

ESRD CAHPS Feasibility Report

**Submitted to the Centers for Medicare and Medicaid Services
by the Agency for Healthcare Research and Quality in
collaboration with the CAHPS grantees**

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**Final
ESRD Feasibility Report**

TABLE OF CONTENTS

I.	Executive Summary	pp. 1-4
II.	Introduction	pp. 5-7
III.	Background	pp. 7-9
IV.	Overview of Research Findings	pp. 9-13
V.	Recommendations	pp.14-18
	Appendix A. <u>Summary of Research Findings</u>	pp.19-33
	Appendix B. <u>Discussion of Recommendations</u>	pp.34-45

Final ESRD Feasibility Report

Executive Summary

The Centers for Medicare and Medicaid Services (CMS) has actively pursued an ambitious quality measurement and improvement agenda that encompasses the quality of care delivered by specific providers and facilities. In the case of ESRD, the CMS quality improvement agenda has been notably successful. However, as was noted by the Office of the Inspector General in 1999, a standardized patient experience of care survey that could provide valid comparative information to the public, is notably absent from the set of quality measures for ESRD.

CMS realized that for a number of reasons, development of such a survey for ESRD might be significantly more challenging and less straightforward than for other facilities and populations.

Therefore, CMS asked AHRQ and its grantees to produce a feasibility report that would make recommendations about the purpose and content of a standardized survey for ESRD after conducting a thorough study of the issues involved. Specifically, CMS asked that AHRQ provide guidance on the proper balance between a survey aimed primarily at internal quality improvement to aid facilities and one that would focus on public reporting to consumers.

Four main sources of information contributed to this report: a literature review; focus groups with patients and their family members, and focus groups with nephrologists; interviews with network executive directors and facility staff; and a summary of a technical expert panel meeting (TEP) held in June of 2003. Findings are organized into three main categories: purpose and use of survey, domains and item content, and method of survey administration.

Some of the main findings are:

Purpose and Use of Survey

- In general, there was moderate to strong support among all constituencies for a standardized survey.
- Several stakeholders expressed concerns about replacing existing surveys that are useful to them both in terms of trending and specific patient information with a standardized survey that may not capture the same information.
- Additional concerns centered on the costs involved, the accuracy and validity of patient feedback and the potential use of survey results for reimbursement.
- There is close agreement among most stakeholders that survey results would be of little use to patients for facility choice, due to insurance arrangements, location, etc. However, patients disagreed.
- Some facilities use surveys as one of several means of communicating with their dialysis population.

Final ESRD Feasibility Report

- Patients and some network executive directors and facility administrators felt that survey results should be reported to all interested parties, including the general public. However, nephrologists did not believe that reporting patient survey information to the public would be of value, and possibly might be misleading.

Domains and Item Content

Proposed areas for the survey to focus on include:

- Communication with and education of patients
- Concern and helpfulness of staff
- Patient involvement in care
- Coordination of care
- Patient perception of staff proficiency
- Interpersonal relationships in the dialysis setting.
- Patient safety
- Facility amenities and environment
- Access and convenience of care including transportation
- Handling of grievances and complaints.

Methods and Survey Administration

Some of the main issues in methods and survey administration are:

- Site of survey administration (e.g., at the facility, at home).
- Low literacy levels, fatigue from comorbidities and the dialysis treatment itself, cognitive impairment, and poor vision are all serious obstacles to self-administration.
- Small numbers of patients at many facilities present special challenges.
- Frequent interaction of dialysis patients with one another and the staff creates a unique culture.

The main recommendations are:

Recommendation 1:

CMS should develop a standardized survey, and in concert with AHRQ, take steps to ensure that the ESRD community is appropriately involved, so that stakeholder concerns are adequately addressed. Potential items generated for ESRD CAHPS should be reviewed by the TEP and other members of the renal community as the instrument is constructed.

