures focused on PD adequacy, PD-specific measures for anemia and patient survival, albumin levels, peritonitis, and other issues of particular concern for PD care. They provided a range of recommendations for website revisions that were focused those issues.

These viewpoint and recommendations were very similar to those we received from PD patients, as discussed in the last chapter. PD patients also expressed strong feelings that the dialysis community is too heavily focused on HD issues, and also made frequent comments about the need for more PD-specific information in the DFC website.

The consistency of these messages from PD professionals and patients was striking. It has led us to recommend several revisions to the DFC website to respond to these concerns. They are presented in Chapter 9.

CHAPTER 5:
PRE-ESRD PATIENTS & FAMILY MEMBERS

This chapter presents our findings from analysis of the data we collected from pre-ESRD patients and family members. As noted in Chapter 1, a total of 42 pre-ESRD patients and family members contributed comments in the focus groups, triads, and interviews conducted with these respondents.

This chapter includes two sections. The first presents detailed issues. It is structured around 16 analytic categories, each including one or more key issues studied through a set of questions presented to the participants. The second section presents more general themes that we identified through analysis of respondent comments. The themes cut across the more detailed issues presented in the first section.

5.1 Detailed Issues

For each of the 16 analytic categories in this section, we provide an overall report based on the responses of pre-ESRD patient and family participants from both site visits where these data were collected. For the longer categories, we also summarize the key findings at the outset using bullet points. Throughout this section, we offer illustrative quotes from participants to represent the points of view discussed. The quotes were selected to exemplify the issues being presented.

In addition, where possible, we identify variations in responses based on different types of participants, including breakdowns by site (city) and patients versus family members. These variations were assessed for each of the 16 analytic categories, although significant variations were not always identified.

5.1.1 What Kidney Disease Education Classes Should Have Explained Better

Each focus group and triad started with introductions and comments about what participants would have liked their kidney disease education class to explain better or in more detail. We also asked what sort of timeline their doctors had given them regarding when they might need to start dialysis or get a transplant.

In general, participants wanted more information regarding kidney disease and what to expect. Most felt they lacked a basic understanding of dialysis, treatment options, and how to get more information. Several participants had not been through formal kidney disease education classes, but even those who had indicated a need for much more information.

Needless to say, it was also evident that few had any understanding of dialysis facilities. Choice among dialysis facilities was not something any were considering prior to this study.

Participants provided a wide variety of responses regarding specific information needs, with most mentioned by only one or two participants. The range of perceived information needs is striking, however, and indicates the breadth of unmet needs among these participants. Specific comments and questions included the following:

- More detailed explanations of kidney disease and treatment options, including HD and PD. (This was the most frequent comment.) A family member wanted to "learn about the process from start to finish." Another said she wanted to know *"Everything, A-Z."* A patient indicated, *"I would like to see more examples of different stages of going through the process of PD and HD. Maybe people who already have all the attachments and everything, to kind of see in person what to expect."*
- Why are some patients sick after dialysis treatments?
- How often are the treatments?
- What are the side effects?
- How to tell other people about dialysis.
- What are the facilities like?
- What a fistula is. As a patient put it, *"What [does] it do?"*
- Medications and machines
- What about patients who are HIV positive? What do they do?
- More information on preventive care, diet, exercise, and how to keep healthy.
- Do dialysis patients suffer from depression?
- More information about the blood tests patients on dialysis have to have. As a patient said, *"I'd want to know what those are and what they mean."*
- More information about transplants. Do all patients get transplants?
- Do patients ever get off dialysis?
- How can family members help the patients?

The limited understanding of kidney disease and dialysis issues reflected in these questions and concerns was surprising to us, since most of these participants had been through some pre-ESRD education. The responses may reflect high levels of denial among pre-ESRD patients and family members, or the limited effectiveness of pre-ESRD educational programs.

Patient participants also expressed anxiety regarding what their future would hold. Several indicated they were in "a state of shock." Family members also expressed anxiety, but less strongly. Although they did not say it outright, many patients seemed concerned for their lives. Just dealing with those concerns seemed to be occupying a great deal of their time and concentration.

In general, participants did not have a clear idea of the timeline for when they or their family members would need to begin dialysis. Some indicated they knew it was assessed by blood tests, and one indicated he thought it would be about six months, but without much conviction. A few knew they were close to needing dialysis, and indicated it would start in a few weeks or a month. These responses probably reflect doctors' preferences for not discussing specific timetables for dialysis onset until patients are fairly close to needing dialysis.

5.1.2 Information Sources

We asked participants about the sources they use for information about health or medical care. We probed especially regarding Internet use, whether for medical issues or for other uses. Later, we asked participants about the sources they use for information about kidney disease, dialysis treatments, modality choice, or dialysis facilities. We probed regarding Internet use.

In general, participants indicated that their doctors were their primary sources of information regarding health and medical issues. A majority also mentioned talking to other laypeople, including friends who are on dialysis or people in support groups. In Phoenix, a patient said that a local hospital has a hotline where patients can talk to others who have already gone through the transition to dialysis. Several use reading materials from a library or medical pamphlets.

Several participants indicated that an information barrier they face is that physicians often do not take enough time to explain things, and frequently use medical jargon that laypeople cannot understand.

Another barrier mentioned was that when patients and family are experiencing a new disease, they do not know where to start or what questions to ask. One admitted to a fear of knowing more information about the disease.

All but one or two participants use the Internet themselves or have friends or family who can help them with it. About half use it for health, medical, or kidney disease information. Specific websites mentioned included: WebMD, renalfailure.com, NKF, PKD, ESRD15.org, kidney.org, and various search engines.

The breadth of Internet access reported by these participants is encouraging for future DFC utilization. It appears that if pre-ESRD patients believe they will find useful information on the DFC, then it may be possible to encourage them to seek it out. Denial will likely remain a barrier, but it maybe mitigated by expanding efforts at pre-ESRD education. The recent AAKP initiative entitled, “Kidney Beginnings” and the NIDDK’s new National Kidney Disease Education Program are only two examples of the increasing efforts at pre-ESRD education and intervention nationwide.

5.1.3 Finding a Facility

We asked participants about the things they would like to know about dialysis or dialysis facilities. We asked if they had visited a dialysis facility or had talked to anyone about dialysis facilities. We asked participants about the things related to dialysis facilities or treatments that they think are important. Finally, we asked how much choice between dialysis facilities they think they have and what information they think kidney disease patients should have to help them make choices.

Most focused on basic facility information, such as location and staff. Several participants wanted information on how to know if their dialysis treatment is going well or poorly. As a family member said, *“What is the best I can expect?”* Several also wanted an opportunity to speak with someone who had been treated for a while at a particular facility. One asked if there would be a 24-hour help line available for people being treated at a particular facility.

Both pre-ESRD patients and family members had a notable lack of information on dialysis or facilities. This was indicated by a range of questions posed at this point by participants, along the following lines: What do they [dialysis facilities] do? What goes on there? Who gives treatment? How is dialysis paid for? Is it affordable? Is it the same treatment all the time? What is the effect? How long do you have to be on the machines? How long do you have to be on dialysis? What are the procedures while patients are on the machines? How does the machine work? What are the patients' responsibilities? How can families be encouraged to talk about it in their denial?

Less than half had visited dialysis facilities, either for themselves or to visit relatives on dialysis. A few had talked to someone about dialysis facilities. Most were not sure about the important things to know regarding dialysis facilities. As a family member said, this is *"all very new."* A patient said, *"Aren't they all the same?"*

These comments struck us as indicating the need for lists of questions or checklists on the DFC website that pre-ESRD patients and family members could use when visiting dialysis facilities for the first time. They seemed to need guidance as to what questions to ask.

Issues mentioned by participants as important mentioned included: cleanliness (a frequent comment), location, convenience, transportation, schedules for treatment, what types of insurance are taken and what it covers, the services provided, how informed they keep the patients, if staff are available, staff experience, and whether the staff are friendly or make patients feel comfortable (a frequent comment).

About half expected to have some choice between dialysis facilities when prompted on this issue. Others said they were not sure or thought the choices would be made by the doctors or the insurance companies. Several suggested tours of facilities would be helpful for making choices. Only a few had seen lists of dialysis facilities. Most wanted as much information as possible. As one put it, patients should get, *"whatever they have from A to Z to give them a choice."*

Patients seemed to believe that exercising choice would be a good thing for them to do. They did not seem to want to defer those decisions to their doctors. At the same time, some seemed intimidated by physicians and insurance companies, and unsure if they *"deserved"* to have a choice. This seemed to be an area where pre-ESRD education, and DFC messages, could be useful in promoting the viewpoint that patients should take an active role in disease management and decision making, on facility selection issues and others.

5.1.4 Exploring the DFC Website: Expectations

We asked participants what they would expect from a website called "Dialysis Facility Compare." None had seen the DFC website prior to this study.

It is striking that none of these patients – most of whom had pre-ESRD education – were familiar with the DFC website. This seems to represent an opportunity for raising awareness and utilization of the DFC in the future. We believe the DFC could be presented to pre-ESRD educators as a resource for patients, and potentially also integrated into the curricula of their programs. It could be use to show patients ways they can increase their decision-making abilities and link to self-education resources as well.

A majority of family members found the name unclear. They were not sure what to expect. As one put it, *"What does 'Compare' mean?"* Some thought it meant that Medicare approves the facilities and will pay for their treatments. However, that led others to say that they thought Medicare was about insurance, not facilities. A related comment (expressing confusion) was, *"Does age have anything to do with it?"*

Patients seemed to understand the intent of the website better. Most indicated they thought it would compare facilities so that patients can have a choice, or "to see what's good." As one put it, *"Line-by-line comparisons, what this one and that one does."* However, most were still unsure as to what characteristics or attributes would appear in the comparisons.

5.1.5 Exploring the DFC Website: Facility Characteristics

We showed participants the DFC website live on the Internet, on a screen using a computer and a projection device. On the overview page, we showed them the list of facility characteristics and asked how they thought that information would be useful.

A range of characteristics were cited as useful, mostly by one or two participants. They included:

- Evening shifts, *"If I had a job."*
- Location, to *"find out what's most convenient to me."*
- Profit/Non-profit, to find out, *"who is benefiting from your illness."*
- The number of treatment stations.
- Information on Medicare certification.

Family members again seemed to understand the issues less clearly than patients. Some family members thought that facility characteristics would specify the type of dialysis a patient would be on. Others had only a few comments, such as a preference for the closest facility or the need for a mapping function.

5.1.6 Exploring the DFC Website: The "Read This" Paragraph

We showed participants the "Read This" paragraph on the overview page of the DFC website, and read it to them aloud. We then asked for their reactions to it. (A copy of the paragraph is included in Chapter 2.)

Family members thought this paragraph sounded useful, and that it made sense to visit facilities before choosing one and to check out the facilities with the patient's nephrologist. However, they were also confused by some of the terminology. They asked about the meaning of the terms, "ESRD," and "local ESRD Network." They suggested less use of acronyms.

Several also asked for a description of a "State Survey Agency." One thought it was, *"just a survey of people."* Another thought the paragraph sounded like a warning, saying, *"Is there a danger if you don't do these things?"*

As was found with other types of respondents in this study, it is apparent that some of the specialized terminology needs to be taken out of this paragraph, or at least better explained. Perhaps the functions of the ESRD Networks and State Survey Agencies could be briefly described at some point, with links to more detailed explanations for those interested.

Patients seemed more clear on the intent of the paragraph. They indicated it means patients should visit facilities, gather additional information, and evaluate them according to their individual needs. As one put it, *"Check it out before you go."*

5.1.7 Exploring the DFC Website: Quality Measures

We showed participants the list of quality measures on the overview page of the DFC website, and asked how many had heard about them. We also asked if they had discussed those measures with a provider and what each of the quality measures meant to them.

About half of the family members had heard of one or two of the quality measures, especially hematocrit levels, but they had not had discussions with providers about them. Most of those had a general notion of what they meant, but not any specifics.

All agreed the quality measures could be useful to them, and that they would like to have the information. They understood the potential of the measures and believed they could, *"tell you if you are getting adequate care, if the facility is doing their job, the success rate."* As one put it, the measures could be particularly useful if they are presented as a, *"regular in print read-out about how the patient falls in comparison to the measure."* Another said the DFC website was like, *"The Consumer Reports of dialysis."*

As illustrated in the quotes, at least some participants seemed to think the quality measures were providing individual-level information instead of facility-level information. Nonetheless, the high degree of enthusiasm regarding the quality measures was noteworthy.

Patients were more familiar with the anemia quality measure. About half reported already being treated with Epogen or Procrit as a pre-ESRD patient, or knowing about the importance of hematocrit levels. A few seemed to have a good understanding of the anemia issues. As one said, *"At 40 they cut you off, so I've been on and off of it for four years."* Another said, *"But my insurance company won't cover the cost of Epogen or Procrit until you go down to 29."* Other patient participants, however, had only a vague notion of the importance of Epogen or could not recall the meaning of hematocrit.

Moreover, only one or two had heard of URR. And only a few had comments on patient survival. Few seemed to have a clear understanding of the factors affecting survival. Some had misinformation about this issue. As one said, *"It depends on the type of dialysis you do. PD filters better than HD."* Several others indicated a desire to know more about the factors affecting survival.

Patients also agreed that the information on quality measures would be useful. As one said, *"It would help you decide where you want to go."* Another indicated, *"You'd pick the one with the best percentages on all three."*

Patients' lack of knowledge about quality measures was again striking for a group that had been through pre-ESRD training programs. We expected that at least the dialysis adequacy and anemia topics would have been covered in pre-ESRD education. Patient survival may be more sensitive or scary to patients, although some discussion of factors affecting long-term survival of dialysis patients would seem to be appropriate for pre-ESRD education as well.

5.1.8 Scenario of Moving to a City in Florida: Facility Characteristics

We presented participants with a scenario in which they would be moving to a city in Florida, and needed to choose a dialysis facility in that city. We walked participants through the process of identifying the dialysis facilities available in that city using the DFC website. We selected four facilities in that city and showed participants their facility characteristics using the website. (We pre-selected the four facilities to ensure they varied on several characteristics, including size, ownership status, availability of evening shifts, and chain membership.) We asked participants what the information told them about those facilities.

Overall, both patients and family members were pleased to have the facility characteristics available to them. They seemed to appreciate having relatively easy access to information they did not previously know existed.

There were a range of comments on the specific characteristics that would be particularly useful. They included the locations of the facilities (addresses), the contact information (telephone number), the presence of evening shifts (a frequent comment), the number of dialysis stations, nonprofit/for-profit status (a frequent comment), chain membership, and the initial date of Medicare certification (a frequent comment).

5.1.9 Scenario of Moving to A City in Florida: Quality Measures

Continuing the Florida scenario, we showed participants data on each of the three quality measures for those same four facilities. (The facilities were also pre-selected to ensure they varied on two of the quality measures, adequacy and anemia.) We compared the results for those four facilities with the national and state average data also available on the DFC website for each of the quality measures. One facility (Facility A) was selected since it was much higher than the others – and higher than the national and state averages – on both adequacy and anemia. Another (Facility C) was selected since its results showed all of the quality measures as "Not Available." We asked participants what the information on the quality measures told them about those four facilities.

Both patients and family members did not like the fact that the data for Facility C were "Not Available." In general, they indicated they would not go to Facility C because it was not providing any information. A typical comment was, *"It kind of makes you worry that there's no information on the one…"* Another said, *"If you don't know, you don't go."*

Both patients and family members were impressed with the higher results shown for Facility A for adequacy and anemia outcomes. As one put it, *"I'm...headed for [Facility A]."*

This reaction was similar to the responses from other respondent groups in this study, including patients already on dialysis and their family members. The graphical display of the quality data seemed again to have a powerful effect on participants. As with the other groups, it was evident that they "lit up" when seeing the colored bar graphs with this information. The text paragraphs, while also informative, were clearly less interesting and less engaging to the participants.

Several indicated they would like additional information on what to do if the numbers are too low. This seemed to be again confusing the perspective of an individual patient with data on facility averages.

In general, the explanations of adequacy and anemia below the graphs were considered clear. The graphical displays of information for the adequacy and anemia results were also viewed as understandable and well presented.

Neither patients nor family members were pleased with the information provided on patient survival. They indicated that it did not tell them anything since the same "Average" rating was given to all of the facilities in this scenario.

Many found the survival information more confusing than the adequacy or anemia results. For example, a family member said it is, *"not telling you what is expected.*" Another said, *"Expected as compared to what? What does it mean?"*

They seemed to want more detailed information on the patient survival issue. Or perhaps a more obvious link to the FAQs on patient survival, and instructions to read them before reviewing the results.

The fear, or emotional reaction this topic generated was again noteworthy. Careful explanations seem to be needed to keep patients' attention focused on the facility comparisons, and on the positive messages regarding modifiable risk factors.

5.1.10 Most Important Information

We asked participants what they thought was the most important information on the DFC website. Comments were quite diverse on this point, possibly reflecting the limited time that participants had been exposed to the website; as noted, all of them were seeing it for the first time.

Specific topics were mentioned as most important by one or two participants; none were frequently mentioned. They included: facility characteristics, quality measures, graphs, survival, adequacy, accessibility, information on facilities to help patients who are traveling, and information on the chains, so patients can contact other facilities in the same chain for traveling.

Several participants indicated that all of it was important. This again seemed to reflect their limited experience with the website. As one put it, *"All of it is new, all of it is good information."*

5.1.11 Does the DFC Website Meet Participants' Expectations?

We next asked participants to think back to before we showed them the DFC website, when we asked what information they expected it would provide. We then asked to what extent the website had met their expectations.

Participants said the DFC website did meet their expectations. Most learned about many types of information that they did not know existed, and indicated they plan on learning more about what else is available. A patient said, *"It enlightens me."* They indicated it will help them make informed choices about dialysis facilities and the services they offer.

Several participants expressed an interest in getting additional help in developing questions to ask facilities and providers about dialysis care. Many were unsure of what questions they should be asking. As a patient put it:

> *One thing I would like to see is, when you decide to go to a facility that you have some kind of checklist of questions, like what are the qualifications of the nurses and the technicians, what are the amenities.*

5.1.12 Content of the DFC Website – How Would Participants Use It and Recommend It?

We asked participants how likely they would be to use the DFC website, what information they would use, and how they would use it. We inquired about potential barriers to its use. We also asked under what circumstances they would recommend the website to others.

The majority of participants said they would use the DFC website, and they would recommend it to other CKD patients and family members. Travel needs were cited as a particular use, as was investigating possible alternate facilities in the patient's current area. Several also mentioned accessing the website links and Medicare information as likely uses.

In addition, some participants noted again at this point a number of ways the website could be improved. These comments mainly referred to ways the number of data elements could be expanded, or the website made easier to use. Several participants indicated they would need help from more computer-savvy relatives or others in order to use it.

As a family member said, *"It still leaves a lot of questions, but answers some questions."* Another suggested, "Give more information – more PD information."

A patient added, *"I would want the medical dictionary, the breakdown, and diagrams and pictures. So you're not just going there to compare; I want to know are they going to provide you with the other information."*

5.1.13 Content of the DFC – Is It Complete?

We asked participants how complete the DFC website seemed to them. Most seemed satisfied, although there was limited response to this question.

As with other types of respondents in this study, these participants seemed hesitant to make a judgment on "completeness," since virtually all of them were seeing it for the first time. As one patient put it, *"It's all new to me."*

5.1.14 Content of the DFC – Is It Up To Date?

We asked participants how up to date the DFC website seemed to them. There were mixed responses to this question. Some were satisfied with the age of the data. Others thought the data were too old.

In general, those who were satisfied were less certain of their opinion. They did not seem to be focusing on the age of the data specifically, but rather to be responding with their general impressions of the value of the data they saw. They did not cite specific numbers regarding the age of the data.

Those who believed the data to be too old were more likely to cite specific numbers. For example, that three-year-old data are too old. As one put it, *"There are a lot of changes every year."*

5.1.15 Other Information Participants Would Like To See on the DFC Website

As part of the scenario with the city in Florida, we asked participants what additional information they would like to have on facility characteristics and quality measures for the four facilities they were comparing. We also asked again, at a later point in the group or interview, what other information they would like to see on the DFC website, including information about dialysis facilities, kidney disease, or how to better manage their own care. As noted, participants also volunteered suggestions for additional information that could be added to the website in response to other questions. We combined all of those recommendations into this section.

Numerous suggestions were made for additional data elements, including additional data on facility characteristics, quality measures, and additional dialysis or health-related information. In order to be comparable with the companion reports on data collection with other types of respondents, the specific recommendations are listed below in the same 15 categories used in previous chapters.

The first nine categories include recommendations on facility characteristics. The tenth includes recommendations on quality measures. The last five categories include recommendations on additional dialysis or health-related information.

While still lengthy, the lists of recommendations are much shorter for these respondents. In particular, they are much shorter than the recommendations suggested by dialysis patients and family members. The limited recommendations here again shows the lack of information that pre-ESRD patients and family members have regarding dialysis facilities, dialysis care, and kidney disease. This is especially noteworthy since most of these participants were selected based on their previous participation in pre-ESRD education programs or classes. Their pre-ESRD education appears to have been limited in actuality, and not retained in some cases.

The recommendations are as follows:

Physicians

- Add a measure of doctors' quality. As one put it, *"Who's a good nephrologist?"*

Dialysis Staff

- Include patient to staff ratios.
- Include a patient to nurse ratio for PD
- Describe how many staff provide treatment at each facility.
- Describe which staff are available at which times.
- Present lists of questions to ask dialysis facility staff about staff qualifications and experience.
- Provide information on staff certification.

Equipment and Facility Information

- Include the number of treatment stations.
- List how many openings are available in different time slots.
- Add a mapping function, like MapQuest.
- Describe which facilities have the correct equipment.
- Describe the age of the equipment?
- Describe the average age of patients at the facility.
- Provide demographic breakdowns for the patients treated at the facility.
- List whether the facility provides pediatric dialysis services.

Amenities

- Include a separate section on the website for amenities offered by each facility. As a patient put it, *"What's come up quite a bit is the environment when you're there, so if they could have a title 'amenities' and then a link to whether they have TVs and all that. [The DFC] is very clinical, but it doesn't tell me how I'm going to feel when I'm there."*
- Include lists of questions to ask dialysis facility staff about amenities.

- Organizational Information and Policies
- Include all of the hours of operation. (This was a frequent recommendation.)
- Describe whether the facility provides transportation.
- Whether there are training or educational classes available.
- If there are support groups available.
- Does the facility accept traveling patients?
- Do different units allow you to go to other units in the same chain?
- Pictures of the facility. As one put it, *"You could kind of tell if it's clean, well-set-up, well organized."*
- A virtual tour, so patients can see the stations and the degree of privacy.
- Driving or public transportation directions.
- Does the facility have a day care service?
- Describe the types of insurance taken by the facility.

Clinical Policies

- [no recommendations]

Patient Issues

- Add a chat line so patients can exchange information.
- Provide a patient evaluation form or patient satisfaction form on the website.

Accreditation and Regulation

- Describe the standards for facility certification.
- Describe the standards for dialysis facilities.

Peritoneal Dialysis

- [no recommendations]

Quality Measures

- Add PD patient information on all of the quality indicators.
- Calculate the indicators for all patients, not just Medicare patients.
- Add patient satisfaction data.

- Provide more up to date information on the quality measures.
- Provide more information on survival rates.