Recommendation 2:

The new survey should focus on in-center hemodialysis patients and address public reporting and accountability needs as well as quality improvement. Both the survey and patient reports should be developed in both English and Spanish. An

Final ESRD Feasibility Report

assessment should be conducted to determine the distribution of languages among non-English speaking dialysis populations. In addition, CMS should consider the development of surveys for other dialysis populations.

Recommendation 3:

CMS should carefully consider which items are and which items are not under the control of facilities when deciding how to publicly report and use survey results.

Recommendation 4:

CMS should develop and test two separate reports of survey results: one targeted toward the provider audience and one targeted toward the ESRD patient audience.

Recommendation 5:

CMS needs to support efforts to determine how most patients will use reports for choice, education, or advocating for improvements in their facilities and what providers need from reports to guide their quality improvement efforts. This effort should include determining the best way to disseminate information to these groups (e.g., the use of information intermediaries to help the low literacy ESRD population; web-based tools for providers).

Recommendation 6:

To obtain the most comparable data across facilities, an independent third party is recommended for administration of the survey. This could be a set of licensed vendors (excluding chains themselves) or a vendor or vendors under contract to CMS. Analysis and reporting should be conducted by CMS or a vendor under contract to CMS.

Recommendation 7:

With respect to patient eligibility for the survey, CMS should evaluate, through field and cognitive testing, the impact of excluding patients hospitalized during the survey period. CMS should also evaluate whether patients who have been in treatment for a minimum of 3 months is sufficient for inclusion in the survey, or whether the prevailing standard of 6 months experience with a caregiver is appropriate.

Recommendation 8:

CMS should conduct a field test to examine two critical areas:

1. The mode effects and other important differences (i.e., costs, response rates) among the following:

Final ESRD Feasibility Report

- a. Telephone interviews
- b. Interactive voice response (IVR) interviews
- c. Mail surveys with telephone follow-up
- d. Internet-based surveys

2. Case-mix issues

Recommendation 9:

More information is needed to resolve several analytic issues, including the number of patients that would be available to estimate a CAHPS score for a facility. Therefore, CMS should support analyses of available ESRD data to address this issue.

Recommendation 10:

In general, we do not recommend that CMS allow proxy respondents to complete patient surveys. However, due to the many debilities ESRD patients suffer that may interfere with their ability to complete a survey without assistance, some help in completing the survey may be needed.

Final ESRD Feasibility Report

I. Introduction

CMS Quality Improvement Strategy

For a number of years, but particularly over the last decade, the Centers for Medicare and Medicaid Services (CMS) has actively pursued an ambitious quality measurement and improvement agenda that encompasses the quality of care delivered by specific providers and facilities (e.g., managed care plans, nursing homes, home health agencies, and dialysis facilities) and for specific conditions (e.g., diabetes, acute myocardial infarction (AMI), stroke, breast cancer, flu and pneumonia, heart failure, and End Stage Renal Disease). This agenda involves a clear set of specific activities that include:

- Identifying core sets of clinical quality measures;
- Measuring beneficiaries' experience of care through standardized surveys;
- Monitoring measures over time to identify opportunities for improvement;
- Encouraging interventions to address identified opportunities for improvement (either internally through the individual provider/facility or externally through Medicare's Quality Improvement Organizations and/or ESRD Networks); and
- Public reporting of a subset of measures to beneficiaries and their families as well as the general public.

It is important to note that public reporting has two distinct purposes, viewed by CMS as equally important: 1) to provide consumers with valid and reliable comparative information about the differences in performance between facilities so they can make more informed choices about where and how they get their care; and 2) to motivate providers to improve quality by disclosing their performance. To further these goals, CMS publishes facility-specific comparative quality performance information on its consumer-oriented website, www.medicare.gov, for managed care and fee-for-service health plans, nursing homes, and dialysis facilities that serve patients with end-stage renal disease (ESRD). Plans are underway to publish such information on hospitals, home health agencies, and to augment and refine the currently published information for nursing homes.