Dialysis and Kidney Disease Information

- Add information on diet, including what kinds of food to eat and menus. (This was a frequent recommendation.)
- Add information on vitamins and natural foods.
- Include information on pre-ESRD diets versus dialysis diets.
- Add information on kidney disease. For example, *"How does kidney disease relate to diabetes?"*
- Include information on how dialysis equipment works.
- Provide an FAQ section on the website.
- Include checklists that patients can use to assess a facility.
- Discuss whether patients have to sign a contract to receive dialysis services.
- Discuss whether patients are obligated to go to a particular facility.
- Discuss whether patients can change facilities.
- Include a list of patients' rights.
- Explain what happens if you miss a dialysis treatment.
- Describe how patients feel when the come off of dialysis.
- Explain the differences between Epogen and other medications.
- Include a list of warning signs of kidney disease.
- Describe the steps involved in the dialysis process.
- Explain what happens in the kidney.
- Provide animated explanations of kidney disease and dialysis.
- Refer patients to other sites that are specialized to particular topics on kidney disease, dialysis, diet, etc.
- What should patients consider when planning international trips, such as to Mexico or Europe?
- Provide advice on how to adjust to the lifestyle changes, such as what things are needed to ensure comfort.

General Health Education

- Provide information on related diseases. For example, how to take care of diabetes.
- Medicare Information

- Describe how much a treatment costs. Is the price different at different facilities?
- Include information on how to get help to pay for dialysis.
- Include a place on the DFC website to provide suggestions about the website.
- Include information on what Medicare will pay for and what they will not pay for.

Transplant Issues

- Provide information on the transplant option for kidney disease.
- Explain why some people receive both a kidney transplant and a pancreas transplant.
- Peritoneal Dialysis Issues
- Explain restrictions for PD patients, such as they can only use private swimming pools, not public ones.

5.1.16 How Medicare Could Let Dialysis Patients & Family Know About the DFC Website

We asked participants about the best ways for Medicare to tell other pre-ESRD patients and family members about the DFC website. A number of suggestions were made:

- Health programs or commercials on TV, or videotapes. (This was a frequent recommendation.) As one put it, *"Advertise [the DFC website] a little more – it's foreign to me."*
- Dialysis facilities should provide computers that enable access to the DFC website. Or other alternatives should be provided for patients who do not have computers or Internet access.
- Provide pamphlets or flyers in dialysis facility waiting rooms or doctors offices.
- Arrange for the pre-ESRD educators to provide information about this website.
- Provide information on the DFC by mail, or in bills sent to patients.
- Include information on the DFC in the Medicare and You booklet.
- Send e-mails to patients about the DFC.
- Arrange for health plans to send out information.
- Arrange for advertisements regarding the DFC to be included with medications available for diabetes and anemia.
- Obtain sponsored links from internet search engines, so that when "dialysis," "ESRD," or other key words are entered the DFC website will be listed prominently.

We found the recommendation regarding pre-ESRD educators particularly promising. As noted, they could be a vehicle for promoting greater patient and family involvement in disease self-management by providing recommendations on websites that can be used for ongoing self-education. The DFC might not be the whole story, but it could be a major part of that approach.

The idea of sponsored links on Internet search engines also seems promising. Many participants in this study, including dialysis patients and providers as well, reported using search engines to find information on kidney disease, dialysis, and dialysis facilities. Sponsored links are a centerpiece of Google's business model, a major source of its revenue. So presumably Google would welcome an effort by CMS to list DFC (and possibly other Compare websites) as sponsored links for patients using it for web searches.

At present, if the word "dialysis" is typed into Google for a search, the DFC shows up on the second page of links, but not on the first page that patients initially see. (Dialysisfinder.com does show up on the first page.) There are two sponsored links that show up on the first page of results, for the "New York Dialysis Center," and "Dialysis At Home, Inc." There is currently room on the first page of results for a number of additional sponsored links.

5.2 General Themes

The focus groups, triads, and interview we conducted with pre-ESRD patients and family members also included several more general themes. They cut across the more detailed issues presented in the last chapter.

5.2.1 The Current Lack of Information Among Pre-ESRD Patients

We noted the general lack of information regarding kidney disease, dialysis, or dialysis facilities among pre-ESRD patients at several points in the last section. While avoidance or denial may of course play a part in this situation, it is still surprising that people with such a severe chronic disease have not taken steps to learn more about it and its treatment. This is especially serious given the recent evidence that a range of early interventions – in the pre-ESRD phase of the disease – can have many positive impacts in terms of slowing progression to ESRD, reducing complications and comorbidities, and providing for a smoother transition to dialysis.

It appears that pre-ESRD education still has a ways to go in its development. Although the pre-ESRD classes have only begun to be offered widely in the past few years, our respondents were selected to be those who had received some type of educational program regarding their kidney disease. Our interviews with pre-ESRD professionals, discussed in a companion report, indicate that in many cases the education is quite limited in terms of its depth and length. Some programs only include one session lasting two hours. The curriculum may also vary, depending on the educator's perception of students' needs.

Funding for pre-ESRD education may of course be limited at present, and that may partly explain the limited nature of the programs we found. However, in that situation it would seem that the Internet could potentially have a large role to play in providing a source of ongoing information and education that could be accessed directly by patients and family members themselves. Most of the educators were aware of the limitations of their programs, so they might be willing to consider ways of supplementing them with Internet resources, including the DFC website and others.

Patients could also be encouraged to access the DFC for pre-ESRD information if they are not involved in formal programs. It is evident that their needs for information are large, and that once they see the types of information available on the DFC they become interested.

CMS should consider several ways of facilitating those pre-ESRD roles for the DFC. For example, it could actively promote the DFC website among pre-ESRD educators. Modules could be developed to enable educators to more easily demonstrate the use and benefits of the DFC. CMS could also provide funding for development of pre-ESRD educational programs that use the DFC, and possibly other websites, as integral parts of their curricula.

Another approach would involve creating a special link or "tab" on the home page of DFC that is labeled as providing information for pre-ESRD patients. Their information needs are different from those of patients already on dialysis, so they probably deserve to have a special series of web pages within DFC that address their issues and concerns.

5.2.2 Clarifying the Role of Pre-ESRD Family Members

Pre-ESRD family members exhibited even less knowledge of kidney disease, dialysis, and dialysis facilities than patients. They seemed in many cases to be unclear on the topics under discussion, such as dialysis facility characteristics. Several of them also asked about the types of roles they could expect to play in support of patients.

This led us to consider ways to promote greater involvement of family members using the DFC. It may be that the information intermediary role needs to be taken on more actively by family members in the pre-ESRD stage of the disease. Once a patient is on dialysis there are more resources available for that role – such as nurses, dietitians, and social workers. Moreover, many of the dialysis chains now provide patients with routine, monthly "report cards" that provide them with data about their disease and treatment, and provide a focal point for discussion and education with providers.

Given the denial and fear that many pre-ESRD patients experience, it may be appropriate to consider a larger role for their family members in information gathering and education. Family members could access the special link or tab discussed above for the DFC for pre-ESRD information.

Explicitly promoting the use of the DFC by family members is another possible approach. They certainly have their own concerns and information needs, but often seem to be unsure of their role. The DFC could include a discussion of the roles that family members can play. Each family will need to work out its own method for dealing with the disease, but family members may find an outline of possible roles to be helpful in providing some structure for their considerations.

5.2.3 The Benefits of Graphical Displays of Data and Diagrams and Pictures of Clinical Processes

The potential benefits of graphics and pictures were emphasized by these respondents at several different points during responses to questions in the focus groups, triads, and interview. The use of graphics, diagrams, and pictures may be especially salient for pre-ESRD patients since most have not had the chance to visit a dialysis facility or to experience the dialysis process. As one respondent put it, they are often scared at this point in their disease, and diagrams or pictures may provide some reassurance or at least de-mystify the process to some extent.

We also noted the positive response of participants to the graphical displays of the quality measures data for adequacy and anemia. Those colored bar graphs seemed to be easier for participants to understand. As noted, they became more alert and enthusiastic in discussing them, in comparison to their affect when discussing text passages. It may be that patients and family members will retain more information regarding quality data if it is presented in that way. They may also leave the DFC website with a more positive impression of it that may then be transmitted to other potential users as well.

Our discussions with CMS web staff have included review of a number of limitations on the ability of DFC or other medicare.gov websites to use extensive graphics, diagrams, or photographs. Nonetheless, it seemed that a simplified approach such as the bar graphs was effective, so perhaps other simplified methods could also be applied. We believe that increasing the use of graphics, diagrams, and pictures on the DFC website – to the extent possible – will increase its appeal to patients and family members. Those methods may also increase the ability of DFC to communicate effectively with patients and family members.

CHAPTER 6
PRE-ESRD PROFESSIONALS

This chapter presents our findings from analysis of the data we collected from pre-ESRD professionals. As noted in Chapter 1, a total of eight pre-ESRD professionals contributed comments in the interviews conducted with these respondents.

This chapter includes two sections. The first presents detailed issues. It is structured around 16 analytic categories, each including one or more key issues studied through a set of questions presented to the participants. The second section presents more general themes that we identified through analysis of respondent comments. The themes cut across the more detailed issues presented in the first section.

6.1 Detailed Issues

For each of the 16 categories in this section, we provide an overall report based on responses of participants from interviews in the two site visits during which these data were collected. Throughout this section, we offer illustrative quotes from participants to represent the points of view discussed. The quotes were selected to exemplify the issues being presented.

6.1.1 Background Information on Pre-ESRD Professionals and the Programs They Provide

For this section, we asked pre-ESRD professionals what type of pre-ESRD or chronic kidney disease (CKD) educational programs they provided to patients and their families. We also asked for more specific details about the programs, such as who developed them, how patients were referred to the programs, class size, how much one-on-one time was spent with patients, and if the pre-ESRD professional communicated with the patient's physician about the class.

Most pre-ESRD professionals provided a 2-hour class to participants on a group or one-on-one basis. Groups ranged in size from 2 to 25 patients and family members. Most pre-ESRD professionals reported that patients were referred to the classes by physicians, although a couple of programs received patients as self-referrals. Only three pre-ESRD professionals responded regarding whether they communicated after the program with the patient's physician, with two reporting no and one reporting yes.

We were surprised by how limited these pre-ESRD programs were in duration. A single 2-hour class seems like a very limited educational effort given the many issues that need to be covered regarding pre-ESRD care, modality choice, placement of vascular access, the transplant option, the transition to dialysis, and others. It would seem that a series of classes would be needed to cover all of those topics in depth, with additional sessions for family members as well.

Funding is an issue that limits the scope of the classes, but this may indicate that there is a need for alternate educational vehicles that patients or family members can access on their own, such as the DFC website. It also points to the potential role the DFC website could play as a resource for pre-ESRD educators, to show patients where they can go for additional information and resources after the class has ended.

Materials Used

Professionals were asked about the types of teaching materials they used in their classes. A follow-up question inquired about Internet use in the classes. Several participants stated that they recommended websites to patients. Websites mentioned are included in below.

Materials used included handouts, slides, packets of information, PowerPoint presentations, videos, diaries to track progress, tear sheets related to dialysis concerns (blood pressure, hemoglobin, etc.), and props (tubes, catheters, dialysis machines, needles, etc). Two pre-ESRD professionals reported using the computer in teaching their class to show actual websites or to do presentations.

Learning Objectives

We asked pre-ESRD professionals about their main learning objectives for patients and family members. Their responses varied, but the most frequent response was to provide patients with basic information about dialysis and their options for treatment. Other responses included the following:

> *Hoping to bring them to the best optimum state of health despite their advancing kidney disease.*
>
> *To let them know that they have choice if they end up on dialysis, to understand their options, and what they can do now to keep the function they have.*
>
> *To leave the class with a sense of renewed control over their lives and an ability to maintain a viable lifestyle.*
>
> *One, to ease them into ESRD being educated and two, we'd like them to stay active and continue working.*

Again, it is interesting to note the disparity between the length of the classes and the broad and ambitious learning objectives. It would be interesting to discuss with these educators their views on the length and number of class sessions they would like to have available to better fulfill their objectives.

Topics Covered

We asked these pre-ESRD professionals about the main topics they cover with kidney disease patients in pre-ESRD education. These responses also varied widely.

Some apparently varied their curriculum among different class sessions. One participant stated, "*I think I pick and choose what is important.*" Respondents listed the following topics:

- social issues
- payment concerns
- coping

- labs
- compliance
- blood pressure
- medications
- treatment options
- patient experiences
- diet information
- basic kidney function
- information about diseases that cause kidney disease

Common Questions

We asked participants to describe the most common questions and concerns that patients have in general. We also inquired specifically about patients' common questions regarding kidney disease, dialysis, and dialysis facilities.

The following is a list of patients' commonly asked questions:

- What are the chances my kidneys will recover?
- How long can I live on dialysis? (This was a frequent question.)
- How is kidney disease going to change my life?
- What is hemodialysis (HD)? What is peritoneal dialysis (PD)?
- How long do I have to be on dialysis?
- Why is PD 7 days a week versus HD 3 days a week?
- What caused my disease?
- How much will I have to pay?
- Are the people nice? (Referring to staff at the facilities.)

The basic nature of these questions is consistent with our observation that pre-ESRD patients and family members attending our focus groups and triads had, in general, little knowledge of kidney disease or dialysis. This reinforces the point made above regarding the potential of the DFC website to serve as a complement to pre-ESRD education programs.

6.1.2 Finding a Facility

For this section, we asked participants what they look for to determine whether a dialysis facility is a good one, what they think is most important to patients in finding a dialysis facility, and what their role was in helping patients find a facility. We also asked how much choice patients have between facilities when they are first starting on dialysis and later, when they may consider switching facilities.

Following are the factors ***pre-ESRD professionals*** said they consider in looking for a good dialysis facility:

- ratios of patients to nurses and other staff
- location of the facility in relation to patients' homes and workplaces
- infection rates at the facility
- how frequently the doctors see patients
- cleanliness of the facility

In comparison, the factors that pre-ESRD professionals think ***patients*** look for in a facility are as follows:

- location—proximity to home or work
- cleanliness of the facility
- the different shifts available to accommodate their schedules

It is evident that there is some overlap between the two lists of factors. However, it seems that professionals do not believe that patients consider some of the more clinical factors. That may be true at present for most patients, but it may also be an issue that could be affected by more intensive pre-ESRD patient and family education.

Most participants stated that their major role in helping patients find facilities was to provide lists of facilities that are located close to the patient. Several indicated taking this a step further and encouraging patients to tour the centers and talk to staff:

> *[Find out] where they are locating to, and we will give them the clinics in the area. I give them all clinics.*
>
> *We have a master list of facilities. Usually when they tell me where they live, we look at what facilities are located close. We say this is what's out there—a lot of times patients will say they want to visit it, and I call the social worker.*

A few participants mentioned that they do not have a big role in helping patients find facilities because insurance often constrains their choices:

> *Insurance may dictate what centers patients have to go to. I encourage them to advocate for themselves with their HMOs about location and shift times.*

Most participants thought that patients do not usually have much choice when first starting out on dialysis. Two respondents thought that choice was further limited if patients wanted to go where their doctor went or their doctor recommended:

> *[Choice] is very limited if [they] want to stay with [their] nephrologists.*
>
> *I don't think they even think they have a choice. Some of them don't even think to ask, "What's the closest unit to my house?" Some of them drive past three units on the way to the one their doctor sent them to.*

Several participants thought that patients had more choice than they realized:

> *I think they have a choice but I think they don't know the right questions to ask and don't have methods of comparison. There isn't anything concrete and objective that they can measure.*
>
> *They probably have more choices than they realize. I think they think they can [only] go to the one their doctor chooses for them. There are some companies who have placement coordinators who actually place the patients at the dialysis units that [have] the most available seats and also the ones closest to their homes. But they can go on the waiting lists to go to a different center.*
>
> *They actually have 100% choice. But whether they utilize it [is another question].*

These comments indicate that facility choice is another issue that could be addressed in more depth in pre-ESRD education. The checklists of questions for facilities and doctors that are envisioned for the DFC website could be one way to promote patient and family involvement in those choices.

Moreover, some participants agreed that patients have more choice after they have been on dialysis for a while. They believe patients became more aware of their choices at that stage:

> *When they switch units, I think they have more choice than they used to. I haven't had any physicians when a patient wanted to change who'd just downright say no.*

Participants indicated that some patients switch facilities to get away from a doctor or staff member that they do not like. Conversely, some stay where they are because they do not want to create conflict with their doctor. As one participant stated,

> *I think they know they have the choice, but what they're not comfortable in doing is if they choose a facility that their doctor doesn't go to and they have a good relationship with the doctor…they're going to stay with their doctor.*

6.1.3 What Defines Good Dialysis Care?

We asked participants what "high quality" dialysis care means to them. We also asked how they know if patients are getting good care.

These questions generated a wide range of responses, with numerous clinical and amenities issues cited by participants. The responses are summarized below:

- Well-trained, experienced staff who genuinely care about patients' well-being.

- The ratio of nurses and other staff to patients.
- Interdisciplinary staff working together as a team, including the physicians, nurses, dietitians, social workers, technicians, and the patient and family. (This was a frequent comment.)
- Credentials of staff.
- How often doctors go on rounds in the dialysis facility to see the patients.
- Whether there is effective patient education at the facility.
- Cleanliness of the facility.
- Timeliness of the staff regarding treatments. As one participant said, *"Do they get patients on and off on time?"*
- Presence of an active continuous quality improvement (CQI) program. Quality improvement and quality assurance programs in participants' facilities include measurement of Kt/V, urea reduction ratio (URR), hematocrit, iron saturation, phosphorous, calcium, and albumin.
- Whether the facility follows the Dialysis Outcome Quality Initiative (DOQI) clinical guidelines.
- Good lab results for patients, including URR, hemoglobin/hematocrit, nutrition, and bone management.
- Patients who say they feel good.

It is interesting to compare these responses to those regarding selecting a dialysis facility above. It is evident that the list in this section is longer, including more clinical factors. Presumably, the additional factors here are also important for selecting a dialysis facility.

6.1.4 Information Sources

We asked participants about the sources they use for information about dialysis care or dialysis facilities. We probed especially regarding Internet use, whether for finding dialysis facilities, other dialysis or kidney disease issues, or other applications. The majority of these pre-ESRD educators use the Internet to get information about dialysis and other medical issues or for personal use. Only a few had used the DFC website, however. Websites cited by participants as helpful for dialysis-related issues included the following:

- Dialysisfinder.com (the most frequently mentioned website)
- Therenalnetwork.com
- ESRD networks' websites
- Health Care Financing Administration (HCFA) website
- Medicare.gov
- Dialysis Facility Compare website

- Kidneyschool.com
- DaVita.com
- various search engines
- Tristate website (Indiana, Illinois, and Ohio)
- Renalmd.org
- Renalnet.org

Other information sources for these pre-ESRD professionals included the Dialysis & Transplant List (an annual issue of *Dialysis and Transplantation* that lists dialysis facilities), professional journals, textbooks, class curriculum, seminars, network list, staff colleagues ("word of mouth"), and in-service training.

6.1.5 Exploring the DFC Website: Expectations

We asked participants what they would expect from a website called "Dialysis Facility Compare." We also asked if they were aware of the DFC website before this study and if they had ever used it before the study.

Responses were split on whether participants had heard of the DFC website before this study, with four "yes" and four "no." Only three respondents had actually used the website.

Expectations for the DFC included a comparison of facilities across a range of data. As one participant commented,

> *Compare means exactly what you're saying, compare is putting them in a class where you can judge one is better than another, or pick out certain features that are important to you and select on the basis of that.*

Other expectations for the website included information about staffing, patient ratios, number of chairs and doctors in the facility, and other areas. One participant commented that she expected the website to *"compare not only the physical layout, but also hours, flexibility, docs, staff, nurses, chairs."*

6.1.6 Exploring the DFC Website: Facility Characteristics

We used a computer during these interviews to show participants the DFC website live on the Internet. On the overview page, we showed them the list of facility characteristics and asked how they thought that information would be useful to patients who had to choose a dialysis facility.

These pre-ESRD professionals generally reported that information on the facility characteristics would be useful for patients. One thought that the information in this section could be retrieved from other sources: *"That information I can get by going onto the Network website. The ESRD Forum, and then you go to the states. You can find that information."*

In fact, the facility characteristics information available on the DFC does not seem to be available on the Network Organization websites. A check of the website for Network 1 revealed that data on individual facilities is very limited, with facility-specific data only on numbers of patients by modality.

The Network 9/10 website has some additional data on individual facilities, including the number of shifts and days of the week the facility operates, the number of hemodialysis stations, deaths, and transplants. This includes some data not available on DFC but also lacks some of the DFC facility characteristics, such as facility ownership status. However, for each facility the data are presented in tables focusing on one variable at a time for all facilities, rather than all variables for an individual facility as is found on the DFC website. As a result, the range of data for a single facility is much harder to find than on the DFC.

6.1.7 Exploring the DFC Website: The "Read This" Paragraph

We showed participants the "Read This" paragraph on the overview page of the DFC website and read it to them aloud. We then asked for their reactions. (A copy of the paragraph is included in Chapter 2.)

The majority of the pre-ESRD educators thought that this information could be confusing to the average patient. One participant expressed concern that sometimes patients "*don't know what they are looking for, so sometimes they don't ask the appropriate questions."* As one participant suggested, many patients do not have enough insight to know there is *"more to the picture."* This respondent thought that more of an explanation is needed for patients on how this information would be useful to them.

Participants also noted that patients might not know the meaning of some of the terms used, such as "ESRD" or "ESRD Network." As one commented,

> *ESRD should be written out. They probably don't know what the "ESRD Network" and "survey agencies" are, so that might be a little confusing to them [patients]. The patients are confused, this is the first time they have heard these terms.*

In addition, it was mentioned that many patients may not have a lot of education. As a result, the information may be difficult to comprehend.

These comments are consistent with others from the site visits that stressed the need to bring down the reading level of the explanations and information on the website. Our initial analysis puts it at about the 12th grade level, mainly due to the large number of medical terms. We plan to look into ways to revise the text passages on the website to bring the reading level down to the 6th or 7th grade level, if possible.

In general, participants understood and liked the message that patients should visit facilities and talk to staff before making a decision about which facility to choose, rather than relying solely on data from the DFC website. They also liked that the paragraph emphasizes making patients more proactive by getting them more involved in their care and talking over their concerns with their doctors.

6.1.8 Exploring the DFC Website: Quality Measures

We showed participants the list of quality measures on the overview page of the DFC website and asked if they had discussed those measures with patients. We also asked how that information would be useful to patients who had to choose a dialysis facility.

These pre-ESRD professionals generally thought that the information in this section would be useful to patients. As one participant stated,

> *I think that it might give them a feeling of comfort if the numbers looked good. It also might have them question a physician as to why they're sending them to this facility vs. another facility. The problem is that patients are still really afraid to question the physician. I encourage them to talk to their physicians about certain things.*

Different respondents reported discussing survival, URR, and anemia with patients, but none reported discussing all of the measures.

One participant mentioned that some of the information may be difficult for patients to understand:

> *I think the second part, the quality measures are very good, but most patients wouldn't understand what a URR is. Again I understand the percent patients treated with Epogen, but I think they would understand the patient survival information most.*

6.1.9 Exploring the DFC Website: Links of Interest

We showed participants the links on the overview page of the DFC website and asked which links they would like to explore. Several links were selected by the participants. The Dialysis Publications and Related Sites link was mentioned most often as being interesting.

The dictionary of the National Institute of Diabetes & Digestive & Kidney Diseases (NIDDK) was mentioned as being useful, especially for patients. As one participant stated, *"There [are] a lot of people who don't have a medical background and don't know what these terms mean."*

The Helpful Contacts were also viewed as positive. Other links mentioned were the Facility Compare Database, the Glossary, and the Mailing List.

We also asked these interview participants to assess the DFC's Glossary definition of adequacy of dialysis. Most participants thought that the explanation given would be difficult for the average patient to understand:

> *Too much "garble." They will not understand this. The first paragraph would lose me completely.*
>
> *I think patients just reading it on their own, it's still a little bit difficult to understand. I'm not judging the people I see, but most of our information is geared at a fifth grade level. I think this is above that.*

One participant thought that this section provided too much information for pre-dialysis patients: "*I am not sure they need all that information, pre-dialysis. I think it is a little overwhelming to a non-professional.*"

These comments regarding the Glossary definition of adequacy are consistent with concerns raised by dialysis professionals in our companion data collection efforts. They also indicated that the material may not be understandable to many patients. They noted that the presentation of the material added to the difficulty, with dense paragraphs of text that are hard to read.

6.1.10 Exploring the DFC Website: How Is the Information Useful?

We asked participants how the information would be useful to them in teaching kidney disease education classes to their pre-ESRD patients. Many participants thought the information would be useful for varied reasons. Comments included the following:

> *Would put it on my list of resources. This would be helpful to those patients that research. [Patients would appreciate] knowing the different types of units. Location of the units.*
>
> *I think if they knew their doctor was at this facility but wanted to find something closer to home.… I could tell them about the website and if they don't have a computer, I could print the information off.*

One participant thought that the information would not be very useful for pre-ESRD patients: *"Would not really use it for pre-ESRD because they are not at this stage yet."*

It appears that the DFC website does have potential for use in pre-ESRD education, especially if materials are added that are relevant to that population. We believe that there would be substantial benefit to getting patients and family members involved with the DFC website at this early stage of their disease. In this way, the potential for patients to be more involved in their treatment decisions, and more involved in self-management, would be presented to them earlier and could be reinforced more often.

Participants recommended a number of facility characteristics and quality measures that could be added to the DFC website to make it more useful. They are included below.

6.1.11 Scenario of Moving to a City in Florida: Facility Characteristics

We presented participants with a scenario in which a patient would be moving to a specific city in Florida and needed to choose a dialysis facility in that city. We walked participants through the process of identifying the dialysis facilities available in that city using the DFC website. We selected four facilities and showed participants the facility characteristics using the website. (We pre-selected the four facilities to ensure they varied on several characteristics, including size, ownership status, availability of evening shifts, and chain membership.) We asked participants what the information told them about those four facilities.

Most of these pre-ESRD professionals liked the detailed information on the website regarding facility characteristics. In particular, they liked the data on evening shifts, nonprofit vs. for-profit status, size, number of units, whether HD or PD are offered, and whether home training was offered.

Several participants commented that they liked knowing which facilities are nonprofit: *"I think nonprofit might provide better service, because they're not worried about money. I mean, of course they are, but I think patients might choose that."*

Several recommendations were made at this point for additions to the website. They are also included below.

6.1.12 Scenario of Moving to a City in Florida: Quality Measures

Continuing the scenario of moving to a city in Florida, we showed participants data on each of the three quality measures for those same four facilities. (The facilities were also pre-selected to ensure they varied on the quality measures, including adequacy, anemia, and patient survival.) We compared the results for those four facilities with each other and with the national and state average data also available on the DFC website for each measure.

One facility (Facility A) was selected because it was much higher than the others—and higher than the national and state averages—on both adequacy and anemia. Another (Facility D) was selected since it was significantly lower than the others on patient survival. A third (Facility C) was selected because its results showed all of the quality measures as "Not Available."

We asked participants what the information on the quality measures told them about those four facilities. We also asked what they would say to patients about the quality measures. Most participants thought the information was useful:

> *This is a good thing to show.*
>
> *Scary for some patients to look at this information, but I would definitely like to look at it.*

Some of these pre-ESRD professionals mentioned that, although the data were useful, patients may not be informed enough to look at quality information and would still focus more on facility characteristics at this stage:

> *This means nothing to them. A lot of this stuff is told to them, but they do not retain it.*
>
> *I don't know how many patients would want more information. You will have the patients who want to know everything, nurse/patient ratio, how clean is the unit, what does it look like, colors, is it easily accessible from the highway.*
>
> *[This would be useful] if the patient knew about quality. Because I'm guessing that once patients find out where [the facility] was, they may not look at quality.*

Participants again recommended a number of quality measures that could be added to the website. They are described below.

6.1.13 Most Important Information

We asked participants what they thought was the most important information on the DFC website. Anemia and survival were mentioned most often. Others thought all of the quality measures were important.

One participant mentioned that anemia was important but was unsure the average patient would understand its implications:

> *For me, the anemia, because I know those studies exist. But it won't be helpful for the average person who would pull this up. I think it's helpful maybe to social workers, or maybe for a very well-educated and astute person who's done a lot of research and is seeking information. On the whole, I can't think of a whole lot of patients who would benefit.*

Several participants indicated that selected elements of the facility characteristics were most important. Several suggested that location is most important to the patients, since the convenience of the facility is key for them: *"I think location and phone numbers and the information about every one of them. The other stuff is added information."* In addition, the contact information was seen as important.

6.1.14 Does the DFC Website Meet Participants' Expectations?

We next asked participants to think back to before we showed them the DFC website, when we asked what information they expected it would provide, and asked to what extent the website had met their expectations.

All of the participants who responded to this question stated that the website did meet their expectations:

> *Did meet expectations, I'm surprised that I didn't know about it. I feel dumb that I didn't know about it. This would almost make me want to go to it and run off all the information on ours, do a little research for a patient in a particular zip code.*
>
> *It's an excellent site. It's a good site.*

Two participants that indicated that the website generally met their expectations but thought there were other things they would like added.

6.1.15 Content of the DFC Website—How Would Participants Use It and Recommend It?

We asked participants how likely they would be to use the DFC website in their everyday practice and what they would use it for. We also asked under what circumstances they would recommend the website to other pre-ESRD professionals and under what circumstances they would recommend it to pre-ESRD patients and family members.

Most participants agreed they would use the DFC website in their everyday practice to locate facilities in the area and obtain data for patients:

> *I would use it. Probably, again, when patients ask me to help them find a unit, or for someone in the pre- class, I would use it as, "this site is out there" and give it as one of the four that I usually give.*

Some participants also mentioned that they would use the website to gather information to compare facilities:

> *I think I would probably use it to at least get the information so I would have it. We do a lot of data comparison, and if we had some outliers that didn't seem to match, I might look up a facility to see where it falls. I only have one or two patients in each facility. We also try to see how we can impact hospitalization.*

Most participants stated that they would recommend the website to their colleagues. Reasons cited were to compare their facility to others, for job hunting, or just for an information source:

> *I would say if a friend of mine was looking for a job I might have her look at this to see how a facility does!*
>
> *They should compare their unit to another unit.*
>
> *I would make sure all the doctors knew about it. They should be aware of the site and look at the information on it.*

Most participants would also recommend the website to patients, especially patients who were going to be traveling, moving, or faced with a decision about where to obtain dialysis care:

> *Anyone who is going to choose a dialysis therapy is going to have to look at this.*
>
> *I will make sure my patients know about this site. If they travel, you will want to know where all the dialysis facilities are.*

6.1.16 Content of the DFC Website—Is It Complete?

We asked participants how complete the DFC website seemed to them. Six of the seven respondents to this question thought the website was complete or fairly complete. Specific responses varied from "more than adequate" to "not complete." For example, one participant stated, *"I think it's complete. I think that is what Medicare's looking at, probably, and it meets Medicare's needs."*

One participant thought that the website was not very complete and suggested that information on whether the facility accepts transients be added. Another participant, who thought the website was fairly complete, indicated that adding a map as well as information on the "*not-availables*" would be useful.

A number of suggestions were made at this point regarding data elements that could be added to the website. They are included in Section 2.19.

These results are somewhat more positive in comparison with the findings from the data collection conducted during the site visits. Those respondents expressed ideas for many additional data elements they would like added to the website. Few viewed it as complete in its present form, although most viewed it as useful or as a good beginning. In contrast, these pre-ESRD professionals may be viewing the website as more complete from the perspective of their patient population, considering its lower level of knowledge regarding kidney disease and dialysis. Nonetheless, these participants also suggested a number of additions to the DFC website.

6.1.17 Content of the DFC Website—Is It Up-to-Date?

We asked participants how up-to-date the DFC website seemed to them. The majority of these pre-ESRD professionals were concerned with the age of the data. Most wanted more recent data to be used and suggested that 1-year-old data would be much better than the 2- to 3-year-old data they saw on the website:

> *This info is outdated.... 3 years old is old data.*
>
> *Not [up-to-date]. It's going back to 1998 to 2000 data. I'm assuming by now that if they're going to update, they should be able to pull in 2001 to 2002 data.*

A few participants suggested that the website data were adequate:

> *Well, I think it's as up-to-date as it's going to get, because I know where the Medicare data comes from.*
>
> *I think it is updated more than enough.*

CMS staff have noted that the new VISION information system, currently under development, will address this issue. Once completed, it should substantially improve the timeliness of the DFC data. Although it does not appear that this issue is considered vital by all potential DFC users, many see it as an important concern, and any improvement will increase the face validity of the DFC.

6.1.18 Internet Access

We asked participants what ways they thought patients could access the Internet in order to use the DFC website. Two participants stated that computers were available at the dialysis facilities for public use: *"All of their facilities have computers, if they couldn't get it [the Internet] at home."*

Two participants stated that the patients could use their computers to access the website or that they could print out hard copies from the website to give to patients without access:

> *I could sit down and if the patient didn't have any access to the Internet, I would run this off for them for their zip code or geographic location, give them a hard copy and they could look at it with their family.*

Other participants stated that they sometimes refer patients to libraries or coffee shops. Most participants stated that patients might not use the Internet or be computer literate even if there were places available to them: *"We're going to have a computer in the lobby. I don't know if I have anybody who will know how to use it."*

6.1.19 Other Information Participants Would Like to See on the DFC Website

As part of the scenario of moving to Florida, we asked participants what additional information they would like to have on facility characteristics and quality measures for the four facilities they were comparing. We also asked again, at a later point in the interview, what other information they would like to see on the DFC website, including information about dialysis facilities, kidney disease, or links to other websites. As noted, participants also volunteered suggestions for information that could be added to the website in response to other questions. We combined all of those recommendations into this section.

Numerous suggestions were made for adding data elements to the website, including additional data on facility characteristics, quality measures, and dialysis- or health-related information. The specific recommendations are listed below in these three categories.

Facility Characteristics

- Indicate the affiliation of facilities with hospitals. (This was a frequent comment.) As one participant stated, *"Patients like the hospital-based better. Gives them a sense of security."*
- Include the hours of operation. (This was a frequent comment.)
- Include facility capacity.
- Add staff-to-patient ratios. (This was a frequent comment.)
- Add information on whether staff are full or part time.
- Include the name and background of the medical director. (This was a frequent comment.)
- Add listings of staff doctors, social workers, and dieticians.
- Include information on the education and certification of staff.
- Add pictures of the inside and outside of the facilities.
- Include shift times. (This was a frequent comment.)
- Include the name of a contact person at the center. (This was a frequent comment.)

- Add information on whether the facility allows self-care. As one participant put it, "*CMS licenses centers for self-care. You have to have policies and procedures in place and make a request for certification. You have to show that you trained them and they performed correct needle placement. As the staff shortage gets more acute, you'll see more PD and more self-care.*"
- Include a map search function.
- Provide information about group counseling or diet classes at facilities.
- Provide information on the availability of TVs—individual or group. (This was a frequent comment.)
- Add information about transportation options at facilities.
- Add information about support groups in the area.
- Include information on whether facilities are affiliated with nursing homes.
- Include the number of patients in a facility, as well as information about patients such as their average age.

As also noted in our companion reports, the intensity of interest in staffing ratios has been noteworthy throughout this study, including both the site visits and the telephone interviews. This may reflect concerns about shortages of nurses and other trained staff, and the temptation to rely on lower-paid staff, such as technicians, to provide more care to boost profit margins.

In this regard, Medicare's Nursing Home Compare website may provide a useful model for DFC. Nursing Home Compare includes several types of staff-to-patient ratios, including RN hours per resident [patient] per day, LPN/LVN hours per resident [patient] per day, and CNA hours per resident [patient] per day. In that way, prospective patients and their family members can clearly see the allocation of resources from the most highly trained staff (RNs) to the lowest trained staff (CNAs). Although nursing homes may have different types of reporting requirements than dialysis facilities, that website at least demonstrates the potential for reporting these types of data through a Medicare website.

Quality Measures

- Include dialysis-related infection rates. (This was a frequent comment.)
- Provide information about quality control measures that monitor anemia, etc.
- Report albumin levels for PD and HD patients.
- Provide information on parathyroid hormone (PTH) and C-reactive proteins.

Additional Dialysis- or Health-Related Information

- Include a short list of questions for patients to ask their doctors.
- Provide information about PD and HD, including the advantages and disadvantages of each.
- Include information regarding diabetic and hypertensive care.

- Provide family-related information, including risk factors.
- Include links to ikidney.com, www.renalmd.org, www.renalnet.org, or kidneyschool.org.
- Provide information on vascular access.
- Include information on transplant survival.
- Add information on patients' rights and options. As one patient put it, *"Understanding that their physician may like them to go to a [particular] facility but they still have the right and the option to visit facilities and make a decision."*

6.1.20 How Medicare Could Let Dialysis Patients and Family Know About the DFC Website

We asked participants about the best ways for Medicare to tell dialysis patients and family members, and other pre-ESRD professionals, about the DFC website. Suggestions for *"getting the word out"* to these two groups are presented in two categories below.

Dialysis Patients and Family Members

- Provide information in clinics and nephrologists' offices. (This was the most frequent comment.)
- Use magazines, such as *Modern Maturity.*
- Provide a 1-800 telephone number for information.
- Include flyers in mailings from Medicare or Social Security.
- Develop TV commercials about the website.

Dialysis Professionals

- Pursue contacts through the Networks, with mailings, e-mails, etc. (This was the most frequent comment.)
- Send letters or e-mails directly to professionals.
- Place advertisements in medical journals.
- Send information to social workers to disseminate.
- Contact professionals through the Medicare manager billing service.
- Provide information in journals, such as Nephrology News & Issues.
- Include postings in the break room.
- Provide information booths at conferences.
- Have organizations such as the American Nephrology Nurses' Association (ANNA), Council of Nephrology Nurses and Technicians (CNNT), or National Kidney Foundation (NKF) include DFC information at their booths.

- Provide the medical directors of clinics with information to disseminate to their staff members.

6.2 General Themes

The interviews we conducted with pre-ESRD professionals also included several more general themes. They cut across the more detailed issues presented in the last section.

6.2.1 Much of the Clinical and Quality Information May Be Too Complex for Pre-ESRD Patients

The pre-ESRD professionals thought that, although the information on quality measures currently on the website was important and should be important to patients, it may be too new for them and, hence, too difficult for them to understand. Dialysis patients may be better able to understand the information due to their experience of dialysis treatments. Indeed, we found that many of the dialysis patients in our site visits were receiving monthly “report cards” that included adequacy, anemia, and other lab values. They also received explanations of those data from their providers, which helped them to better understand the information they saw on the DFC website when we presented it to them.

The pre-ESRD professionals also stressed that many of the clinical and medical terms used and the topics of the website may be unfamiliar to pre-ESRD patients just learning about their kidney disease for the first time. For example, some may not understand what “ESRD” means. We also noted the limited knowledge of pre-ESRD patients in our focus groups and triads with them.

Moreover, patients may still be in denial about the seriousness of their medical problems. As a result, they may resist learning about the future treatments and the future complications of their illness that they are facing. This could cause them to become frustrated with the DFC website if they view it as too complex or too technical. They might give up on trying to learn from it too easily.

These concerns lead us to recommend that a specific “tab” or “link” be placed on the home page of the DFC website that is clearly identified as providing information focused on pre-ESRD patients and family members. It could provide resources focused on learning about the basic issues in kidney disease. It might also provide links to websites that provide on-line support groups.

For example, information geared toward pre-ESRD patients is currently being developed by the American Association of Kidney Patients (AAKP) as part of its “Kidney Beginnings” program. Its website includes a booklet, magazine articles, and a past issue of an electronic newsletter. Other websites and other pre-ESRD resources could also be located in this special section of the DFC website.

In addition, the home page of the DFC website should provide a brief explanation of the purpose, use, and functions of the website as they relate to pre-ESRD patients and their families. We believe the home page needs to engage patients of all types more actively, to encourage broader levels of utilization of the website. Patients need to understand up front why they should care about using the DFC website and the types of benefits it can provide them. This may be especially true for pre-ESRD patients, who may be nervous about their disease and unsure if the website is aimed at them or not.

6.2.2 Pre-ESRD Education Programs are Still in Their Early Stages of Development

We found a fair amount of variation in curriculum and teaching methods among the eight pre-ESRD educators who participated in our interviews. It seems that there are no standards or criteria for pre-ESRD education available at present.

Notably, at least two of the participants reported conducting "as needed" education based on what they believed the patients needed. This was sometimes a single, one-on-one session.

Nonetheless, some of the educators had systematic programs for their pre-ESRD education. We know of some other programs that are well established, such as the pre-ESRD education provided by Southern California Kaiser Permanente. It may also be that the new emphasis on pre-ESRD issues at AAKP and NKF may lead to additional educational materials and curricula. Recent efforts to develop renal disease management programs may also lead in that direction.

The variety and flux in these programs may indicate a need for additional testing of pre-ESRD materials with pre-ESRD patients and family members. There is less consensus on the types of materials that would be most valuable for pre-ESRD patients. This contrasts, for example, with the general agreement on the value of data on dialysis adequacy and anemia for quality measures aimed at dialysis patients.

Despite these challenges, we believe that pre-ESRD patients are an important audience for the DFC website and deserve special consideration. Pre-ESRD educators were aware of the limitations of their programs, so they might be willing to consider ways of supplementing them with the DFC. The goals of increasing patient self-management and involvement in decision making may be best achieved by involving patients early on in the disease process, in the pre-ESRD stage. In that way, the expectations and habit of active involvement can start early and be more easily sustained after the transition to dialysis.

6.2.3 There Is a Need to Increase Use of the DFC Website by Pre-ESRD Professionals

Most of our pre-ESRD professional participants stated they would tell patients about the DFC website by mentioning it in their classes and that they would add it to the resource lists that they give to patients. However, many stated they were not sure how many patients would use the website.

Several respondents mentioned other websites that they believed were easier to access and had similar information to the DFC website. As noted, several respondents suggested that the DFC website was too complicated to use for patient education right now.

Given this situation, we believe it will be important to find ways to increase use of the DFC website by pre-ESRD educators. That will be an important method for increasing utilization of the website by pre-ESRD patients. It may be that a special section or “tab” targeted to pre-ESRD issues, as recommended above, would help in this effort.

Another approach could be to develop DFC-based modules or scenarios for pre-ESRD educators to use in their classes. A module could provide the educators with some examples of how to apply the DFC website in their classes. It might include pursuing links to educational resources or an exercise of investigating dialysis facilities in a new city to which patients might be moving or traveling. It could also provide patients with an advance “preview” of the facilities in their area, to help them begin the process of considering where they might choose to receive their treatments in the future.

A more modest approach might be to provide educators with examples for demonstrating some of the capabilities and links provided by the DFC website. Instead of simply listing the website in a longer list of resources, the examples could get patients more involved in “hands-on” exploration of the website during or after the pre-ESRD classes. In that way, patients would be more likely to return to the website since they would be familiar with the site and its potential benefits.

CHAPTER 7
REPRESENTATIVES OF DIALYSIS FACILITY CHAINS, DISEASE MANAGEMENT ORGANIZATIONS, AND MANAGED CARE ORGANIZATIONS

This chapter presents our findings from analysis of the data we collected from representatives of dialysis facility chains, disease management organizations, and managed care organizations. As noted in Chapter 1, a total of 18 representatives from those organizations contributed comments in the telephone interviews conducted with these respondents.

This chapter includes two sections. The first presents detailed issues. It is structured around 14 analytic categories, each including one or more key issues studied through a set of questions presented to the participants. The second section presents more general themes that we identified through analysis of respondent comments. The themes cut across the more detailed issues presented in the first section.

7.1 Detailed Issues

For each of the 14 categories in this section, we provide an overall report based on participant responses, followed by discussion of differences, if any, by the type of organization represented. Throughout the chapter, we offer illustrative quotes from participants to represent the points of view discussed. These quotes were selected to exemplify the general themes being presented.

7.1.1 Prior Use of Dialysis Facility Compare

Of the 18 participants, 7 had not visited the website before we contacted them for this study. Those who had not visited the website were split between health maintenance organizations (HMOs) (4) and disease management firms (3); all of the dialysis facility representatives had visited the website. The reason most frequently cited (by 6 respondents) for not visiting the website was not being aware that it existed. Some also noted that it would more likely be used by others in their organization (their staff, or staff on the clinical side rather than the business side).

Among the 11 respondents who had visited the website previously, reasons for use varied. Some visited out of curiosity—“*to see what’s out there.*” Several respondents from dialysis facility chains mentioned visiting the website to look at the data, to compare it with their own data, or to assess its accuracy. Respondents from both dialysis facility chains and disease management firms discussed visiting the website to learn more about dialysis facilities in their region or to analyze the market, as in this description:

> *The purpose of going to the website was to try to identify who were the owners of facilities in a certain region of the country, how many facilities were in that area, what were the capacity of each of the facilities, who had the market share of the dialysis patients, not the number of facilities, but the actual market share of patients in that area, and, like you say, the corporate owners of the facilities.*

As for how the information on DFC had influenced their organization, the most frequent response was that it had not influenced the organization. Market analysis was noted by one representative from both a dialysis facility chain and a disease management firm:

> *Well, ... I look to see other doctors on the list that are practicing nephrology in my market area that I don't know, that I need to go talk to, that I need to learn about. So it helps me to expand the physicians that I talk to. And as far as centers, ... using the idea of how many centers are in a particular zip code, for instance, or in county, and then, is there room for another center? Do I want to look at a center that's just an independent, that's not part of a chain? Do I want to go talk to them about possibly selling? So there's a few different ways I use the information.*

This reference to the other doctors on the list pertains to other information on the Medicare.gov website, rather than information on the Dialysis Facility Compare website.

These findings suggest that CMS has been successful in raising awareness of DFC among dialysis facility chains. Outreach to other organizations, such as HMOs or disease management firms, could increase website use, especially among the disease management firms, which identified a clear use for DFC in market analysis.

7.1.2 Expectations of the DFC Website

Most participants were not able to articulate their initial expectations; in some cases it had been a year or two since they had first visited DFC, and so some difficulties with recall were to be expected. Most respondents reported that they had no expectations or it was as they expected. Only a handful deemed it either better or worse than expected. We saw no pattern of responses by organizational type or participant role (business or clinical leader).