Need for an ESRD Patient Survey

In the case of ESRD, the CMS quality improvement agenda has been notably successful. Much impressive progress has been made since the mid-1990's when the antecedent of the current Clinical Performance Measures Project (CPM) began, a direct result of close collaboration with the private sector using the National Kidney Foundation's guidelines. Since January of 2001, comparative performance information on three measures for dialysis facilities (hematocrit, urea reduction rate (URR), and patient survival rates) has been published on the Dialysis Facility Compare (DFC) website, currently under

Final ESRD Feasibility Report

evaluation¹. However, as was noted by the Office of the Inspector General in 1999, patient experience of care is notably absent from the set of quality measures for ESRD. As the health care community moves toward more patient-centered care that emphasizes outcomes such as mortality, morbidity, quality of life, and satisfaction, it is important to continue to work closely with the ESRD community to develop standardized measures that are of particular significance to beneficiaries.

A patient experience of care survey can capture critical quality information not available through other sources and that is of equal importance to the clinical indicators of the CPM in providing a complete picture of the quality of care for ESRD patients. In sum, patients' experience of care can be a legitimate outcome measure in itself.

Fortunately, CMS has made great strides in the development of standardized tools to measure the consumer perspective on quality, through the CAHPS survey effort. In concert with the Agency for Healthcare Research and Quality (AHRQ), CMS has developed Medicare-specific versions of the CAHPS surveys for beneficiaries in managed care and traditional fee-for-service Medicare. It administers these surveys nationally each year and publishes the plan-specific results on its website. Further, CMS and AHRQ are currently collaborating on a version of CAHPS for hospitals patients (HCAHPS) and one for nursing homes residents (NHCAHPS). In 2002, CMS approached AHRQ and its grantees about the possibility of developing a CAHPS patient experience of care survey for the ESRD population.

Purpose of Feasibility Report

CMS realized that for a number of reasons, development of such a survey for ESRD might be significantly more challenging and less straightforward than for other facilities and populations. Chief among these is a concern over the proper balance between a survey aimed primarily at internal quality improvement and one that would focus on public reporting to consumers. Many facilities currently administer their own patient surveys for use in internal quality improvement activities, and CMS would like to encourage and strengthen such efforts to improve quality. However, in accordance with its broader strategy of patient outreach public reporting for informed choice, as well as the necessity to be responsive to the IG directive, CMS is equally interested in obtaining a standardized patient experience of care survey that would produce comparative data useful to beneficiaries and providers. In addition to the challenges surrounding purpose and content, there are practical challenges; for example, many facilities are small and may yield too few respondents to allow for statistically valid comparisons. In light of this and other considerations, CMS asked AHRQ and its grantees to produce a feasibility report that would make recommendations about the purpose and content of a standardized survey for ESRD after conducting a thorough study of the issues involved.

¹ CMS has contracted with RTI to conduct a systematic review of the use of the Medicare's Dialysis Facility Compare website by both patients and providers. The work under that contract is almost completed and a report will soon be released with the results of that evaluation.

Final ESRD Feasibility Report

Organization of Report

There are four main sources of information that contribute to this report: a literature review; focus groups with patients and their family members, and focus groups with nephrologists; interviews with network executive directors and facility staff; and a summary of a technical expert panel meeting (TEP) held in June of 2003. The last event was a meeting of a variety of stakeholders, including representatives from facilities, networks, the research and provider communities, and patients to discuss the issues involved in developing a patient experience of care survey for this population. There are separate sections in the report summarizing relevant information from each source according to the schema explained below.

The information gathered from these sources is organized into three main categories:

- 1) Purpose and Use of Survey. This category covers information pertaining to both public reporting for consumer choice and internal quality improvement. For example, stakeholders have different perspectives on whether choice, education, or providing a basis upon which beneficiaries can press for better quality care in their facilities should be the goal of published information for beneficiaries on ESRD care.
- 2) Domains and Item Content. Included in this category is information about the specific topics that have been suggested for inclusion in the survey and the kinds of items that different stakeholders think should appear in a standardized instrument.
- 3) Methods and Survey Administration. This category addresses implementation, including mode and site of administration, self-administration and the issue of staff assistance with completion, sample size, response rates, and confidentiality.