Two respondents reflected in different ways on what it meant to have no expectations:

> *I don't know that I had any specific expectations, to be very candid. In looking at it, it was all new for me, for the first time, so I went into it with really no expectations, other than here's a potential resource tool. And basically, from that perspective, I'd say it met the expectation. But, you know, if you ask if I went in, what did I expect, I didn't really have any expectations, and I was pleasantly surprised by the level and quantity of data that was available.*
>
> *If you have no expectations, you're never disappointed. And, you know, I felt it's another measure. I didn't think much of it either way.*

Some respondents commented on the ease of navigation or accessibility of the site, as in this comment from someone who had not visited it before being contacted for the interview:

> *We were actually very excited about the website, that we didn't know it was there, but that it had some information that was, even for the health plan, was interesting to be able to see, and compare facilities and some outcomes data. So we went in there and, you know, pretended to be our beneficiary and looking up for facilities, and local areas, and it appeared to be pretty user-friendly.*

Others were pleased with the content that they found and did not distinguish between DFC and other information on the Medicare.gov website in their appraisal:

> *Actually, I thought I would just get a listing of centers. I never expected the doctor information [on Medicare.gov], and I also never expected the compare feature. So those were two big surprises for me.*

Not all comments were favorable, however:

> *My expectations. The first time,…I didn't know what to expect, and so I was just looking to see what was there. Then it seemed like just the ease of it [I] didn't see, it seemed like a lot to go through to get to the comparison. And I think it has a lot to do with the structure of the actual Medicare page, but you had to learn that first, and then I went there. And there are a lot of disclaimers throughout the whole thing, which you have to keep reading to figure out where you're going.*

Respondents' difficulty elucidating their initial expectations may be due in part to recall issues. However, for those whose initial visit was more recent, these findings suggest that there is room for improvement in the naming and marketing of DFC to give first-time visitors a better sense of what to expect. Visitors do not seem to be accessing the website with a clear idea of what they will find, and some needed to explore quite a bit to discover the purpose and capabilities of DFC. Although renaming the website may not be feasible, CMS should consider developing a concise and accessible statement of purpose that would engage visitors as soon as they arrive at the home page.

7.1.3 Reaction to DFC Website Materials

The great majority of respondents were positive in their initial assessment of the DFC materials, with no association between their assessment and organization type or respondent role:

> *Well, it gives the basics that you'd like to know about … what the size is, and what the ownership situation looks like. It also has some of the basic quality data … included in it. There are perhaps other quality features that one would like to have, but they're going to be harder to get. In fact, that's the next level of scrutiny that we do as part of our job.*

Others remarked on how easy the website was to use:

> *My overall impression is that CMS has done a very good job in making their websites very user-friendly. In fact, you know, it's not what you would expect of a quote, bland and drab webpage, unquote. I mean, there's color, it's easy to navigate the webpage, the search engine within the webpage itself, the search help, is good, the site map. I think the banner down the side that has the frequently asked questions and the highlights are very helpful. I would just say … it's a user-friendly website.*

However, another point of view was less positive:

> *Overall, my only comment is, again, it seems like for only three indicators, you have to go through a lot to get to those three indicators. I understand you have, and there are a lot*

> *of words in between what you have to do from one button to the next, and all that kind of stuff. So I may get, if I wasn't used to websites, I may get lost.*

Facility Characteristics

Respondents were mostly positive in their assessment of the information on facility characteristics. An HMO staff member saw it as useful from multiple perspectives:

> *I thought it was very good information, for both on the plan side, as well as on the member side. I thought the information was a little more pertinent to the plan, like the ownership, that kind of information, more so than the members. But the information that's there for the members, in particular, how many beds, the shifts, I think that was very good.*

The presence of the ownership (for-profit/nonprofit) indicator sparked differences of opinion over the importance of ownership:

> *I know that the facility ownership, even though a lot of other people don't know it, has been the subject of investigations and reports on whether they're meeting the kidney quality standards, that the non-profits have generally been better than the profits, at the … and, you know, infection rates, like that. But I don't know that a lot of other people know that. So to me, it would be of some interest, but maybe not to the general public.*
>
> *Ownership type, with putting that in, is initially prejudicial and I don't see what any value of that is, but it's a prejudicial comment.*

Others noted that these structural characteristics can and do change:

> *Well, I suspect that the facility name and address hasn't changed, but I know that facilities get bought up fairly quickly and treatment stations are really dependent upon what their staffing is. They may have done peritoneal dialysis when they got their license, but they may not be doing it now, those kinds of things. So I'm not so sure how accurate those kinds of things are, a moving target in time.*

Other concerns raised included the fact that the website did not note days of operation, although it did provide information about whether evening shifts were offered. In addition, a few respondents wanted more information about ownership of facilities that were not in chains, and one noted that initial date of Medicare certification *"is a meaningless thing to even me, or patients."* These responses did not vary by organizational type.

The varied reactions to the inclusion of facility ownership in DFC echo some of the discussions in site visits, particularly among dialysis professionals. This suggests that there may be some benefit to explaining the meaning and intent of this item. Although DFC does contain an explanation, it is clear that many of our respondents did not pay close attention to it. Some of that may be attributable to inattention on the part of the user; however, it also suggests a reconsideration of the way in which that information is presented to facilitate visitors' grasp of the issues.

The issue of what services the website says the facility offers (e.g., evening shifts, peritoneal dialysis) versus what is actually available is another item that was raised by other groups. Because real-time updating of these facility characteristics may not be feasible, an alternative would be to explicitly acknowledge that certain characteristics may have changed and to encourage patients to contact the facility for more information. Although that message is present on the website (in the "Read This" section), it is clear that many visitors are not fully absorbing the message.

Quality Indicators

For the most part, respondents' initial reactions to the quality measures were positive. Most were pleased to see outcome measures on the website:

> *That's the most important thing, really, is how good the outcomes are.*
>
> *Oh, well, that's excellent, because that's what everyone uses. Those are the benchmarks that everyone works off of. The dialysis chains compare themselves against those benchmarks. I mean, basically you're looking at USRDS-type of data, and so that's what everyone is basically saying, how do you compare against a benchmark? And so, when you see where individual dialysis facilities fall out, that's very helpful.*

They recognized that the amount of information that could be presented on the website was limited; that is, participants did not expect that DFC would include all the quality measures that are available:

> *Well, I think they're very limited, but again, I know how difficult it was just to get these chosen and agreed upon. So I think that they're limited, but they're of some value to patients trying to select a facility.*
>
> *Well, I thought the quality indicators are certainly what we're looking for, although there are only three, and we, obviously, expand the quality indicators. But, of course, I felt like you just really zeroed in on the top, you know, the most important three.*

Some noted the value of presenting the data so that an individual facility could be compared with the state or national average:

> *The quality indicators, I like them because they go with the state. It shows you the national average, for the national rate, the state rate, and then it gets down to the individual facilities. So that's kind of nice.*

However, others expressed concerns about the quality measures. Some recognized that the nature of their work made them more likely to question the data or to ask questions about risk adjustment and other technical details:

> *I think the indicators were fine. ... Because of my position here, ... when we look at data, we always want to know the sample sizes, we want to know all kinds of things. So I'm not sure it was that useful to me.*

> *I mean, that was one of the things that was difficult for me to figure out was, how they actually calculate those measures and what they're using for those measures. That wasn't particularly easy to find. Well, how did you get this information and how did you calculate it? And then, when I did find out, it was generalizations of generalizations, and so I didn't think it was very accurate for that reason.*

Another concern was whether these are the right quality measures to include:

> *The adequacy measure, we've done so well in the United States that I think it becomes sort of a measure that, I don't know if it's going to be of any great significance. I guess it shows significance in those few units that are terrible at it.*

This issue of the amount of variation in the quality measures arose in telephone interviews with national renal organizations as well. Although the majority of dialysis facilities in the United States are meeting quality standards, we found that many respondents in our study (patients, in particular) did notice the outliers when we presented them with DFC quality data in scenarios for choosing among several dialysis facilities. Nonetheless, it may be useful to detail the range of results to be found on the DFC website (perhaps as an adjunct to the national and state averages for each quality measure); this could put the limited results that any individual user may review in a broader context.

The responses to the quality measures were not associated with organizational type. The concerns about how the measures were calculated may reflect the relative sophistication of these respondents, although they are similar to comments made by some dialysis professionals during the site visits. Because methods for calculation and risk adjustment may not be of interest to all DFC visitors, it may be worth including a hyperlink to a more detailed explanation for those visitors who would seek more information. We present respondents' discussion of other ways to measure quality below.

Links to Other Sites

Few respondents had explored the links in detail. Some explained that this was due to time constraints; others noted that they were not seeking additional information:

> *I may not be your typical user. I mean, I'm pretty familiar with the renal websites out there, and I've got most of them bookmarked, so if I stumbled across it in here, I'd use it. But otherwise, I have the stuff that I frequently use bookmarked.*

One pointed out that renal professionals have different informational needs:

> *Okay. ... When I went in, what I want to see is a link. I know this is also a patient-oriented ... type of website, but I would think it could be enhanced by making it a dual website, and making it a professional website also. Because like I say, I'm a professional. I'm in there, I'm looking for discovery. But yet, ... it would have been nice to go from there to the American Journal of Kidney Disease, or it would have been nice to go [to] Nephrology News & Issues.*

They generally offered positive assessments of the available links, both in theory and in practice:

> *Having a website where the dialysis patient can go and then, and their caregivers and family members, and have supporting links, is just absolutely a marvelous resource.*
>
> *Yeah, I noticed there were a lot of sites recommended there. I didn't really get to go to many of those, but it looks like, I mean, to me, it looks like there's a pretty broad spectrum of sites that are available to patients to link to.*

These responses reflect two schools of thought among these participants. One is that, as professionals, they have other sources of information and so would not expect this website to provide links appropriate for professionals. The other perspective is that it would be useful to include links that would meet professionals' needs as well as patients'. This could be done without compromising the patient focus of the website by adding links to professional societies or journals, for example.

Explanations of Terms

Not all respondents had reviewed the explanations, either due to lack of time or because they were already familiar with the information:

> *I didn't read it. ... I mean, I'm a nurse and everything, so I already know about what's done.*

The great majority offered positive assessments of the explanations:

> *That's very good. ... I understand this. I like the explanations. You know, it's just a reminder. The happy consumer, if his physician had not really gotten into this with them, they may get a little lost. ... You have to have a little bit of education to understand what you're reading. You have to know about your disease. ... However, ... you do have a glossary that tries to help you. You do have a nice question and answer section that also tries to help you, as far as understanding terms.*

They recognized that explaining complex elements necessitated a more advanced reading level:

> *Well, I would say this is really more like a twelfth-grade level, more than eighth grade, probably. The one I'm looking at is on the explanation of URR, which is probably a little difficult for most patients. ... On the other hand, they [will probably be] a better educated patient or family member. And, you know, they're going to want to have more specific information. It's very hard. As a writer of patient education material, I know that you have to make choices, and there's no exact right way to do it, you know. ... So my feedback to you then, after thinking about it, is that this is probably appropriate. Maybe a little bit too high level, but I think it's pretty good.*

However, the minority opinion was that the information was not useful:

> *Basically, superficial and did not provide any great insight for the average patient.*

These comments, which did not vary substantially by organizational type, are consistent with findings from site visits that the reading level of some of the DFC materials may be too advanced for some users. These respondents also recognize the challenges in presenting material to patients that is both accurate and accessible.

Once again, a tiered approach could be considered. The basic explanation on the website could be simplified, while links could be provided to access more detailed information.

7.1.4 Timeliness of Website Content

In this section, we discuss the issue of how up-to-date the DFC website seemed to participants. We also address the issue of how frequently the content should be updated. A few did not notice the age of the data on the website: *"Oh, it seemed to me that it was updated in March, so I thought that was pretty up-to-date."*

However, most noticed that many data elements were at least 2 years old. As one respondent pointed out, this is particularly problematic in web-based information, as people often have expectations about information on the web being up-to-date that they do not apply to print materials. Several respondents were pragmatic in their assessment of the timeliness of the data:

> *You know, I've dealt in other jobs with Medicare information, so I know not to expect anything that's very timely. ... I don't mean that insulting at all, but that's just the way it is.*

> *You know, I'd love to have the data from just right now, the last six months, on there to see, okay, how are we doing, that sort of thing, but I know that that's unrealistic, that that can't be done. So I think, as far as compared to other things, I think it's pretty up-to-date.*

Others pointed out specific drawbacks to posting data that may be 2 or more years old:

> *Well, I think that, you know, since the dialysis market is quite volatile, and that one company is eating up another company and then spitting them out the other door as a different name, that I think it probably needs to be looked at quite a bit.*

> *That's frequently a comment, I think, from providers is, the data is old, and we're doing a whole lot better than that now. It doesn't reflect the current situation in the facility.*

However, there was a difference of opinion on the rate at which the quality of care could change:

> *My big criticism of this site is one you'll hear from everybody, and that is, it's out-of-date information. But, you know, with all that in mind, you're not going to turn mortality rates around that quickly, you know what I'm saying?*

When we probed for how often the data should be updated, responses ranged from quarterly to annually. Respondents from dialysis facility chains noted that they report data more frequently:

> *I think, you know, ideally one quarter behind, two quarters at the most. Two years is a tad too long to make, you know, two years really makes this useless data.*
>
> *We are required to report information to the Network, you know, our local Network. Well, we're required to report by a certain time. And I can tell you, there's not that big of time lag in there.*

One additional suggestion was that the website note not only when the data were last updated, but when they would next be updated as well; this might serve the secondary purpose of encouraging return visits to the website.

> *So maybe the frequency of update would be helpful, too. Instead of, you know, last updated, maybe it could say, next update, June 1st, or whatever.*

Providing more timely information on DFC is a concern to many users, especially those from dialysis chains, who are well aware of how frequently they report data to CMS. Although some of these respondents recognize the challenges in keeping data up-to-date, it is clear that improving the timeliness would increase the face validity of DFC.

7.1.5 Understanding of Website Content

This section summarizes participants' comments about how understandable the website seemed to be. Most responded from the patient perspective, that is, noting how easily a patient or family member would be able to understand and navigate the website. A few were able to discuss separate audiences:

> *Well, as I said, [my colleague]'s a nurse, and I'm a pharmacist. So from our perspective, it was very understandable. We're not laypeople, so it was very easy to follow and understand. ... And although it does link you if you have questions, it does. And I read the definitions, and they were to the point that I felt a layperson could understand.*

The majority opinion was that the website was very easy to understand. Only one respondent voiced a negative opinion:

> *I understand it all. Everybody in our company who works with that, you know, all our [staff] would understand it. But for the average patient, you know, I'd give it a C.*

Ease of navigation was closely linked to respondents' assessment of how understandable the information on the website was:

> *I think it's very easy to access. The drop-down menus are, I mean, you can walk through it. You don't need to be very computer savvy to understand how to use it.*

However, others were able to separate navigation from content and expressed concerns over the former rather than the latter. As one noted, "*I have to work to get it, but I can get it.*" This respondent believed that getting to the clinical indicators required too much scrolling, including passing contact information and explanations (described as "*a bunch of the same stuff over*").

Overall, some respondents found the website accessible and understandable, with others suggesting simplifying content or navigation. The concerns about scrolling, in particular, echoed those expressed by some patient focus group participants, who also pointed out the odd (to them) placement of explanations relative to the findings.

A menu of hyperlinks at the top of the quality measures webpage, with links directly to findings farther down the page, might be a workable solution. We have engaged in some preliminary discussion with CMS web development staff regarding this alternative, and they have indicated that it may be possible.

7.1.6 Relevance of Website Content

In this section, we focus on the perceived relevance of the DFC website to respondents and their organizations. We found a difference of opinion, with about twice as many respondents deeming the information relevant as questioning its relevance to their work. In assessing its relevance, respondents sometimes spoke to specific uses, as discussed above. A disease management organization representative noted one use:

> *Well, because of the peculiar nature of what we do, which is respond to health plan requests to explore whether we are going to do a management relationship for the dialysis patients, it is, at least, an initial way of figuring out what facilities exist in the geographic area that we're potentially going to work in. That is, now it's a quick and dirty way to sort of get some baseline information. I wouldn't write a business plan necessarily, based on just this base, but it gives you the baseline information you need to at least make your preliminary steps.*

A representative from a managed care organization discussed another:

> *It's relevant for the purpose of, I mean, we have, you know, quality measures here, obviously. We have standards for the facilities that we contract with, and it would be a good quick reference to say, okay, we know that this facility is CMS-approved and has the things that we're looking for. It's a good quick reference, I think.*

Respondents from dialysis facility chains were more likely to question the relevance, insofar as they have access to more (and more timely) data:

> *You know, it's not really relevant, because we have our own, you know, CQA-, CQI-type of QA, QI program.*

Although the chains did not find the DFC content especially relevant to their work, it is clearly pertinent to the work of both HMOs and disease management firms. This suggests that CMS could increase DFC use by raising awareness of the website among those organizational types.

7.1.7 Completeness of Website Content

Many respondents offered positive assessments of the completeness of the website. Others had mixed opinions, depending on the perspective they took, and a few had negative opinions. For some, this issue was tied to the discussion of relevance:

> *For my needs, I don't know that I have any needs for that website, to be honest with you.*

The question of the intended audience arose again:

> *Well, the website wasn't designed for me or for my needs, so that's a little bit of a funny question. You know, I think, again, it fulfills the needs of those it was designed for, that is, patients and family members. In terms of my role as [clinical leader], which is why I was selected for this, I don't think it fulfills my needs very well, in terms of screening dialysis facilities, because of the limited quality data.*

One respondent offered useful insight about the issue of completeness:

> *There's no such thing as a complete website. I would never score someone on that basis. I think it is an appropriate website. I think to categorize it any other way would be inappropriate and a disservice. So what I prefer to leave it as is, I think it is an appropriately adequate website.*

As the last quote points out, it is not necessarily appropriate for DFC to strive to be complete. That might lead to a website that contains too much information for the intended audience and, hence, is less user-friendly. These responses highlight the need to reinforce the message on DFC that the website itself is not intended to provide all the information necessary to select a dialysis facility.

7.1.8 Quality of Care

Respondents indicated that they routinely examined adequacy, anemia management, and patient survival (or, more often, a standardized mortality rate) in considering quality of dialysis care. However, more respondents used the measure Kt/V than the urea reduction ratio (URR) in assessing adequacy. Anemia management had several variations: more used hemoglobin than hematocrit, and several looked at other measures of treatment for anemia in addition to the proportion of patients on Epogen.

Several other quality indicators were mentioned by five or more respondents:

- albumin
- calcium phosphorus
- vascular access type
- various indicators to assess cardiovascular health (e.g., blood pressure, cholesterol)

Three or four respondents cited the following as measures they examined to assess quality of dialysis care:

- patient adherence to treatment
- hospitalization rates
- infection rates

Other indicators mentioned by just one respondent included transplant rates, transfusion rates, patient quality of life, patient satisfaction, health outcomes and quality of life (e.g., SF-36), staffing ratios, disease management (e.g., monitoring vaccinations, diabetic foot exams), the type of dialyzer used, and compliance with paperwork.

Respondents' reactions to the three quality measures currently in use on the DFC website were relatively positive. The majority believed that the existing measures did a fairly good job of reflecting the quality of care:

> *Again, I think from my standpoint, it seems to me it covers the quality quite well. I'm not sure what other measures you'd put on that would be ... really meaningful to all patients, in general. ... There may be some patients, depending on where they have an option of going, or where their provider has talked to them about certain things they should look for, you know, that are important to them, that might be on an individual basis. There might be some other quality measures that a patient might look for in individual cases. But as a whole, ... it seems to cover really the most important and the most general quality measures a patient could look for.*

Several expressed the opinion that more quality indicators are needed and that the current ones do not capture all the relevant aspects of quality:

> *I mean, I think they're a piece of it, but ..., obviously, we think there is more than that. Do we want to report that to the government and have it on a website? I don't know, I guess we could. But just three of those is to say, how well is your community if you look at the roads, and their sewage treatment, and their schools.*

Different opinions surfaced regarding the number of measures that should be included:

> *I think these are probably, if you're going to start with three, you'd start with these three.*

> *I think getting that one measure that, you know, most patients can relate to the fact that, when they were in school, they either got an A, B, C, or D, you know, in school. And having one number just makes such a whole lot of sense to me.*

With regard to the specific measures, some respondents favored Kt/V over URR as an indicator of adequacy:

> *I think URR is not adequate anymore, because if somebody is dialyzing frequently, their URR doesn't have to be as high. For instance, in our unit we have many patients who dialyze four to six times a week, and so their URRs don't need to be as high, especially the six- or five-times-a-week patients. Those URRs are going to be low. So Kt/V, I think, is a better indicator, total delivered Kt/V is a better indicator than just URR.*

Others pointed out issues with using hematocrit and not hemoglobin to assess anemia:

> *And then, of course, hematocrit, ..., I think I would look at hemoglobin models, because, again, hematocrits are very influenced. Because if they happen to draw them prior to dialysis, you get dilutional effects, you get concentration effects at end of dialysis. ... My understanding of the industry, they're leaning towards hemoglobin.*

In addition, several respondents noted general concerns about using outcome measures as indicators of quality of care provided in a facility, insofar as outcomes are influenced by multiple factors:

> *There are a lot of factors, you know, that go into other measures that, when you just do the average or whatever, it may not be as meaningful. For instance, with hemoglobin, that's something that the facility or the doctor, you know, pretty much can manage. But when you talk about other measures, like perhaps calcium and phosphorus, a lot depends on the compliance of the patient. Are they taking their medicines, are they eating like they've been directed?*
>
> *One of the big problems that I don't think we've been able to solve yet is, some facilities, like an inner-city facility that has poorly educated and socially disadvantaged patients, do have a harder time getting good outcomes, because the patients come in much more ill to start and it's hard educating, getting the patients and families to cooperate. So such facilities may be doing an admirable job, yet their mortality rate is higher than we like it to be. But that's beyond their ability to control. Same thing with URR and hemoglobin. So, you know, the limitation, I think, is in that, these measures don't directly allow you to take into account the patient base you're working with. This was discussed long and loudly at the stakeholders meetings. And in the end, we agreed that some measures are better than no measure at all. But I think that, it still bothers me that, you know, this is something that, this is to respond to your question, how well do I think this really reflects quality of care?*

Respondents suggested several additional quality indicators, including nutritional parameters such as albumin, bone disease management indicators, vascular access, and patient satisfaction:

> *I still think that a real key here is patient satisfaction, because we're very provider-focused as well at what we do, I certainly want to know about provider satisfaction. But what's really, really important to me is, is the patient satisfied? To me, that's really going to indicate whether they're going to do well overall. ... If they're satisfied, feel like their needs are being met, it's a very good marker.*

Finally, one respondent spoke about the value to the dialysis industry of having quality indicators available publicly:

> *I think they're essential. I think they push the facilities to achieve the best possible outcome. I think the concept of a rising tide lifts all boats, one of the reasons why I spoke about looking at more outcome or more diverse basis of outcome, is because it gives the*

> *opportunity for a greater review process. And in so doing, it stimulates the response from the dialysis facilities to enhance the outcomes.*

This echoes comments from providers in our earlier site visits. Several of them noted that public reporting of quality data will motivate providers to work harder to achieve better outcomes. Just knowing that the data are being published can be a useful incentive for quality improvement that can benefit many patients.