Preceding an overview summarizing research findings, and in alignment with the above three categories, is a background section that summarizes some unique characteristics of the ESRD population and the treatment of their disease, as well as information about the renal provider community that bear on the content, implementation, and reporting of results of a patient survey. The final section of the report provides recommendations to CMS concerning the focus and purpose of an ESRD CAHPS survey. Two Appendices provide more detailed information on, respectively, the research findings (Appendix A) and the recommendations (Appendix B).

II. Background

Characteristics of the ESRD population

As noted above, a number of characteristics of the ESRD population may bear on survey content, implementation, and reporting of survey results. These population

Final ESRD Feasibility Report

characteristics are presented briefly below, and include race/ethnicity, low literacy levels, age, general levels of well-being, frequency and intensity of treatment, and family involvement.

Demographics

Almost 20 million Americans, representing one in nine adults, have chronic kidney disease (CKD), and an additional 20 million more are at risk for the disease.¹ CKD may lead to ESRD, defined as kidney function at less than 15 percent of normal capacity.² ESRD patients require either dialysis or a kidney transplant to survive. Currently, more than 375,000 Americans receive long-term dialysis treatment.³ The number of kidney failure patients is projected to double to 650,000 by 2010, related in part to the corresponding rise in diabetes. Based on legislation passed in 1972, Medicare pays for the vast majority of ESRD care provided.

African Americans and Native Americans have a disproportionately high rate of ESRD: it is four times more prevalent in African Americans and three times more prevalent in Native Americans than in non-Hispanic whites. Among Hispanics, the increase in prevalence has been more striking than in other groups.⁴

The economic effects of ESRD are substantial, both from the perspective of the individual patient suffering from the disease and from the broader perspective of the health system. With respect to the former, it is estimated that only 24 to 31 percent of ESRD patients are employed.⁵ A significant number of ESRD patients are officially disabled and qualify for Supplemental Security Income (SSI) benefits. With respect to the latter, the direct costs of providing treatments are substantial; in 1999, over \$18 billion dollars was spent on ESRD care.

Forty-five percent of hemodialysis patients are 65 years or older. Fifty-five percent of adult patients have been on hemodialysis more than two years. Due in part to the regional differences in racial and ethnic populations and access to transplant centers and organ availability, the highest dialysis rates occur in the southwest, while the highest transplant rates are in the central northern states.

The prevalence of cognitive impairment in the ESRD population is 30 percent higher than that of the general population, even among patients with no psychiatric or neurological comorbidities, as a consequence of higher rates of conditions such as Alzheimer's disease and stroke.⁶ In addition, low levels of literacy and illiteracy are common. Patient comprehension and basic literacy skills are critical factors in the construction of a survey that patients can understand and complete and in designing ways to clearly communicate survey results to them.

Frequency and intensity of treatment.

ESRD is a complex chronic condition. Patients typically have overall diminished health and comorbid conditions such as diabetes, hypertension, or depression, in addition to

Final ESRD Feasibility Report

their primary diagnosis, resulting in frequent contact with the health care system. The average hemodialysis patient is hospitalized 17 days and takes an average of eight medications during the course of a year.⁷ Adhering to a schedule of dialysis therapy can be a challenge for patients, resulting in a lack of timely treatment and further health complications. Five-year survival rates are below 50 percent for patients on dialysis.⁸

Family Involvement

ESRD poses a significant challenge to patients and their families. There are medical, social, employment, emotional, and financial consequences of this chronic condition. Family support is a key predictor in 5-year mortality rates: patients with low family support have a three times higher than estimated mortality rate compared to those with high family support.⁹ The vital role of family support strongly suggests that ESRD providers should include the family in patient education and treatment.