These respondents are well aware of the challenges of measuring quality, from risk adjustment to developing reliable measures that capture facility-level quality independent of patient-level factors. They suggested refining the current measures as well as considering additional ones. They also raised the issue of the optimal number of quality measures to report.

In considering improvements to the website, CMS should continue its analysis of patients' understanding of these quality measures and consider expanding it to ascertain how many quality indicators would be ideal. It may also be useful to consider whether creating a single summary score would be beneficial to patients.

7.1.9 Use of the Website for Patient Education

In this section, we present participants' thoughts on how helpful the information on the website was for patient education. Many respondents' initial reaction was that it was very helpful. However, as they discussed the issue, it appeared that they believed that the information presented on the site was consistent with and reinforced other patient education materials. One characterized it as *"informational, not educational."*

Only a few were able to articulate ways in which the information could be used for patient education. One respondent discussed it for pre-ESRD patients:

> *I think it would be very helpful, extremely helpful. If you're in predialysis and you knew that you would end up without kidneys, I think you could be starting to choose where you're going to go. And I think they should look at it, but I don't think they do, quite frankly. The problem is that, patients who have kidney failure get into denial.*

This may be an issue to raise with the DFC Consumer Workgroup and at the Stakeholders Meeting next spring. It would be interesting to hear their views on how best to improve utilization of the DFC by pre-ESRD patients and their family members. Many of the pre-ESRD participants in our site visits had little knowledge of kidney disease, dialysis, or dialysis facilities. They seemed to be a group that could benefit greatly from the information available to them on DFC. But breaking through their denial may be a challenge. Greater involvement of family members during the pre-ESRD phase might be one possible avenue.

Another participant noted a potential application for enhancing patient self-management:

> *I think it probably needs augmentation in just day-in and day-out, how do I deal with this? You know, should I, as a patient, have like a little mental checklist of what I ought to be watching for when I'm in the dialysis unit? You know, what's going on with me while I'm being dialyzed? Do I notice this time, do I feel any different than I usually feel*

> *during the dialysis? In other words, am I being adequately dialyzed? Is anyone here shortening the timeframe of my dialysis, and why is that? Am I being left for long periods of time, with no interaction with staff? I think there ought to be like a checklist, you know, we really want patients to be very proactive in their own care, because they're the ones who are right there.*

This comment indicates some of the potential benefits of the checklist development work we will be pursuing later in this project. Moreover, providing checklists on DFC could also enable greater involvement by family members.

Several respondents felt that the website was not well suited for patient education and did not believe it had been designed for that purpose:

> *I think it's a poor patient education tool. I think that, and I don't know that it was meant to be a patient education tool, I don't know. So I would give it like a C- as a patient education tool.*

Some wanted to see more educational materials, in part because of the special role that CMS could play in dissemination:

> *I would say [usefulness for patient education is] limited, given what this has here. I mean, I guess they could go into the glossaries, but there are much better websites from a patient education standpoint. You know, it's always hard to sort out, because if [one firm is] doing patient education, or [a chain] is doing patient education, you have to understand what their motives are. Whereas, CMS may be viewed as being sort of a point impartial, they don't really care what dialysis unit you go to when you start dialysis. They want to give you information to make that choice. If you're on a [chain] website, they're going to obviously direct or guide you into their own units. So it could be helpful, in the sense that its objective and people may trust it more.*

CMS is seen as an honest broker of information on dialysis and dialysis facilities. This perception, along with findings from our site visits, suggests that expanding the patient education focus of the website could be particularly valuable.

This suggests a need for enhanced explanation of how patients can use the DFC content—not just to select facilities, but to be active participants in their own care. It seems that a range of content could promote this goal, including links to other websites, checklists of questions, explanations of clinical terms, and other resources.

7.1.10 Use of the Website for Patient Care

Fewer respondents saw its utility for patient care than noted its value for patient education, and several responses to this query led to discussion of patient education rather than direct care. Several representatives from dialysis facility chains noted that the information on the website would be useful for patient care in a general approach to practice and quality improvement, as these quotes illustrate:

> *Well, I think for one thing, it lets us know quality indicators, what they are. So we can look and say, well, you know what, we're below the curve, we really need to fix this up. We're above the curve, we need to stay there. We need to become an example for other centers. So, you know, it gives you that little bit of a competitive edge, that you're, if you're willing to look at it and to use it in that respect.*
>
> *I thought that was also one of the things that was self-evident. The reason this is done is because you're creating an environment where no one wants to be last in their class. So everyone is striving to move up, in terms of their quality outcome. That has a direct correlation to patient care, in terms of how you deliver it, how it's received, and how much resources you put to it.*

The above quotes focus once more on the benefits of public reporting of quality data. That can have an impact on its own, in terms of motivating staff throughout an organization, in addition to the measurable impact on indicators. The following quote describes a complementary issue, that quality measures can help identify outliers, or patients that are far above or below the average for a given facility or national or state benchmarks:

> *The quality outcomes you've enumerated will sort of pinpoint whether there are potential problems in a facility. It would cause you to investigate why there are outliers, perhaps, present in the facility. It may not exactly pinpoint why ... there's more of the ability to flag that there are issues that need to be investigated, as opposed to identifying specific issues.*

Perhaps because they are directly involved in the provision of care, dialysis facility chain respondents were more likely than those from HMOs or disease management firms to note the links between public disclosure and efforts to enhance the quality of patient care. In its outreach to other organizational types, CMS should consider clarifying this issue and highlighting the intended benefits of public disclosure.

7.1.11 Making the Website Available in Spanish

All 18 respondents agreed that a Spanish-language version would be beneficial. Several were from areas of the country (e.g., New York City, South Florida) with large Spanish-speaking populations. Several noted that their companies made patient educational materials available in both English and Spanish (and, depending on the location, other languages as well) and pointed out the high incidence of ESRD in Spanish-speaking populations.

We recommend that CMS explore translating DFC into Spanish, as has been done with the Nursing Home Compare website. If funding is an issue, this could possibly be phased in over time, with the main webpages translated first and some of the FAQs later on, although it would probably be ideal to implement a complete translation at one time.

7.1.12 Future Use of the Website

Respondents were fairly evenly split between those who said they would use the website in the future and those who said that they did not know or that it was not likely. As with prior use, contemplated future use varied by organization type.

Respondents from dialysis facility chains discussed two uses: periodic comparisons of DFC data with their own data and research to facilitate recruiting nephrologists:

> *It may be something that I would look at to compare with our internal data. Our internal data is so superior that, other than that, I wouldn't have much use for it.*
>
> *When I'm talking to physicians and they say, well, why would I want to come to your center over somebody else's? I can say, well, our treatments are very effective. ... And I can use your website as reference. I can tell the physician if he's very interested in finding out who does what where, I can refer him to your website. ... It's a nice third party. I mean, we're not associated with [Medicare].*

Representatives from all three disease management firms discussed using the information on the website as a tool for exploring local markets:

> *Well, in the future, as we expand areas of the country where we are working with dialysis companies, I would want to go in and see, first of all, how many sites are available in a particular area and who is running those sites. Just from my experience, I know I have an easier relationship with some of the dialysis companies than with others, so this might help me to decide, you know, where I'm going to make my first contact. Plus, I like that you separate out the quality measures. I can get demographic information on dialysis sites, but then I get the quality measures that are obviously important to us and to our customers.*
>
> *So I can see, you know, looking at it to see how we or associated facilities are presented to the public. Secondly, it could be used as a way to screen for dialysis centers that we may be associating with, although I'm wise enough to know that, you know, if something looks questionable on these three quality measures, that doesn't mean that that's the whole story. And as a medical professional, I would go further into it then. I wouldn't rule anybody out, you know, based on this data, but it would be a way to just get some basic information on facilities that we might be looking at.*

Likely uses for managed care organizations included checking out dialysis facilities. However, these respondents were a little less specific about the type of information they would seek and how they would use it (one respondent referred to *"licenses, stuff like that"*):

> *…We have our own network, but for purposes of maybe, this is a facility that gets credentialed, and they want to be part of the network. It's nice to be able to see what kind of services they offer, ... what their data is like, what's their background, how do they measure up, compared to maybe whatever we have already in the network.*
>
> *We may be able to use it to identify potential new facilities that we'd want to bring on, based on population needs in a specific region.*

Respondents across organizations noted that they would refer their colleagues to the website. Likely colleagues included quality management staff in dialysis facility chains, and care management staff and provider relations staff in managed care organizations.

Those who were not certain about future use or said they would not use it tended to point out that the information on DFC would not be useful for their work:

> *We have our own CQA- CQI-type of projects here. I guess it could be used, comparing our units to other units in the state, but we get that information from our Network, so I don't need to go to the website for that. ..., it's the same or less of the information that I get from our Network, comparing with the state and then nationally.*

It is clear that DFC is potentially useful from a business perspective. Disease management firms and, to a lesser extent, HMOs represent a potential new audience for DFC. To promote business use, CMS should consider an outreach effort explaining the kinds of information available and the website's benefits to potential users.

7.1.13 Recommendations for Improvement

For the most part, respondents spoke from the perspective of patients; that is, they offered suggestions that would make the website more accessible or useful to dialysis patients, rather than to professionals like themselves. A minority opinion regarding the audience being addressed was expressed as follows:

> *I think it's almost 50/50, the person who's looking because they're on dialysis, and the professional who wants to find something out about their area for professional reasons.*

Most of the suggestions below were offered by one or two respondents, indicating a broad range of viewpoints about website improvement. One respondent noted the importance of clarifying the purpose prior to making improvements:

> *Well, you know, for me to answer that, I would like a clear definition of what the purposes are of it. If it's for patient selection, then, you know, it has to include more timely data, you know, more demographic data, things like that. If it's a goal to help the companies as a, you know, with keeping up with statistics, there's no reason. We're real time in our company, so it would be of no value. If it's for the facilities to keep up with statistics, again, we supply our facilities with all of that data. So, you know, I think they need to have a clear sense of what the purpose of it is. If it's a patient tool, then, you know, get some educators, some clinical-nurse-dietician-educators in there to really design it as a teaching tool, like we do with our education department. But if it's to really help us in the industry, the best thing you could do is have it go away, because we're ahead of you.*

Several suggestions had to do with format and navigation:

- getting rid of the left frame (which links to various other Medicare information sources)
- offering fewer "disclaimers," allowing readers to get to the information more directly
- reformatting the comparison charts to enable viewing more than two columns at a time

Others recognized that web-based information seeking would be new to some patients and suggested several ways to make it easier for them:

- explaining how to use the website, including hyperlinks and toggle switches
- offering a toll-free number so people can call and request that the information be sent to them in regular mail

A few suggestions had to do with adding capabilities. One respondent wanted a section for professionals; another suggested a mapping function that would allow users to enter an address and get a map to a facility or the distance to it. One respondent wanted the capacity to obtain aggregate scores for particular chains:

> *The one thing that would be nice when comparing the different units, it would be nice to be able to say, all right, you have all these units in this area owned by this company. Let's get an average of what this company does, because, you know, so many of these are owned [by for-profit] organizations now. ... So let's say that, let's compare the [chain]-owned units in this area to the privately owned units, you know, in some way that a physician or a consumer could say, okay, which of these companies, these networks, which of them really are doing a better job at taking care of their patients? Because that may be a reflection on the training of the nursing staff, how the unit's run, the physicians that are employed by these or contracted to be directors of these units. That would actually be very helpful.*

Finally, two respondents noted the need for more or better promotion of the website and its content. They suggested the American Association of Kidney Patients (AAKP) and ESRD networks as potential venues for informing people about the website.

The number and range of recommendations here indicate that participants see value in DFC and support its improvement. They have highlighted several of the navigational issues that RTI and other respondents have identified. Making the website more engaging to patients and family members and more accessible to them will likely increase use.

The particular challenges of presenting comparable patient satisfaction data are starting to be addressed by the CAHPS working group; we encourage CMS to continue its exploration of this possibility. The responses from our site visits indicated that data are potentially very engaging to patients.

7.1.14 Additional Information

We conclude with a discussion of other data elements that participants would like to see added to the website. Often these data elements or functions arose at several points during the interview; some have also been addressed in preceding sections. Comments were quite wide ranging; most issues were raised by one or two respondents.

The element mentioned most frequently (by three respondents) was patient satisfaction; respondents offered some interesting insights regarding this issue:

> *I wonder if there's something also to add about some type of satisfaction surveys, because all clinics do that. And I'm going to assume that all companies do that, as far as some kind of satisfaction surveys for their patients, you know, and rating it. Now, of course, you're always going to get the patient who loves everybody and the patient who doesn't like anybody. But I think sometimes with satisfaction surveys too, you might also see some trending.*
>
> *If I were a patient and I looked and I saw that they had a high hospitalization rate, mortality rate was so-so, but everybody liked being there and they felt that their quality of life was good, that would mean a lot to me in making a decision, yes. The problem will be getting the major providers in the country to agree on which specific measure...*

Various quality measures were suggested, including nutrition (e.g., albumin), vascular access, hospitalization rates, transplant rates, and parathyroid hormone (PTH). Respondents also made a case for adjustments for acuity.

All of these quality measures had been recommended by dialysis professionals in earlier data collection for this study, so these did not break any new ground. It is interesting to see that some recommendations have come up repeatedly, however, such as those for measures of transplants, nutrition, and vascular access.

A host of facility characteristics were recommended as additional data elements; each was mentioned by one or two respondents:

- whether the facility had a 24-hour hotline
- ownership (for facilities that were not part of a chain)
- patient demographics
- language spoken
- number of patients
- medical director
- days of the week the facility is open
- links to the facility's website
- staffing ratios
- staff turnover
- availability of social work and dietician staff
- frequency of physician rounds
- physician biographical sketch
- other activities at the facility (e.g., research)
- insurance/managed care coverage

- hemodialyzer reuse policy

These recommendations are also familiar from our other data collection efforts for this study. Again, several potential new facility characteristics have been mentioned frequently, including patient demographics, languages spoken, days of the week the facility is open, staffing ratios, staff turnover, and insurance coverage.

Finally, several respondents suggested adding information that could be used for patient education. Specific suggestions, each mentioned one or two times, included information on medication, diet, and treatment options:

> *The one thing is to make sure that there is education on different options for dialysis. And in those options for dialysis, to definitely put in the home dialysis options and options for nocturnal dialysis and more frequent dialysis.*

In addition, one respondent offered suggestions about other information sources to link to:

> *My interest and my focus would go towards the health information, and that seems pretty comprehensive if you know specific conditions. But then again, if you add something more general, like Healthfinder or the NIH site, ... but just to give people, maybe, a couple of direct links, Healthfinder.gov, NIH.gov, Medlineplus, perhaps. A patient could go into more of the articles….*

These suggestions were varied and dispersed. Many echo issues raised by other respondent groups as well.

7.2 General Themes

The telephone interviews we conducted with the representatives from dialysis chains, DMOs, and MCOs also included four more general themes. They cut across the detailed issues presented in the last section.

7.2.1 The DFC Website's Purpose Needs Better Explanation and Better Promotion

Respondents' difficulty elucidating their initial expectations may be due in part to recall issues. However, for those whose initial visit was more recent, these findings suggest that there is room for improvement in the naming or marketing of DFC to give first-time visitors a better sense of what to expect. Participants did not seem to be accessing the website with a clear idea of what they would find, and some needed to explore quite a bit to discover the purpose and capabilities of DFC. Although renaming the website may not be feasible, CMS should consider developing a concise and accessible statement of purpose that would engage visitors as soon as they arrive at the home page.

This issue was also raised with respect to particular data elements. For example, the varied reactions to the inclusion of facility ownership in DFC echo some of the discussions in site visits, particularly among dialysis professionals. This suggests that there may be some benefit in better explaining the meaning and intent of this item. Although DFC does contain an explanation, it is clear that many of our respondents did not pay close attention to it. Some of that may be attributable to inattention on the part of the user; however, it also suggests a reconsideration of the way in which that information is presented to facilitate visitors' grasp of the issues.

7.2.2 Few Differences Were Found in Responses by Type of Organization

We found few differences in responses by type of organization. With the exception of the issues of use, responses were quite similar across the organizational types. We would not have predicted this finding. It may reflect the fact that our respondents were high-level professionals with similar outlooks. In addition, we know that there is some mobility across these organizational types; at least one representative of a disease management firm had previously operated a dialysis facility chain, for example. Nonetheless, this suggests that the potential for business use of the website is broad and that CMS should be encouraged to promote DFC to a wide audience.

For example, the responses to the quality measures were not associated with organizational type. The concerns about how the measures were calculated may reflect the relative sophistication of these respondents, although they are similar to comments made by some dialysis professionals during the site visits. Because methods for calculation and risk adjustment may not be of interest to all DFC visitors, it may be worth including a hyperlink to a more detailed explanation for those visitors who would seek more information.

7.2.3 CMS Is Viewed as an Honest Broker of Information on Dialysis and Dialysis Facilities

Participants noted that many ESRD stakeholders are viewed as at least potentially promoting their particular interests in the data and information they provide on their website. In contrast, CMS is seen as a more objective source of information on dialysis and dialysis facilities. This perception, along with findings from our site visits, suggests that expanding the patient education focus of the website could be particularly valuable.

This also suggests a need for enhanced explanation of how patients can use the DFC content—not just to select facilities, but to be active participants in their own care. It seems that a range of content could promote this goal, including links to other websites, checklists of questions, explanations of clinical terms, and other resources.

7.2.4 Public Reporting of Quality Data Has Benefits for Quality Improvement

A number of participants noted the potential for enhancing quality of patient care by motivating dialysis facility staff through public reporting of quality data. This was also noted by dialysis professionals in our site visits. The natural competition of facilities and their staff in local markets means that they will strive to be viewed as the best in their area—or at least to avoid being the worst—and this will push them to work harder and make a range of improvements in care. Comparisons on the DFC to state and national quality benchmarks may also serve this goal.

It may also motivate staff to work harder on patient relations to improve patient compliance with treatment, since that is known to affect some quality measures such as adequacy. The resources devoted to patient care may also be affected, since facilities may have a range of alternate uses for available funds.

CHAPTER 8
REPRESENTATIVES OF NATIONAL RENAL ORGANIZATIONS

This chapter presents our findings from analysis of the data we collected from representatives of national renal organizations. As noted in Chapter 1, a total of 6 representatives contributed comments; they represented the NKF, AAKP, RPA, ASN, ASPN, and NRAA. ANNA was contacted, but decided not to participate.

This chapter includes two sections. The first presents detailed issues. It is structured around 14 analytic categories, each including one or more key issues studied through a set of questions presented to the participants. The second section presents more general themes that we identified through analysis of respondent comments. The themes cut across the more detailed issues presented in the first section.

8.1 Detailed Issues

For each of the 14 categories in this section, we provide an overall report based on participant responses, followed by discussion of differences by the type of organization represented, if any such differences emerged from our analysis. Throughout the chapter we offer illustrative quotes from participants to represent the points of view discussed. These quotes were selected to exemplify the issues and themes being presented.

8.1.1 Prior Use of Dialysis Facility Compare

Five of the six national renal association representatives had visited the website before participating in this portion of the evaluation. The one who had not visited previously was not aware that it was available.

The most frequently cited reason for visiting DFC was curiosity; three participants noted that they had visited to see what was available on the website. Some of these respondents had also been involved in meetings and discussions around the time of website development; this spurred some visits as well. A respondent from a national patient organization noted having visited in response to queries from patients or family members.

Three respondents were not regular users of the website. Among the three who were regular visitors, uses varied. Respondents from the two national patient organizations discussed seeking information on facilities that might be useful to patients, including those new to dialysis, traveling, or considering changing dialysis facilities. A respondent from a national renal professional association discussed using the website to check the accuracy of the information presented there; this use was spurred by finding some incorrect information on initially visiting the website.

Representatives from the two patient organizations highlighted ways in which the website had influenced their organization. One described it as a convenient way to access some information of interest to patients; another discussed the organization's efforts to inform patients about DFC through newsletters and in response to telephone queries.

We view these responses as encouraging for future efforts to promote use of the DFC website by patients and their family members. The patient organizations participating in these interviews are able to reach many dialysis patients nationwide. We believe there are a number of ways these and other patient organizations could increase the visibility of the DFC website. For example, the current (July 2003) issue of AAKP's magazine *aakpRENALIFE* lists the DFC website as a resource (along with several other websites) in an article on traveling issues for dialysis patients. However, the list of "Useful Links" on the AAKP website does not list DFC separately. There is a link to www.medicare.gov, with no mention that DFC is a part of that parent site.

Similarly, NKF's website includes a link to www.medicare.gov, but not to DFC directly. Moreover, the link to www.medicare.gov is included under "Professional Resources," instead of being highlighted as a patient or family resource. Encouraging direct links to DFC on these patient-oriented websites is one simple method that could increase patient use of DFC.

Participants from the four renal professional organizations said they saw no direct influence on their organization. As one noted:

> *We would never use this information to make decisions as an organization. I don't see how we could, because it is old data.*

However, one representative from a professional association did note the potential for some indirect influence:

> *Indirectly I would say that because of the results of those three parameters that are there, we feel that it tends to stimulate some positive quality improvement with some healthy competition. But that is very indirect.*

In previous reports, we noted that professional participants in the focus groups and interviews viewed the competitive effects of public reporting of the quality data as having a more direct impact on quality improvement efforts, as did the representatives from dialysis chains and disease management organizations. Many of them noted that they saw the DFC website as a way to check up on other dialysis facilities and to see how their facility stacked up against the others. Some pointed out that just knowing that the data were available on the DFC for public viewing would stimulate everyone to work harder. These comments indicated to us that public reporting of quality data can have positive effects on quality improvement through these effects on the professionals as well as through enhancing patient involvement and choice.

Half of these organizations had used the website in their work with their members. Both of the patient organizations had used the website in working with patients and family members; such use was described by one as follows:

> *I tell them some things they may be interested in because they don't use the Internet often. I don't share much about the quality usually. I'll tell them all aspects of what information is available and whether or not it is a hospital-based facility, profit or non-profit, and this helps them make their decision. I've never found someone tell me they're using it.*

Another patient association respondent noted the following:

> *Patients don't seem to be comparing facilities, though. They seem to be just looking up facilities near them.*

One professional association had discussed it with members:

> *They ask me, "Why should I go to it?" I say that I get useful information on what it is saying about their unit and what information patients are getting.*

The other three professional associations did not use it in working with their members and did not think that it would be useful to their members, whose information needs may be more detailed or sophisticated:

> *I think most medical directors of dialysis facilities get their own quality improvement results, patient outcomes and processes measures, from their own software and that the Dialysis Facility Compare website kind of pales in comparison to the amount of data that is generated by most dialysis facilities for internal quality improvement.*

Although this may be true for the most part when considering professionals' work with their colleagues on internal facility or clinical issues, these comments do not address the issues of professionals' roles as information intermediaries for patients and their roles in patient education. Those areas where professionals interact with patients represent other ways that professionals could use the DFC website.

8.1.2 Reaction to DFC Website Materials

Half of the responses to the information on the website were negative; the other half were tepid or mixed. This overall assessment was not related to the type of association (patient or professional). This was not consistent with our findings from interviews and focus groups with patients and professionals. Our analysis of the data collected in the site visits indicated that patients generally offered more favorable assessments of the DFC website than renal professionals. Patients demonstrated a hunger for information, and many patients viewed DFC as providing them with access to new information. It often seemed to provide them with a sense of empowerment or enhanced independence. This viewpoint does not seem to be reflected by the representatives of patient organizations involved in these telephone interviews.

Facility Characteristics

Responses to the facility characteristics were largely positive. Items receiving positive mentions included addresses, availability of evening shifts, and availability of peritoneal dialysis (PD) and home hemodialysis training. However, representatives from one professional association suggested that these structural measures may not capture the issues that are most important to patients:

> *Some of my patients would say that what they really want to know is: how are the TVs, are you allowed to eat in the dialysis unit, [...] They care about the things*

> *that are important to them at the interface with the dialysis facility—how often are they put on dialysis late, how often do they need to be taken off early, how often do they leave the dialysis facility feeling worse than when they came in.*

Issues of amenities and patients' experience of dialysis may not be directly measurable at this time; however, they touch on concerns that could be captured in assessments of patient satisfaction. These comments support the inclusion of patient satisfaction information on the DFC website.

One respondent from a professional association described the chain membership and ownership (for-profit or nonprofit) indicators as good information to have, but expressed uncertainty about how that information was helpful. This is consistent with our findings from the site visits. Although many patient, family, and provider respondents believed this was important information, we also found that it was subject to a range of interpretation and uses. Among dialysis professionals in particular, the value of knowing whether a facility was for-profit or nonprofit was hotly contested at times.

Respondents from patient associations mentioned modality issues. One noted that the website tells visitors what modalities the facility is certified to offer; this may be different from what they actually do offer:

> *For patients that do want to switch to some of the newer modalities, they may find that the facility is certified, but not if the facility is not offering it to them at that point. This makes it difficult for them to make a decision.*

Another noted that it would be helpful to have information about the availability of daily dialysis, whether at home or in the facility.

These comments echo those we heard during the site visits, especially from patients and professionals with experience with PD. They noted the need for more information about how many patients were taking advantage of the different modality choices available; this information would provide a context for decision-making. For any of the modalities with smaller numbers of patients participating (home hemodialysis, PD, or daily dialysis), information needs go beyond knowing whether the facility offers such treatments. Patients need to know whether and to what extent those modalities are being used.

Quality Indicators

The reaction to the quality indicators was mixed. Half the respondents offered positive comments, describing these as good or interesting indicators. One noted the value of being able to see how a facility compares on a national or regional basis. One person questioned the accuracy of the data, and another pointed out the age of the data. Two respondents (one from a professional association and one from a patient association) noted that there was not a great deal of variation in the measures, suggesting that they were not especially helpful for differentiating between dialysis facilities:

> *Either everyone is doing a good job or (from the point of view of selection), this is not a very useful tool.*

The issue of variation in the quality indicators is an interesting one. The anemia and adequacy indicators do show some variation, especially in those facilities that can be considered outliers. For the patient survival indicator, it is true that the great majority of facilities fall into the "as expected" category. Our experience with patient interviews and focus groups indicates that the data do give patients pause when they find a particular facility with quality indicators that fall at the extreme ends of the distribution. It may be useful to provide additional explanation of the range of results to be found on the DFC website; this could put the limited results that any individual user may review in a broader context.

One representative from a professional association raised concerns about whether the indicators adequately adjust for differences in the patient populations across facilities:

> *I don't think it's accurate to compare one unit to another when the demographics of patients are so different.*

It is not clear whether this comment represents a request for additional risk adjustment or a misreading of the ways in which the DFC adjusts for variations in patient populations. Risk is adjusted in calculating the patient survival measure; this remark may reflect a desire for risk adjustment in the other quality measures as well.

The discussion of age, race, sex, and diabetes risk adjusters is presented in several of the frequently asked questions (FAQs) for the patient survival measure on the DFC website, although users do need to click through to the FAQs to get that information. It is not included in the main quality measures page under the table with the patient survival data. It may be useful to at least give a brief description of the risk adjustment methods on the main quality page, to better ensure that users understand how those factors were taken into account.

Another professional association respondent addressed the issue of risk adjustment in greater detail, suggesting excluding from the denominator those patients who have exercised their right to choose not to adhere to recommended treatment. This respondent also stated that patients whose comorbidities could affect their clinical markers (e.g., hematocrit) should be taken into account in aggregate assessments. It is worth considering how risk adjustment could be applied to the adequacy and anemia measures; respondents in our site visits expressed similar concerns.

This association respondent further posited that quality indicators should meet several criteria. They should reflect a process of care that is within the facility's power to modify, and they should be operationalized by data that are rigorously collected, meeting standards of reliability and validity. This is acknowledged to be no small task:

> *I can't rattle off a list of markers that would work because this is a very problematic thing that a number of organizations have been grappling with and trying to figure out exactly what represents a true way of indexing quality of care.*

In our site visits, most respondents seemed to view the quality indicators as providing useful information regarding quality of care, although they noted that they are not perfect measures. This suggests that DFC should place some additional emphasis on the need for patients to review multiple sources of information on quality as part of their decision-making process, similar to the messages currently presented in the "Read This" paragraph on the DFC.

We present some additional comments from these respondents regarding other ways to measure quality below.

Links to Other Sites

Five of the six respondents had explored the links in some detail. They had mostly positive assessments of the links. Two pointed out the links to the end-stage renal disease (ESRD) networks and the state survey agencies as particularly useful; however, it is not clear whether they had explored those links, which do not take the user directly to those external sites. One mentioned the links to other Medicare sites (e.g., long-term care, enrollment) as especially helpful. Another noted the link to the Kidney Disease Outcomes Quality Initiative (KDOQI) website. A respondent from a patient association suggested including links to patient organizations; this individual mentioned a specific organization that is linked from the DFC, suggesting that she had not explored the links fully.

Explanations of Terms

Not all respondents had reviewed the explanations in detail. Their assessments were mostly positive, although representatives from both patient and professional associations expressed concerns about patients' ability to comprehend all the explanations. One respondent suggested that DFC users were not likely to be average patients:

> *[The explanations] certainly would be understandable to people who are smart enough to log on to a website.*

Respondents found the explanations of facility characteristics to be more accessible to patients than the quality measures. They acknowledged that it is challenging to provide explanations that are comprehensive and comprehensible, while noting the need to do exactly that:

> *I'm wondering how clear this information is for someone that has been just diagnosed with ESRD. Just looking at it, it looks difficult to read. I'm just wondering if there is a better way to explain this information. I just think if someone reads this, their eyeballs are going to cross. I think there needs to be a way for the lay person to understand this information.*

These comments are consistent with others from the site visits that stressed the need to bring down the reading level of the explanations and information on the website. Our early analysis puts it at about the 12th grade level, mainly due to the large number of medical terms. We plan to look into ways to revise the text passages on the website to bring down the reading level to the 6th or 7th grade level, if possible.

8.1.3 Timeliness of Website Content

One respondent pronounced the website "*pretty up-to-date*"; the other five found it outdated. Opinions differed on how often the data should be updated; several suggested that updates every 6 months or once a year would be acceptable, pointing out the increased emphasis on electronic data transfer with CMS. One representative from a patient association said that *"a facility can easily have changed in 3 years."* However, a representative from a professional association demurred:

> *Depends on what goals are, dialysis care is not going to change dramatically, rapidly. I don't think it has to be updated so rapidly because it's not going to change dramatically. It should be updated if new units open so people know what they are. Depends on what you're updating for.*

The mix of comments suggests that because data are reported often and via electronic means, they should be updated more frequently; however, facility characteristics are not expected to change, and even quality indicators may change slowly over time.

CMS staff have noted that the new VISION information system, currently under development, will address this issue. Many DFC users see the timeliness of data updates as an important concern, and any improvement will increase the face validity of the DFC.

8.1.4 Understanding of Website Content

All of the respondents found the DFC understandable, and two highlighted ease of navigation as a strength. One representative from a patient association had walked patients through the website over the telephone, finding it easy to use in that regard. In addition to the concerns discussed above about some of the explanations on the site, two representatives from professional associations mentioned a related issue: misgivings about patients' ability to understand what they should be getting out of the information on the website:

> *For hematocrits and adequacy, they understand the concepts, but not how it applies to them. They need to understand what their personal role is in making these numbers better. It explains what the concepts are, but not how it applies to them.*

That is, although patients may understand what they are reading, they may not understand what they should do with the information. This suggests that by expanding the explanations on the website, CMS may be able to serve the combined goals of increasing patients' participation in facility choice and improving patients' involvement with their care more effectively.

8.1.5 Relevance of Website Content

Participants generally agreed that the website was not especially relevant for renal professionals, in large part because, as noted earlier, they have access to more sophisticated and more detailed information:

> *My suspicion is that providers would use it primarily for the facility characteristic information. I don't think the quality measures would be helpful to a physician because they are already familiar with the quality of care they provide.*

Opinions differed with regard to how relevant the website is for patients. One representative from a professional association drew this distinction:

> *There are lots of other ways doctors can compare their sites. So the people who will benefit the most are patients and I don't know how relevant it is to patients. The kind of information they really want may not be readily available.*

Although a representative from a patient association said that the website is very relevant in terms of helping patients learn more about a facility, a professional association respondent said, *"I don't think these are the measures that are useful for selecting a facility."* These comments may represent an overstatement of the goal of DFC; participants did not seem to take away the message that the DFC data alone are not sufficient grounds for making facility choices. Emphasizing the points made in the "Read This" paragraph more strongly may help to mitigate similar misconceptions.

8.1.6 Completeness of Website Content

Over the course of the interviews, most respondents suggested additional data elements that they would like to see included; these are discussed in detail below. One of the six respondents pronounced the DFC website complete; the others were less positive in their assessments.

The respondent who found the website complete was from a renal professional association and made the following comment:

> *I thought it was complete. I think that for a person, assuming that this is being put together for patients and families, the facility characteristics are helpful because this is the logistical stuff that is helpful for people. The same thing goes for the quality measures. These are good for people that are trying to make an informed decision.*

The other respondents discussed various concerns. They suggested that more information is needed for patients and family members to make informed decisions. A representative from a professional association expressed concerns about both qualitative assessment and risk adjustment:

> *In order to view quality, you have to look at more than just the numbers. You can have very good numbers, but the facility may be dirty, or the staff has bad attitudes. This can also work in the opposite. There is a great unit that is very small, and any variation in the numbers makes them look [bad] (one patient's bad numbers make a huge difference).*

These results are consistent with our earlier findings. Other respondents also expressed ideas for many additional data elements they would like added to the website. Few viewed it as complete in its present form, although most viewed it as useful, or as a good beginning. Respondents suggested additional information that they would like to see; these issues are addressed below.

8.1.7 Quality of Care

Respondents enumerated a number of ways in which they and their associations assess quality. The following measures were mentioned by multiple participants:

- type of access, mentioned by three (from both professional and patient associations)
- infection rates, mentioned by two (from both professional and patient associations)
- amenities or accommodations available to patients, mentioned by two (from both professional and patient associations)
- frequency of care or physician presence, mentioned by two professional association representatives

The remaining ways of assessing quality were mentioned once. Some clinical outcomes were mentioned by both patient and professional association representatives:

- albumin levels
- potassium levels
- hospitalization rates
- mortality rates
- anemia rates
- adequacy

Others had to do with staffing and the process of care; these were also mentioned by both professional and patient association respondents:

- frequency of supervision
- ongoing input from ancillary staff
- staffing ratios
- availability of social workers

One respondent discussed adherence to guidelines generally, with a particular focus on processes of care that were linked to good outcomes. Other process indicators mentioned once included the following:

- educational services
- other patient services
- diabetes management

- cardiovascular disease risk reduction

Finally, a respondent from one professional association mentioned water quality, and another discussed patient satisfaction as an important way of assessing quality.

Respondents' overall reactions to the three quality measures currently in use on the DFC website were discussed above. Here we focus on their assessment of how well these three measures capture the quality of care in a dialysis facility. We have already established that all six national renal organizations examine a wider range of quality indicators to assess quality of care. Nonetheless, some did agree that the three quality measures currently available are important to consider. However, an equal number expressed the concern that these measures may not reflect the issues that patients think are important. As one noted:

> *We think it is important but I don't know if patients think it is important. When I hear patients complain, I never hear I don't like my adequacy, I hear I don't like the way they take me off, it's not clean, they don't check my medications, etc. My concern is: are you telling them what they want to know?*

This suggests that the DFC website could be a useful tool in explaining quality measures so that they may have more immediate appeal to patients. If one goal of the website is to enhance patients' participation in their care, then education about the importance of adequate dialysis is a valid approach, even if it is not something patients are clamoring for at the beginning. Moreover, we found many patients in our site visits to have a good basic understanding of adequacy issues if their dialysis facilities were among those that provided monthly "report cards" to patients on adequacy and a range of other laboratory test results. The more patients learned about adequacy and other clinical issues with direct bearing on their health, the more they appreciated their value. The DFC could be a means of reinforcing those messages or introducing them in facilities that are less active with patient education.

Respondents' suggestions for additional quality indicators are presented below.

8.1.8 Usefulness of the Website for Patients

Opinions on the usefulness of the website for patients were decidedly mixed; we heard positive and negative comments from both patient and professional associations. Some saw the website as a valuable resource for patients and their family members, helping them to understand their options and to ask better questions to make better and more informed choices:

> *This can be a really good tool. Patients and their family members really want a way to compare facilities. This would be good information if patients want to change facilities. They need to know that the website is available to them for information to help them make a better decision.*

However, others questioned its value. Some noted that patient choices are constrained by location, availability of shifts, and physician affiliation. Pediatric patients, in particular, do not have the range of options that adult dialysis patients have. Although the information on facility location and other structural characteristics was generally considered useful, the overall utility of the website was not rated highly.

Most respondents also noted that to their knowledge, patients were not using the website a great deal. The exception was a representative from a patient association, who reported that some patients were using the website to look for other treatment options (like home treatment) or to change facilities.

Respondents did not think that the website would be useful for patient care, having noted that renal professionals rely on more up-to-date and comprehensive reports on dialysis processes and outcomes. Opinions were mixed as to whether it was useful for patient education. Some saw potential, as in this comment from a representative of a patient association:

> *This is a good opportunity if the patient educator tells them about URR, and shows them how to use the website. This can be a tool, and used as an educational opportunity in the facility. It really depends on if the facility wants to use it that way.*

Others suggested that the website would need to be broadened to be a useful resource for patient education. A patient association representative suggested that each quality measure could have an educational component explaining why it is important. A representative from a professional association saw potential for a wider array of patient educational materials, including information on diet, hypertension control, and other aspects of patient self-management. These comments reflect the understanding that dialysis patients receive a great deal of information on their condition and their treatment, especially at the outset, when many are overwhelmed. The website can be a useful tool for reinforcing those messages throughout the course of treatment.

These comments reinforce the findings from the site visits, which included frequent recommendations for adding more patient education links or materials to the website. We believe they can serve at least three functions for the DFC:

- explaining clinical terms used in the DFC quality measures and facility characteristics
- enhancing patients' participation in their own care and adherence to treatment
- attracting more patients to the website, thereby increasing its overall utilization.

8.1.9 Usefulness of the Website for Renal Professionals

Participants' perspectives on how helpful the information on the website was for renal professionals were largely negative. As noted above, professionals have access to other sources of comparative information about dialysis facilities, including the ESRD networks and their own quality assurance and improvement reports. Within their own facilities, as one respondent put it, *"They know first hand the quality of care being offered."* The response from one professional association also suggested that lack of patient use diminished the usefulness to renal professionals:

> *Because it is not utilized very much by patients and families I don't think that has much of an impact either. It may have psychological impact but not one based in reality. Not having an impact of numbers of patients coming in and out the door.*

Respondents did not appear to consider renal professionals' role in promoting patient use of the DFC website, or the potential role of DFC in reinforcing the patient education messages promulgated by renal professionals. This suggests that CMS efforts to promote visibility of DFC among renal professionals should highlight its potential use in supporting renal professionals in their work with dialysis patients.

8.1.10 Ways to Raise Awareness of the Website

Participants offered several ideas regarding the best ways to let people know about the website. Most focused on raising patient awareness; a few addressed renal professionals.

Specific suggestions for letting patients know about the website, each mentioned once or twice, included the following:

- through patient associations, either via association staff in direct contact with patients or their publications (mentioned twice)
- through ESRD networks, which can let patients and providers know about the website (mentioned twice)
- through providers, who can tell patients about the website (one mention)
- through informational materials included in new patient packages (one mention)
- through flyers or posters at dialysis facilities (one mention)

However, one professional association offered strong cautions regarding patient awareness, pointing out the persistence of the "electronic divide," the limited access to the Internet among people of lower socioeconomic background, and the prevalence of ESRD in that population. In addition, written materials (whether in print or on a website) may not be suitable for the numbers of ESRD patients with visual impairments, low literacy levels, or English as a second language.

Renal professionals may find the website useful themselves; they may also be key conduits in letting patients know about it. To reach renal professionals, respondents suggested network meetings, network e-mails, and professional associations. Two representatives from professional associations also noted that improvements to the website might increase renal professionals' use of it; one pointed out that if professionals knew that the website would be updated periodically, they might be more inclined to check it again to review the latest information. Enhancing professionals' opinions of the usefulness of the website may also contribute to the goal of increasing their use of DFC in working with patients.

8.1.11 Making the Website Available in Spanish

We sought participants' reactions to the idea of making the website available in Spanish. Five of six were strongly in favor, noting the growth in that segment of the population and the number of requests they currently receive for information in Spanish. However, one respondent offered a caution:

> *It is the second language, but many of the Spanish population are not Spanish literate. So it might not be very helpful.*

This was the first time we had heard this particular note of caution, although issues of literacy and reading levels more generally had been raised before. Our other data collection efforts found strong support for providing the website in Spanish. This was especially true among Latino participants themselves.

Medicare's Nursing Home Compare website is already available in Spanish, so presumably the same technology could be applied to DFC. Each page of Nursing Home Compare has a button prominently placed in the middle of the top of the page that says "Vea en Espanol." When it is clicked, the page contents are translated into Spanish. We believe that approach would be a good one to apply on the DFC website as well.

8.1.12 Future Use of the Website

For the majority of the respondents, the intended future use mirrors the current use discussed above. Two respondents from professional associations highlighted the particular usefulness of the facility characteristics, and the respondents from patient associations both indicated that they would offer it as a resource to patients.

Half the respondents discussed ways they would use it differently in the future if the website were modified or improved. One pointed out that the website would be visited more often if the information were more up-to-date. A respondent from a patient association indicated that the website would be useful for promoting the goals of patient choice and self-management if it contained more information on the purpose and importance of patients being educated and engaged with their treatment.

In contrast, a representative from a professional association noted that future use for their membership was unlikely:

> *It would never take the place from a practicing nephrologist's point of view of the USRDS [U.S. Renal Data System] which gives you far more information. The focus of the site isn't the provider, it is for patients and family for selection. It is not focused on what the needs of the provider are and I am not sure that it should be focused on that.*

These comments support our finding that there is a strong potential for increasing the use of the DFC website and increasing its benefits to patients and their families, if a number of improvements can be implemented. It appears the improvements do not necessarily need to be dramatic. Some could be as simple as providing better explanations of the importance of patients' involvement with their care and finding ways to better engage potential users. In addition, clarifying how renal professionals can use this information in their work with dialysis patients could broaden providers' notions of the intent and usefulness of DFC.

8.1.13 Recommendations for Improvement

For the most part, respondents spoke from the perspective of patients; that is, they offered suggestions that would make the website more accessible or useful to dialysis patients, rather than to professionals. Their responses were rather widely dispersed.

Respondents from four of the associations (half patient and half professional associations) suggested some modifications in format and navigation that would improve the website and make it more accessible:

- allowing users to sort long lists (e.g., all facilities in a state) by zip code or city name, rather than by facility name (particularly germane to inquiries about metropolitan areas that span several cities and counties)
- enabling users to locate facilities near them based on mileage rather than zip code
- providing more interactive opportunities
- including links to facility websites
- including less text and more pictures
- listing Washington, DC, facilities under "District of Columbia" in the alphabetized list of states, rather than under "Washington"

These comments regarding website presentation reflect our own analysis. We are considering ways to make the site appear more engaging. Participants in the site visits commented that long paragraphs of text do not appeal to patients and may deter some visitors from exploring the website. Presentation issues are an important factor in our efforts to increase use of the DFC website.

One professional association's suggestions touched on some of the work of this evaluation; they suggested revising the content to make it more relevant to patients and their family members, perhaps through a market research process to determine what patients consider most relevant. They commented that CMS should assess the availability, reliability, and validity of the suggested data elements.

Another professional association stressed the need to provide more context for patients so that they understand what they are supposed to glean from the website and how the information applies to them.

8.1.14 Additional Information

Often, recommendations for additional data elements or functions arose at several points during the interview; many have been addressed in detail in the preceding sections. Comments were quite wide ranging; most issues were raised by just one or two respondents.

Staffing issues were mentioned most frequently and were raised by both patient and professional associations. These included the following:

- staff-patient ratios (four mentions)
- staffing patterns (e.g., how many nurses, technicians, etc.) (two mentions)
- frequency of physician (or physician extender) rounding (two mentions)

The level of interest in staffing ratios throughout this study has been noteworthy. This may reflect concerns about shortages of nurses and other trained staff; it also reinforces the message that staff are a critical component in patients' experience of dialysis care. Here again, Medicare's Nursing Home Compare website may provide a useful model for DFC. Nursing Home Compare includes several staff-to-resident [patient] ratios, including RN hours per resident per day, LPN/LVN hours per resident per day, and CNA hours per resident per day. In that way, prospective patients and their family members can clearly see the allocation of resources from the most highly trained staff (RNs) to the lowest trained staff (CNAs). We acknowledge that nursing homes may have different types of reporting requirements than dialysis facilities; however, that website demonstrates the potential for reporting these types of data through a Medicare website.

Several treatment issues were suggested for inclusion by patient and professional associations, each receiving one mention:

- treatment options actually offered
- patient rehabilitation services available
- availability of night shifts
- availability of daily dialysis
- peritoneal dialysis parameters
- rates of referral for transplants

A few quality indicators were mentioned by both patient and professional associations, with vascular access mentioned twice, infection rates once, and unspecified indicators consistent with the KDOQI guidelines raised once.

Several suggestions had to do with patients' experience of treatment; these were raised by both professional and patient associations, and each of the following was mentioned once:

- cleanliness of the facility
- machine issues: what kinds are in use and reuse policy
- length of treatment sessions
- patient accommodations (e.g., policies regarding food, visitors, and the like)
- patient satisfaction

Although we lack methods to directly measure some aspects of patients' experience of treatment (e.g., cleanliness), assessing patient satisfaction may capture some of these related issues as well.

Finally, one respondent noted that pediatric patients had special information needs and that they and their family members would appreciate information that may not be relevant to adult dialysis patients, such as the availability of school support and presence of other pediatric patients. This raised the question of whether there should be a separate dialysis website for children and their family members.

8.2 General Themes

The telephone interviews we conducted with the representatives from the national renal organizations also included several more general themes. They cut across the detailed issues presented in the last section.

8.2.1 Clarifying the Intent and Purpose of DFC

This issue arose at several different points in the current series of telephone interviews. It has not been directly addressed by other respondents in this evaluation, however. These respondents may have been attuned to this, given their organizations' previous involvement in formative work on the intent and design of the DFC website.

We consider this to be a useful point to address. The home page of the DFC website provides only a brief explanation of the purpose, use, and functions of the website. We believe the home page needs to engage patients more actively, to encourage broader levels of utilization of the website. Patients need to understand up front why they should care about using the DFC website and what benefits it can provide them.

For example, the home page could present the broader goals of Medicare and the DFC for

- promoting broader roles for patients in understanding and managing their own care,
- encouraging greater participation by patients in care planning and treatment decisions, and
- fostering better collaboration among patients, family members, and professionals providing dialysis treatment.

Clearly, DFC is not intended to address all aspects of those issues, but its contribution to them can be stressed.

The home page could also address why patients should care about choice of dialysis facilities. It could point out that dialysis facilities vary in many ways, just as patients do, and stress the importance of finding a facility that is comfortable for each individual. Some patients may want to focus on quality measures; others on facility characteristics or amenities. With DFC, they can begin their investigations of these issues in a systematic way. DFC will not be able to provide all of the information patients need, but it can provide some of it. DFC can also help provide patients with contact information so they can continue their search through the facilities themselves.

The home page could also discuss the types of educational information and links available in DFC and in www.medicare.gov more broadly. Patients can find definitions and explanations of the often confusing medical and technical terms they are faced with. This can help them to feel they have more of a say in the care they receive and a better understanding of it. They can also learn to see DFC as an information resource and as a source for reliable information about dialysis care and kidney disease that parallels that available from their dialysis facility or physician.

In sum, there are a number of ways in which the explanations of the purpose of the DFC website could be enhanced. This could help encourage more patients to use it actively. In addition, this would aid in clarifying to renal professionals the intent of the website and how they can help patients use it.

8.2.2 Current and Potential Use of DFC by Renal Professionals

Responses to questions on several topics suggested that renal professionals do not yet view the DFC website as a resource they can offer to patients or as a vehicle they can use for patient education. They correctly view the website as targeted mainly toward patients and family members, noting that professionals have many other sources of information that are more geared to their needs, such as internal systems of dialysis chain corporations, ESRD networks, and the USRDS. However, in these interviews they did not discuss the potential role the DFC website could serve for professionals in aiding their work with patients and family members.

This leads us to consider the need for marketing of the website to include messages focused toward professionals that emphasize that potential role. This would be consistent with their roles as “information intermediaries.” Several nephrologists in individual interviews during the site visits conducted for this study identified the website as having good potential as an aid to patient education. They indicated that the limited time they have with patients often makes it hard for them to provide the kind of education they would like. Some of that may be supplemented by nurses, dietitians, and social workers, but they saw the DFC website as another potential vehicle for education. That viewpoint was not in evidence during these telephone interviews and could be a way to encourage greater use of the website by professionals.

If there are ways to gain more use of the website by professionals as an aid in their work with patients (rather than for the professionals themselves), then they may also “market” the website to patients more actively, leading to greater use by patients and their family members.

8.2.3 Information Needs of Special Populations

Participants in these interviews raised the issue of pediatric dialysis patients, and their parents, which has not been stressed in this study or in the DFC website to date. Comparison of facilities may be less important to them, given the limited numbers of facilities that treat pediatric patients, but their information needs are significant.

We did include two parents of pediatric patients in our Atlanta site visit triads. They indicated similar concerns, highlighting the challenges of finding recreational or vacation facilities that can accommodate pediatric dialysis patients, for example.

These comments lead us to consider ways that pediatric issues can be brought into DFC planning more systematically. The goals for pediatric dialysis facility information, and the other resources provided, may be somewhat different, but they should be considered along with the more prominent issues of adult dialysis. The DFC could provide some information resources or links for those patients and their parents.

Pediatric patients are not the only special population, however, although they are clearly an important one. We have already discussed the particular information needs of Spanish-speaking patients, and respondents have also highlighted the unique needs of individuals with visual impairments, persons with low literacy levels, and those who do not use the Internet. Obviously, DFC cannot create special pages to address the unique concerns of every special population. We recommend that CMS give careful consideration to the special populations that it serves, perhaps conducting separate analyses to assess the relative size of each group before deciding how much to invest in developing specialized materials. As with any communication strategy, consideration must be given to audience segmentation and to the tradeoffs between the costs of tailoring messages for particular groups and the differential impact of such tailored messages.

CHAPTER 9
RECOMMENDATIONS

Our recommendations for revising the DFC website were developed from the respondents' recommendations described in the previous chapters, our assessment of the respondent recommendations, our own analysis of the strengths and weaknesses of the DFC website, and our experience with other projects on related topics. We also presented and discussed earlier versions of these recommendations with the DFC Consumer Workgroup, a panel of outside experts on dialysis and kidney disease, and with CMS staff.

The recommendations are presented in four sections: 1) website presentation and navigation; 2) facility characteristics; 3) quality measures; and 4) dialysis and kidney disease information and links. Within these sections each recommendation is first presented in summary form in a bolded single sentence. Subsequent paragraphs then describe the rationale for the recommendation and elaborate on its content and applications.

9.1 Website Presentation and Navigation

Include explanations of the context, goods, intended uses, and benefits of DFC on the first page that opens when a link to DFC is clicked by a user. Consider alternate ways of presenting this information.

Participants in the telephone interviews recognized that web-based information seeking would be new to some patients and suggested one way to make the DFC site easier for them would be to explain in more detail the context of DFC, purpose of the website, and how to use it.

The information displayed when a user selects the "Help with Dialysis Facility Compare" hyperlink offers instructions for using DFC and searching for facilities. This information could be adapted for the instructions and should be presented in a link renamed "How to Use Dialysis Facility Compare" at the beginning of the site rather than embedded in the text as is currently the case.

That would explain the mechanics of selecting dialysis facilities and viewing their facility characteristic and quality measures. However, a number of participants indicated that the benefits DFC can provide are not clearly explained for users at the outset. They wanted to know more about ***why*** to use DFC, not just about ***how*** to use it. Given the limited web experience of many dialysis patients and family members, this might help keep them motivated to explore and utilize the DFC more fully.

Reduce the reading grade level of the text in the DFC website to between 7th and 9th grade, wherever possible.

A critical step in developing a usable and successful website is writing or revising content that works for users and meets their needs. This involves using language that the intended audience can easily understand, written for a reading level two to five grades lower than the highest average grade level achieved by users. Jargon, technical terms, abbreviations, and acronyms should generally be avoided.

The current DFC text appears more appropriate for a professional audience than for the average dialysis patient or family member that the site aims to serve. Both patient and professional participants frequently commented that the reading level of many of the text passages in DFC was too high. They found the language too technical, complicated, and often confusing. For example, both groups indicated that too many technical words are used in the website. Terms such as "ESRD" and "erythropoeitin" will be unfamiliar to many dialysis patients and family members. As noted, pre-ESRD patients are even less likely to understand these terms.

We subsequently conducted Flesch-Kincaid reading grade level analyses for the "Read This" paragraph and several of the text explanations and glossary definitions for the quality measures. In each case, the reading level was found to be at the 12th grade level. That is much too high for a website targeted at dialysis patients, who are often from lower socioeconomic backgrounds.

In addition, some patients found the descriptions of the quality measures on the main website pages hard to understand. Dialysis professionals had similar reactions, cautioning that patients might not know the meaning of some of the terms used and the reading level seemed too high. Representatives from dialysis facility chains, disease management firms, and managed care organizations also commented on the difficulty patients may have understanding the DFC text.

The primary revisions should be made within the explanatory text and paragraphs used on the DFC site to help users to better understand medical and technical terms used on the site. This includes text on the DFC overview page, the glossary, and explanations on the results pages.

Although a fifth-grade reading level is often preferable, especially to reach low-literacy users, it will be difficult to avoid necessary polysyllabic words such as "dialysis" and "adequacy" which appear frequently on the site. As a result, a more realistic reading level target may be between seventh and ninth grade.

Improve text formatting.

The DFC site, as currently formatted, contains many dense paragraphs of text. Many patients and professional commented that there is too much text, especially compared to other websites they had used. For example, the explanatory paragraphs for the quality measures were not well received by participants in the patient and family member focus groups and interviews. They were considered too long and too dense. However, most participants saw their value when pushed to read them, or when the paragraphs were read to them. Several suggested summarizing them using bullet points or shortening them.

Most of the time, website users want to find a specific piece of information or the answer to a specific question. They often want to get just the information they need and move on towards a particular goal. Having to read a lot of text is an obstacle to achieving that goal. When text appears dense, users will often try to avoid reading it.

One of the guidelines for preparing easy-to-use content is to break the text into manageable pieces, or what is known as "chunking" (www.usability.gov). Methods for chunking include using columns that limit line length to 30-50 characters (optimal for readability), bulleted lists, short sentences and paragraphs, and subheadings can break text into more easily accessible segments.

Areas where chunking could be applied in DFC are the quality explanations, the "Read This" paragraph, and the glossary definitions. Formatting improvements can help alleviate the potential problem of users who avoid reading these long passages and thus may miss important information.

An option to increase font size would also prove readability. A button with that option is already available on Home Health Compare.

Provide a Spanish language version of all information presented on the DFC site, using the Nursing Home Compare model.

One frequent recommendation from study participants was to have more information in Spanish through the DFC website, or possibly a Spanish language version of the entire website. This recommendation was mad frequently by dialysis professionals. In particular, all 18 respondents in the telephone interviews with representatives from dialysis facility chains, disease management firms, and managed care organizations agreed that a Spanish-language version of the DFC site would be beneficial. Several of those participants were from areas of the country (e.g., New York City, South Florida) with large Spanish-speaking populations. They noted that their companies make patient educational materials available in both English and Spanish (and, depending on the location, other languages as well), and pointed out the high incidence of ESRD in Spanish-speaking populations.

The Medicare.gov website currently has link to a Spanish version in its banner. There are also Spanish versions for the Medicare Personal Plan Finder website and the Medicare Nursing Home Compare website, but not for Dialysis Facility Compare. The current DFC site advertises Spanish materials in its banner that appears on every page but it only directs users to a list of links to available Spanish language publications.

Nursing Home Compare (NHC) provides perhaps the best example of how to incorporate more Spanish language information throughout a Medicare website. NHC includes a button ("Vea en Espanol") linking users to a Spanish version of each page of its site. The Spanish version provides users with a complete Spanish translation of all information and the full searching capabilities available on NHC. Users can also easily switch back to view the site in English by clicking a "View in English" button on each Spanish language page.

Although there is a Spanish version of MPPF available, the site does not have the same type of button navigation as NHC. Users must click on the link for a Spanish version in the banner and then choose MPPF from the list of available publications and tools.

Add more graphics and other non-text content to DFC.

One of the most frequent suggestions from participants in our study was that the DFC website needs more graphics, pictures, or even videos. Several patients who were regular web users commented that it is less appealing than other websites they had used. Many professionals suggested that the DFC website is too wordy and should be more colorful to appeal to patients.

The National Cancer Institute's guide to Making Health Communication Programs Work lists "interactivity and fun elements" as one of the characteristics of a well-designed website. These elements can be used to make an otherwise all-text website more engaging to patients so that they are more likely to use and recommend the information on the site. In addition to providing information about health issues in an informative manner, websites should also be graphically appealing and engaging to users. The professional Medicare website, www.cms.hhs.gov, makes good use of photographs as well. It contains a series of 10 photographs.

A mapping function, such as the one used on Mapquest.com, would also be useful for people seeking dialysis facilities. Ideally, it could also "zoom" into a particular area.

Other federal government web sites, such as Cancer.gov, Kidney.niddk.nih.gov, and CDC.gov use much more non-text content than DFC, including graphics, diagrams and photographic images on their sites. Some limited revision to DFC, following the methods used in those other government sites, may make DFC more appealing to users. The professional Medicare site, www.cms.hhs.gov, makes good use of photographs.

Mapping functions, such as the one used on mapquest.com, would also be useful for people seeking dialysis facilities. Ideally, it could also "zoom" into a particular area.

CMS web staff have noted some concerns regarding these types of revisions. For example, the revisions would need to be Section 508 compliant (accessible to visually disabled users), and refrain from more complex graphics and videos that may require advanced hardware or specialized software to view. However, the developers of the other government websites had to face similar issues, so presumably they can be resolved for DFC as well.

Add an option so that DFC website materials can be mailed to users in hard-copy format.

It is unclear on the current DFC web site whether its information can be accessed in any other format than on the web. Participants in our telephone interviews offered insight in this regard, noting that web-based information seeking would be new to some dialysis patients, and suggested addition of a toll-free number that DFC users could call to request that the data or information of interest be sent to them by regular mail.

Notably, there is a model for this type of service already available on a companion website in Medicare.gov. Beneficiaries and authorized individuals who call 1-800-MEDICARE can receive a printed copy of (Medicare Personal Plan Finder (MPPF) website information mailed to them at no cost. The callers are asked the same questions as those that appear on the MPPF site preceding the results page. All of the information available online is then printed out, bound in a booklet, and mailed to the user requesting the information. A similar option could be made available for the DFC site.

Modify the formatting of the tables displaying facility characteristics data so that users can compare more than two dialysis facilities at a time.

Facility characteristics are currently displayed in tables that DFC users must scroll down to view in their entirety if more than two dialysis facilities are being compared. For example, if a user wanted to compare five sites, that person would need to scroll through three separate tables – two tables displaying two facilities each and a final one displaying the remaining facility. Formatting the tables so that users can see more than two facilities at a time would allow individuals to compare several sites at one time without having to scroll up and down. This also alleviates the potential for users to the miss information available for some facilities.

Our recommendation is to reduce the font size so the columns are still readable, but allow 4-6 facilities to be viewed at one time. This may still involve scrolling in cases where users are comparing many facilities, but it would reduce the amount of scrolling significantly. The columns of facility characteristics should also be set up to fit within a single screen horizontally, to avoid horizontal scrolling.

Organize the DFC webpages with headings hyperlinked to text below to reduce scrolling.

One of the key guidelines for preparing easy-to-use web content is to organize content logically. This includes creating useful headings and providing them as introductory hyperlinks. According to www.usability.gov, headings can be beneficial in two ways. First, they allow users to see an overview of the content of a particular page. Second, they allow users to jump to the right place in the web page by quickly finding the heading that relates to what they want to know.

The current DFC site does not make much use of hyperlinked headers. The exception is a hyperlink on the first page that allows users to jump directly to begin DFC searching instead of having to scroll down to the search function. However, for the majority of the site, users must scroll down through the pages to view all of the information presented. For those who may not be familiar with using the web, this presents a potential to miss information. Those users may not realize they need to scroll and focus instead on the text that appears directly on their computer screen. Headings that serve as introductory hyperlinks can alleviate this problem by allowing users to select from a list of titles at the top of the page that direct them to the specific portion of text on that topic.

One example of where headings would be particularly helpful on the DFC site is in presenting the quality measures information. Currently, users must scroll through several pages of graphs and text to view all of the quality information, without any initial summary of the type of data they can expect to view. Adding headings at the top of that page would alert users to the types of data they can view and allow them to go directly to the particular graphs and text which interest them.

Two government websites that can serve as models for incorporating headings for improved navigation are cancer.gov and kidney.niddk.gov. Both provide an overview of the information available using many headings on their homepages.

Another example of making use of headings can be seen in the prototype for the next generation MPPF website. To reduce the amount of text between the graphs of quality data, its pages now include hyperlinks with titles such as “What does this mean?” and “Why is this important?” that display the related text when users click on it. Although the pages still do not include introductory headings to allow users to jump to specific data, the newly added headings do help to reduce the amount of text on the page.

Create tabs similar to those used in MPPF, NHC, and HHC to enable easier navigation through DFC.

Another effective way to organize website content is to use tabs and sub-tabs. Like headings, tabs can also be used to reduce scrolling and potentially missed information by prompting users to the types of information available on a site. Several of the participants in our focus groups and interviews with dialysis professionals suggested adding tabs to make the website easier to navigate and more user-friendly.

The current DFC contains buttons on one of the results page that users can click on – one for facility characteristics and one for quality measures. However, users must scroll down to view these buttons and read through text to get an overview of the information that is available. Tabs can be created for both facility characteristics and quality measures so that users can view and select these topics at the top of their screen rather than having to scroll down. In addition, sub-tabs or headings can be created to help users navigate further through each of these topics. For example, sub-tabs could be created to separate quality information into HD and PD specific data. Users could then navigate through the site and find information based on the specific type of dialysis and topic that interests them.

The current “next generation” MPPF prototype site uses tabs with specific titles that users can select for information on that topic. For example, after users select specific health plans they are interested in, they are directed to a results page that has tabs labeled: Costs and Benefits, Out-of-Pocket Costs, Quality, Why People Leave, and Resources. These tabs allow users to get an overview of the type of information they can view on the site. Within some tabs, there are also headings that users can select for further specific information. For example, within the Quality tab, there are headings for information regarding: Beneficiary Satisfaction, Helping you Stay Healthy, About your Providers, and How to Read a Bar Graph. Adding this type of organization to the DFC site would give users greater ease in selecting and choosing the content they want to view.

Other government web sites, such as cancer.gov, kidney.niddk.nih.gov, www.cdc.gov, and medlineplus.gov , use tabs to help users navigate through large amounts of content and information. For example, the NIDDK site lists the following tabs that visitors can select: Kidney and Urologic Diseases, Statistics, Clinical Trials, In Spanish, Resources, and About Us. Sites such as these can be used as models for incorporating this recommendation into DFC.

From conversations with CMS staff, there is general agreement that tabs will be a feature of the Next Generation Compare websites, including DFC. Standard tabs will be included, such as those for Search, About, Data Details, and Resources. Our recommendation includes creating some special tabs for DFC such as a Home Page to orient users to the site, and sub-tabs to show readers options for different types of Resources and Quality Measures.

9.2 Facility Characteristics

Checklists should be added to DFC so that patients and family members will have guidance on what questions to ask, about factors not included in the DFC facility characteristics data, when they are visiting dialysis facilities they are considering for future treatment, assessing their current facility, or discuss facilities with doctors or other providers.

Checklists should also address issues related to quality measures and dialysis and kidney disease information. Further research should be conducted on what topics and items to include in the checklists. All types of participants suggested numerous additional facility characteristics that could be added to the DFC website. They covered a wide range of topics, including patients' concerns, staffing issues, organizational factors, and facility policy issues. In our recommendations for additions to DFC, we focus on those that seemed most salient and most easily implemented. However, we also recognize that the DFC website may not be able to contain facility-level data on all of the potentially beneficial variables.

Patients and family members pointed out in focus groups and interviews that they often do not know what questions to ask when visiting a dialysis facility. They suggested that the DFC website could include a set of common questions that patients and family members could ask. Dialysis professionals recommended that the DFC provide lists of questions that patients could ask doctors and staff at dialysis facilities.

Checklists would also promote one of the long run goals of DFC, to promote more patient involvement in their care and decisions affecting their treatment. This type of resource would help patients to take the crucial "first steps" toward getting more involved. This could also serve as a helpful complement to the DFC "Read This" paragraph that indicates the data on the DFC website should be one of several considerations in choosing a facility.

Add additional dialysis facility staffing characteristics including but not limited to the following:

- Staffing ratios for all types of patient care providers (nurses, dietitians, social workers, and technicians).
- Data on the certification or training of technicians.
- The number of staff on site.
- Clinical staff availability, such as the days and hours in the week that RDs are on-site.

More information on a facility's staffing was a frequent recommendation from study participants. Low ratios of patients to clinical staff, having easy access to social workers and dietitians, and having easy access to physicians were all cited by patients, family members, and professionals alike as features of good dialysis care.

The current data elements in the DFC facility characteristics do not include any information on staffing. To better meet the needs of users, the DFC site could include information on whether a site has a doctor, social worker, or registered dietician on site (indicated with a yes/no or checkmark), the total numbers of each type of clinical staff on site including RNs and technicians, how often patients are seen by different staff members, and the ratio of patients to each category of clinical staff.

Medicare's Nursing Home Compare website can be used as an example of how to present staffing information. It includes a tab on its results page entitled "Nursing Staff" that users can select to view a table displaying the number of nursing home residents, ratios for all types of nursing staff (RN, CVN, LPN) hours per resident per day, and the ratio of all nursing staff hours per resident per day. Below that table is information and links on to how to read the table, roles of nursing staff, and explanations of the ratios and why they are important.

Questions and notes about facility staffing could be included in a patient checklist posted on the DFC, as a short-term way of addressing this recommendation.

Allow users the ability to limit their facility searches on DFC based on categories such as the followings:

- Physician on site?
- Social worker on site?
- Dietitian on site?
- Does the facility have two or more FTE registered nurses?
- Evening shifts available?
- Support groups available?
- Peritoneal dialysis available?

The current DFC site allows users to search for dialysis facilities based on zip code, county, city, and states, and then choose specific facilities to view further from the resulting list of dialysis facilities in their area. What it does not allow is the ability to search according to specific facility characteristics. Current DFC users must read through the characteristics for all of the facilities they select to determine whether the sites match their preferences. Providing a method of limiting searches further would make it easier and quicker for users to get the information they prefer.

The above recommendation is a suggested list of fields to include as options for a more customized search of facilities through DFC. They are common characteristics that users may be looking for in a facility.

Medicare's Personal Plan Finder website provides an example of how users can limit their searches to match more specific preferences. After users first answer some eligibility questions and enter their zip code, they are directed to a page that lists all of the health plans in their area. On that same page they have the option to limit the list of available plans further based on average monthly premium, average out-of-pocket costs, flexibility of doctor choice, prescription, vision, and dental services coverage, and plans that member's rate as providing the best care. Depending on their selections, users are then given a list of plans that match these specific characteristics. (They are also provided with a list of the remaining plans available in their area that do not match their specifications, and can view the information listed for them as well.)

Consider adding facility characteristics that may already be collected in the SIMS database.

If data elements for some recommendations can currently be accessed in the SIMS database, then they could serve as short-term ways to provide more facility characteristics in the DFC website. CMS staff indicated some lead time may be needed to verify the accuracy of those data elements, or to gain updated information from dialysis facilities, but that is presumably feasible within a reasonable time frame. These data elements could include information on items recommended by respondents in our research, such as data on the numbers of peritoneal dialysis patients treated at each facility.

Adding a few additional data elements to the SIMS data collection requirements might also be feasible in the long run, but an evaluation would have to be conducted regarding how quickly dialysis facilities could be expected to provide the added data.

Add information on Medicare certification and state inspections.

The DFC currently lists the date of each facility's date of original Medicare certification. However, gaining more reassurance regarding governmental regulation and oversight of dialysis facilities was a frequent request from dialysis patients and family members. Dialysis professionals also supported this idea. This recommendation could include several types of data:

- Date when Medicare certification was last updated.
- The period for which the most recent Medicare certification was granted (if there is variation, e.g., if certification can be granted for 1 year versus 3 years depending on what the inspectors find).
- Date when the state survey agency last inspected the dialysis facility.
- The period for which the most recent state license was granted (if there is variation, e.g., if the license can be granted for 1 year versus 3 years depending on what the inspectors find).
- If the state survey agency cited the facility for any particular deficiencies or violations during the most recent inspection.

The Nursing Home Compare website provides an example of how this information has been collected and presented in another Medicare.gov website. It includes information on the health deficiencies found during the most recent State nursing home survey and from recent complaint investigations.

Include information on a range of facility amenities and patient characteristics, such as:

- Are support groups available for patients and family members?
- Are visitors allowed?
- Number of patients if different age ranges.
- Is the facility accessible for handicapped patients?
- Is public transportation available?
- Are individual TVs, cable TV available?
- Are data ports for laptop computers available?

Providing information on facility amenities was a frequent recommendation. Dialysis patients and family members wanted to know this information and dialysis professionals thought this type of information should available for patients. The amenities listed above represent examples of what we thought to be some of the more useful and important recommendations from those suggested by study participants. Others are certainly possible as well.

Amenity information can be easily presented in a table using yes/no or a checkmark to indicate whether a feature is available. A separate tab for amenities could also be created that users can select to view this information, as the Nursing Home Compare website provides for staffing and other facility information.

Another possibility is to create a header within a tab, as is done on the Medicare Personal Plan Finder website where users can select the “Quality” tab and then click on headers such as “Beneficiary Satisfaction” and “Helping You Stay Healthy” to view facility information on these subjects.

Sample questions about a facility’s amenities could also be included on a patient checklist posted on DFC, as a short-term way of addressing this recommendation.

Provide a complete schedule of the days and hours that the facility is open, and the specific times that shifts start.

The current DFC lists only whether the site has shifts available after 5:00pm. Adding information on other hours that treatment is available, including overnight shifts, was a frequent recommendation of dialysis patients and family members. In addition, some facilities are open only a limited number of days per week.

Sample questions about a facility’s schedule could also be included on a patient checklist posted on DFC, as a short-term way of addressing this recommendation.

Include the distance to closest hospital(s) and the hospital name(s).

Displaying the distance to the closest hospital provides users with helpful information regarding what may occur if a medical emergency arises on site. This was a frequent concern of dialysis patients and family members.

Sample questions about nearby hospitals could also be included on a patient checklist posted on DFC, as a short-term way of addressing this recommendation.

Provide a range of data specific to the needs of peritoneal dialysis patients, such as:

- The number of PD patients treated at the facility. (And those treated using the other main modalities: in-center HD and home HD.)
- The number of PD staff working at the facility.
- The staffing ratio: PD patients per FTE PD nurse.
- Is PD training available at the facility?
- What types of PD supplies and equipment are available (Baxter, Fresenius, or both)?

In our research, we found that peritoneal dialysis patients generally felt the DFC was too much oriented toward the information needs and concerns of hemodialysis patients. They indicated that DFC serves their information needs in a much more limited fashion. Several PD patients indicated that would make them less likely to use DFC in the future. PD professionals echoed those concerns, noting that PD patients often experience this type of bias in dialysis facilities and among their caregivers. As a result, the DFC's neglect of these issues hits a sore point, creating an emotional response that makes it hard for PD patients to see potential benefits from DFC.

We believe that this concern could be mitigated by adding some facility characteristics data to DFC that is oriented toward PD issues, such as the examples listed above. Even including one or two of these additional facility characteristics would go a long way toward demonstrating to PD patients that their needs were not being ignored by DFC.

Add a mapping feature to provide maps and driving directions to each facility.

A number of dialysis patient, family member, and professional respondents suggested that adding maps and directions to facilities would be a helpful addition to the current DFC site. Some participants in the telephone interviews mentioned this as well. The current DFC site lists only the address and telephone number for each facility. Patients and visitors must currently either call the facility or use an alternate mapping website for directions.

One current dialysis facility locator website that has a mapping feature is dialysisfinder.com. It allows users to search for dialysis facilities in their area, but does not list information beyond the contact information. It also allows users to view and print maps and step-by-step driving directions through one of the common Internet mapping sites.

Adding a mapping feature to DFC would also offer consistency with the redesigned version of the Participating Physicians Directory Website now available on medicare.gov that already contains this feature. When users view the information for a particular participating physician, they can click on buttons to view maps or get driving directions.

Adding a mapping feature is also a method of encouraging more individuals to use the DFC site and take advantage of its information. Whereas users may be able to find maps on dialysisfinder.com or other popular mapping sites, adding this information to DFC would create a more user-friendly, "one-stop shopping" approach for kidney patients, their families, and dialysis professionals.

9.3 Quality Measures

Replace "Not Available" with the specific reason a facility's quality data is missing from the DFC website.

When we asked patient and family participants to compare four facilities using DFC quality measures, the "Not Available" results shown for one facility raised a lot of concern. Despite the explanatory footnote about missing data that was pointed out by group facilitators and interviewers, participants were suspicious that facilities whose information was not available were hiding something.

Participants in the focus groups and interviews with dialysis professionals initially had similar concerns with the "Not Available" quality data. Although the professionals were more willing to withhold judgment after the group moderator or interviewer pointed out the explanatory footnote, none of the professional respondents noticed the footnote without having it pointed out to them.

The above recommendation is offered as a way to alleviate users' suspicions. One suggestion would be to add the appropriate explanation from the footnote after the words "Not Available". Alternatively, the appropriate footnote information could simple replace the "Not Available" comment.

Revise the presentation and explanation of the patient survival measure and its results.

Many patient and family participants found the presentation of the patient survival data confusing. Patient survival information was quite interesting to the participants, however, presumably because of the severity of their illness and the ongoing threat of death most dialysis patients feel. The main problem seemed to be that these data are couched in statistical terms (e.g., "worse than expected"), and as a result were less well understood.

Moreover, the text explanations of the survival data were unclear to most patient and family member respondents. For example, some asked what the data presented for facilities meant about the expected survival of an individual dialysis patient.

The frequent comments and concerns raised about the survival measure suggest that the data need to be explained more clearly. One possibility may be to present the data using bar graphs, like the adequacy and anemia indicators, if that is possible given the underlying data. Those graphs were well received by patients and family members, and would make the presentation of the patient survival results consistent with that used for those other quality measures.

Another possibility would be to provide more detailed definitions of “as expected”, “better than expected” and “worse than expected”. More prominent links to the FAQs for patient survival may help as well, since a number of participants found them useful.

It should also be noted that the patient survival data were reassuring to some patients and family members who interpreted the survival categories and associated check marks correctly. However, given the frequent confusion, a clearer presentation and explanation of the survival data is needed so that more users can interpret that data accurately.

Add a new DFC quality measure that includes patient satisfaction (experience of care) information.

One frequent recommendation across all types of respondents was to add patient satisfaction data to the quality measures included on the DFC website. Patients emphasized the importance patient satisfaction plays in what they consider to be a crucial aspect of the quality of dialysis care. A frequent comment was that they would prefer a facility that is recommended by other patients – a facility where other patients report being satisfied with the care they receive. Patients indicated they would like to hear more about dialysis and dialysis facilities from fellow patients, and not learn about them exclusively from professionals as they have up to now. Many patients felt strongly about this; they seem to feel that their “voice” has not been heard.

This would also fit with Medicare’s current initiative to develop an ESRD CAHPS survey instrument. CMS staff have indicated to us that there is an ongoing discussion over whether ESRD CAHPS data should be reported publicly or not. Our research showed that dialysis patients have a strong preference for public reporting of those data, so that they can have access to them.

Patients indicated that dialysis staff should be friendly, have a positive attitude, and have compassion and respect for patients. Staff should also take time to explain things. They should not be detached. Several participants commented that dialysis staff should treat patients like family, since the see them for so many hours per week.

A specific issue for many patients was satisfaction with dialysis technicians. A number of patients expressed unhappiness with the job done by their technicians.

Patient satisfaction with the overall condition and/or amenities of a particular facility also emerged as a factor when patients discussed the importance of equipment and facilities issues. Frequent comments included the importance of the cleanliness and appearance of the facility, comfortable chairs, individual televisions, and good parking.

Dialysis professionals also recognized the importance of patient satisfaction in defining quality care. Most understood that the presence of good “customer service” is vital to their success. Dialysis professionals also noted that most facilities already measure patient satisfaction. Staff from one dialysis chain reported that they conduct a patient satisfaction survey once a year for all patients, including both HD and PD. Staff are then given goals to reach for this measure for the next year.

During telephone interviews, representatives from dialysis facility chains, disease management firms, and managed care organizations also suggested adding a patient satisfaction quality to the DFC. They suggested that it is one of the most important markers of quality of care. Patient satisfaction information was the most frequently mentioned element when participants were asked what additional information they would like to see on the DFC site.

Add a new DFC quality measure that includes information on peritoneal dialysis.

Adding information PD-related quality measures was a frequent recommendation from both PD patients and PD professionals. As noted, PD patients were quite vocal about their unhappiness with the HD emphasis of the current DFC website. They expressed interest in having additional quality measures for PD adequacy and PD-specific measures for anemia and patient survival.

Both PD patients and professionals noted that the adequacy measure for their mode of dialysis is Kt/V. The DFC web site currently has adequacy data only on URR for HD patients. As a result, we believe adding Kt/V data for PD patients would be a good way to implement a new PD-oriented measure on DFC.

There are several alternatives, however. For PD, including albumin levels was also a frequent recommendation by PD professionals. They indicated albumin levels are more important for PD since those patients lose protein in dialysis, gain weight with PD, and feel full on PD. They considered albumin levels to be a very important quality measure for PD patients.

Another frequent recommendation was to provide anemia and patient survival data just for PD patients. This would allow PD users to compare quality outcomes of facilities as they relate to care of PD patients. The current DFC presents data for all patients, who are mostly HD patients.

Add a new quality measure to DFC that includes data on the percentages of patients using catheters and fistulas for vascular access.

Another topic recommended by many respondent for quality measurement was vascular access. This was suggested mainly by professionals, although a number of patients and family members also supported this idea. A vascular access measure would be consistent with Medicare's national quality improvement initiative in this area and with the CPM measures evaluation the percentages of patients using catheters and fistulas and of patients routinely checked for stenosis. Data could include catheter or fistula use, vascular access procedures, or infections at access sites. The last two may be hard to measure, however.

Add a new quality measure to DFC that includes data on the number of patients and the percentages of patients on the transplant waiting list.

Many patients and family members requested a range of additional information be made available on DFC on kidney transplants. They knew that transplants provided better quality of life for most ESRD patients, but felt that their understanding was limited in many areas, including the procedure, the necessary preparation, and the implications for their lives. They requested patient education materials, but also data on the numbers of patients being transplanted at each facility and the numbers of patients on the transplant waiting list. We view the opportunity to receive a transplant as less under the control of the dialysis facility than completing the necessary preparation to gain membership on the transplant waiting list.

Present quality data as trends covering multiple years.

Several dialysis professionals suggested tracking all of the quality measures over time and presenting the results as multi-year trends. Trends would show if facilities were making improvements.

Moreover, a facility that appears to have the best quality data at one particular point in time, as currently shown on the DFC, may not appear to be the best over multiple periods of time. Adding trend data would provide patients, family members, and other stakeholders with a broader picture of the quality of a particular facility – whether it has a consistent pattern or has improved or worsened on each measure over time.

Change the dialysis adequacy measure to Kt/V instead of URR for all patients..

Although most of the patient participants had heard of the urea reduction ratio (URR) and had discussed it with their providers, dialysis professionals and industry representatives indicated that they more often use Kt/V in assessing dialysis adequacy. Although they agreed that adequacy data should be presented, several respondents indicated they favor Kt/V over URR due to concerns with the accuracy of URR data that have prompted many in the dialysis field to switch to Kt/V instead.

Moreover, Kt/V is the measure used in Medicare’s annual Clinical Performance Measure (CPM) survey that evaluates quality of care in a national sample of dialysis facilities. As a result, it seems that switching to Kt/V instead of URR would make the DFC website consistent with the adequacy measure most commonly used in the ESRD community. We recognize that implementing this recommendation may have to defer until all dialysis facilities are collecting Kt/V data, as they are now for URR.

Change the anemia measure to hemoglobin instead of hematocrit.

While most of the patient participants had heard of the hematocrit measure, and had discussed it with their providers, dialysis professionals and industry representatives indicated that they more often use hemoglobin to assess anemia. Although they agreed that hematocrit data are useful, they indicated that its levels can be affected by factors unrelated to anemia, such as the patient’s fluid status, whether a facility has a dietitian on staff, and the extent and effectiveness of patient education.

Moreover, hemoglobin is the measure used in Medicare’s annual Clinical Performance Measure (CPM) survey that evaluates quality of care in a national sample of dialysis facilities.

As a result, using hemoglobin instead of hematocrit would make the DFC website consistent with the anemia measure most commonly used in the ESRD community.

9.4 Dialysis and Kidney Disease Information and Links

Provide more prominent links to all dialysis-related information and materials contained on DFC

Comments from focus groups and interviews with dialysis patients and family members and professionals frequently included recommendations to provide more dialysis and kidney disease information. Pre-ESRD patient and professional participants made similar comments. Websites can easily contain useful public health information and resources, but too often this information is embedded within the site. Without links or other navigational tools directing users to this information, it may go unnoticed or be thought unavailable on the site.

The Dialysis Publications and Related Sites link on DFC currently provides users with access to links to CMS publications and websites with additional dialysis and kidney disease information.

One option for adding a more prominent link to these resources on the DFC site is to create a specific tab titled “Resources for Patients” that would be available on each page of the DFC. This suggestion follows the Medicare Personal Plan Finder website that includes a “Resources” tab as an option on every page that users can select to provide links to additional information. We understand that type of tab will also be included in the next generation release of DFC.

Labeling the DFC tab as “Resources for Patients” would make it clearer for users to know where they can find links to resources. The current label for these resources as “Dialysis Publications and Related Sites” uses technical- and academic-sounding language that may confuse the average DFC user. Leaving it as just “Resources”, as in MPPF, may cause users to overlook it.

Provide additional links to websites with dialysis and kidney disease information.

As noted, frequent comments from focus groups and interviews with dialysis patients and family members and professionals indicated that they would like the DFC to provide more dialysis and kidney disease information. Pre-ESRD patients and professionals made similar comments. The current DFC provides some useful links, as described above, but could also provide a range of others. A selection of the topics requested by patient and family member respondents include:

- The patient’s experience of treatment. For example, “What is it like to be on peritoneal dialysis?”
- More detailed descriptions of the modalities and methods used in dialysis treatments.
- The underlying causes of renal disease, its anatomy and physiology, and its long-term implications.

- Information on health topics related to dialysis and its common comorbidities (e.g., diabetes, cardiovascular disease).
- Dialysis-related self-care priorities (e.g., nutrition, vascular access), techniques patients should use, and potential problems if they are neglected.
- A range of information on kidney transplantation.
- A good source for explanations of medical terms (e.g., "necrotic").
- Meanings of the lab results patients receive. What are their links to quality measures?
- The implications of patient non-adherence to dialysis treatment. What happens if patients skip treatments or sign off early?
- What are the rights and responsibilities of dialysis patients?

A companion report[1] describes 38 websites that we identified as providing potentially useful information for DFC users. That report includes websites providing information on six topics relevant to DFC:

- Chronic kidney disease (pre-ESRD);
- Hemodialysis;
- Peritoneal Dialysis;
- Children and Parents (pediatric dialysis);
- Kidney transplant;
- Caregiver and family support.

The additional website links could be set up in these categories in DFC, with headings and hyperlinks to direct users to their specific information needs.

We do not believe that DFC should become a website that contains patient education materials that are also available elsewhere, but rather that it should promote increased access through expanding the links it contains to other websites that contain them. This would also further the underlying goal of DFC to promote patient self-management and involvement in treatment decision-making.

Add website links to DFC that focus on the needs of special dialysis populations:

- Pre-ESRD (CKD) patients;
- Peritoneal dialysis patients;
- Family members;
- Pediatric patients and their parents;
- Non-English-speaking patients.

Our research indicated that these special dialysis populations often feel that their needs are neglected, with most of the resources and information devoted to hemodialysis issues. This is also reflected in the information provided on DFC. We believe that establishing special links for these populations would help motivate them to use DFC, and to feel that their needs are not being overlooked by DFC. In many cases, they have special information needs as well.

For example, it was apparent in our focus groups and triads with pre-ESRD patients and professionals that patients at this stage of the disease have often very limited knowledge about kidney disease or dialysis. As a result, their information needs may be very different from patients who have been on dialysis for a year or more, and know much more about these issues.

This recommendation would involve adding to DFC a link, tab or button created specifically for pre-ESRD patients. It could include links to other websites that include content focused on this phase of kidney disease, such as those described in our last recommendation, and to other data and resources.

CHAPTER 10
CONCLUSIONS

This final report presents our findings and recommendations for the DFC website based on analysis of the data we collected from patients, family members, and professionals. The wide range of comments, ideas, and recommendations presented in this report illustrates the active level of participation we found among the patient, family, and professional respondents across the focus groups, triads and interviews conducted for this study. The engagement and involvement of participants was evident across all four of the site visits and throughout all of the telephone interviews. They found DFC to have the potential to be very useful. It is clear that they have a keen interest in the continuing development of the DFC website and in its potential to serve their needs for information about dialysis and dialysis facilities.

Hemodialysis and pre-ESRD patient respondents seemed very pleased that the DFC website has been created as a resource for them, and that it contains information they see as relevant. Patients seemed to feel they have been kept in the dark about dialysis to some extent, and that the DFC website gives them access to information that they had previously been denied. They appreciated the opportunity to have access to information independently, without having to rely on their professional caregivers.

At the same time, they indicated a number of additional types of information they would like to see added to the website. The lengthy list of their recommended data elements in Chapter 3 are noteworthy. Ideas and recommendations covered all aspects of the DFC website, including facility characteristics, quality measures, and links to other types of information on dialysis and kidney disease.

Patients saw the DFC's potential to aid them in better understanding and managing the care they receive, and in its potential to aid them in being more knowledgeable consumers of dialysis services and more effective collaborators with their clinical providers. However, they are not active users of the DFC website at present. The website needs to be improved to make it more appealing to patients, and promoted in ways that will encourage patients and their family members to test it out.

Family members were generally more skeptical of the value of the current information on the website. Many did not see the DFC as directly meeting their needs at present. They had more recommended changes than the patients.

Pre-ESRD patients and family members provided a different perspective on the DFC website. They have unique concerns that need to be considered if the website is to reach people in that early stage of the disease, when interventions to increase patient participation and decision-making may have a larger impact.

The availability of access to the Internet was noteworthy among pre-ESRD participants. Some indicated they would need to seek it out from friends or family, but most seemed willing to do so if they believed the information available from the DFC website or others would be useful to them. Moreover, of the themes described in this report is the general lack of knowledge regarding kidney disease and dialysis among pre-ESRD participants. It appears that the DFC may have a potential role in supplementing the limited scope of the pre-ESRD education programs that are currently available.

The role of pre-ESRD family members is also somewhat unique. They may be able to play expanded roles as information intermediaries, since pre-ESRD patients have limited ability to access other types of intermediaries available to dialysis patients, such as dialysis facility staff. The DFC could potentially play a role in facilitating those efforts.

Among dialysis professionals, we found that the information in the DFC website would fit best with the tasks required for social workers, since they often work with patients and family to arrange dialysis for those traveling or moving to other cities. Other professionals also saw its value, however, both for patient education and as a way to benchmark their own performance against other facilities in their area and across the nation. They also indicated that just the existence of the website would spur staff at many facilities to work harder on quality improvement, to ensure they compare favorably on quality indicators with their peers. This illustrates one of the indirect benefits of public reporting of quality of care data.

Nonetheless, some professional participants were concerned that the data on the quality measures may be affected by a number of factors outside the control of dialysis facilities. However, most agreed that the quality data have value despite this concern. Few suggested that the DFC itself provide more extensive casemix adjustments for the quality data. The main concern seemed to be for the patients and their family members to understand the importance and potential significance of variations in the underlying patient population used to calculate the quality measures at each facility.

All of the dialysis professionals and most technicians were active Internet and Web users. Most had access through their dialysis facilities. As a result, they had few barriers to use of the DFC website.

Most of the pre-ESRD professional participants were very pleased that the DFC website has been created as a resource for them and for their patients. Most indicated that it contains information they see as relevant and that they would use it and recommend it to others. However, these pre-ESRD professionals also indicated concern that their patients needed more general educational materials. The DFC website may at present have information on clinical and quality topics that is too complex for pre-ESRD patients to understand. This reinforced the need for development of specialized content on DFC that is targeted to the needs of pre-ESRD patients.

The interviews with representatives from dialysis facility chains, disease management firms, and managed care organizations offered several new perspectives on the DFC website. Their use of the website differed from that of patients and professionals. Dialysis facility chains found the website less useful for their purposes than did the other organizations, noting that they had their own data that were more detailed, comprehensive, and timely. Managed care organizations saw potential use for finding out about dialysis facilities in their service area, although they were less specific than other respondents in their discussions. Disease management organizations had the clearest potential use for the website information in researching facilities and were generally positive in their assessment of it.

We found few differences in responses by type of organization. With the exception of the issues of use, relevance, and role in patient care, responses were quite similar across the organizational types. We would not have predicted this finding. It may reflect the fact that our respondents were high-level professionals with similar outlooks. In addition, we know that there is some mobility across these organizational types; at least one representative of a disease management firm had previously operated a dialysis facility chain, for example. Nonetheless, this suggests that the potential for business use of the website is broad and that CMS should be encouraged to promote DFC to a wide audience.

The interviews with representatives from national renal organizations also offered new perspectives on the DFC. Three groups were largely negative in their assessment of the website; of these, two were renal professionals' groups and one was a patient group. The other three offered mixed reviews or somewhat positive assessments. For the three groups with the greatest concerns about the website, issues of timeliness of data and, to a lesser extent, accuracy of the data were the most prominent concerns.

Several of these respondents raised an issue that had not emerged with other groups: clarifying the intent and purpose of the website. They noted the need to explain to patients, in clear and accessible language, the purpose of the website and how patients could use the information contained therein. If the website is intended for patients, these respondents suggested clarifying whether its purpose is to assist patients in selecting a dialysis facility or to educate patients about dialysis and ESRD.

After completing data collection with the six types of respondents, we developed a series of recommendations for revising and improving the DFC website. Our recommendations were developed from the respondents' recommendations described in the previous chapters, our assessment of their recommendations, our own analysis of the DFC website, and our experience with related projects. The recommendations were developed on four topics: website presentation and navigation; facility characteristics; quality measures; and dialysis and kidney disease information and links. We developed multiple recommendations for each topic.

We believe that our recommendations will make the DFC website more appealing and more user-friendly for its primary audience of patients and family members. That should boost utilization of the website once they gain an understanding of the benefits it can provide them. In the long run, DFC has excellent potential to fulfill its broader goals of increasing patients' involvement in managing their own care and increasing their participation in facility choices and other decisions that affect their dialysis treatment. However, the website needs to be improved in a number of ways to make it more useful and more appealing.

APPENDIX

APPENDIX
NATIONAL DIALYSIS PATIENT STATISTICS, POINT PREVALENCE 1999

Variable	Dialysis Patients	Percent
Age[1]		
0-19	1,857	1%
20-44	41,233	17%
45-64	91,646	38%
65-74	60,214	25%
75+	48,206	20%
Race[1]		
White	133,119	55%
Black	92,356	38%
Native American	4,184	2%
Asian/Pacific Islander	8,766	4%
Other/Unknown	4,895	2%
Gender[1]		
Male	128,101	53%
Female	115,051	47%
Dialysis Modality Type[2]		
Hemodialysis	215,749	89%
Peritoneal Dialysis	22,797	9%
Unknown	4,774	2%

SOURCES:
[1] USRDS 2001 Annual Report, Table p.1 (page 18)
[2] USRDS 2001 Annual Report, Table D.1 (page 349)