The Renal Provider Community

More than 4,000 dialysis facilities in the United States treat ESRD patients; nearly 80 percent of these units are freestanding, for-profit, non-hospital based units.¹⁰ ESRD Networks, under contract to CMS, are tasked to promote improvements in and monitor the quality of care in dialysis facilities, maintain program data, and serve as clearinghouses for federal agencies, renal organizations, and patients and their families. There are 18 ESRD networks, organized by geographic region that oversee between 111 and 369 facilities each.¹¹ Because of the complexity of ESRD and the comorbidities that routinely accompany it, there is a wide range of providers who may be involved in various aspects of the patient's overall care as well as a multi-disciplinary team who provide renal care and dialysis. This multidisciplinary team includes professionals such as nephrologists, nurses, dietitians, technicians, social workers, patient educators, and other specialists.

III. Overview of Research Findings

As noted earlier, four sources of information contribute to this report: a literature review, focus groups with patients and families and nephrologists, interviews with network executive directors and facility administrators, and a summary of a technical expert panel meeting composed of a wide range of stakeholders, held in June of 2003. These findings are presented in three categories: Purpose and Use of Survey, Domains and Item Content, and Methods and Survey Administration. This Overview highlights critical findings across all sources, and notes which ones surface in more than one source. It also highlights where key differences among stakeholders appear on issues of central importance to the survey.

More detail on the research findings from the literature review, focus groups, interviews and TEP meeting summary can be found in Appendix A of the report, entitled, Summary of Research Findings.

Final ESRD Feasibility Report

Purpose and Use of Survey.

In general, there was moderate to strong support among all constituencies for a standardized survey. However, several stakeholders expressed concerns about replacing existing surveys that are useful to them both in terms of trending and specific patient information with a standardized survey that may not capture the same information. Additional concerns centered on the costs involved, the accuracy and validity of patient feedback (based on a focus group with nephrologists in CA) and the potential use of survey results for reimbursement.

Of particular significance for consideration in the development of an ESRD CAHPS survey are the issues of: consumer choice, (whether among facilities or treatment options and modalities); internal quality improvement; and how and to whom the information obtained should be reported.

Quality Improvement

- While many facilities currently administer their own patient surveys, the degree to which they are used for internal quality improvement is unclear; information provided on this point differed by source.

According to the interviews conducted with facilities from six different networks, quality improvement efforts based on survey results are infrequent. In contrast, some members of the TEP indicated that a number of facilities rely on surveys (especially those that are part of chains) to address significant patient concerns and quality improvement issues.

- Patients and nephrologists agree that if patient surveys are administered, they must be used to improve care (focus groups).
- Some facilities use their survey results for marketing purposes (interviews).
- Some facilities indicated that they do not always have control over certain aspects of care, and therefore are limited in the degree to which they can make changes based on survey results (interviews). For example, a chain may have a policy dictating the room temperature level that should be maintained during treatment.

Choice

- There is close agreement among most stakeholders that survey results would be of little use to patients for facility choice, due to insurance arrangements, location, etc.(nephrologist focus groups, interviews, TEP summary).²

² Information collected as part of an evaluation of CMS's Dialysis Facility Compare (DFC) website, indicates that experienced patients--those with a year or more of dialysis—may be more likely to use comparative information for facility choice than patients new to dialysis.

Final ESRD Feasibility Report

However, patients' perspective on the utility of comparative facility information for choice varies markedly (patient focus groups). Some patients felt that this information would be useful when traveling and/or trying to locate another facility. But since facilities often cannot accommodate patients on travel, it is not clear how useful such information would actually be to patients. Others indicated that they would consider switching to a higher rated facility. Nephrologists felt that a survey that focused on providing comparative information concerning treatment options and modalities, rather than facility choice, would be useful to patients.

Although not specifically mentioned in focus groups, interviews or at the TEP meeting, the purpose of an ESRD patient experience of care survey may include encouragement of patient involvement in the delivery of their own care and provision of information that will help dialysis providers learn about and better respond to patients' needs.

- Some facilities use surveys as one of several means of communicating with their dialysis population (TEP meeting summary).

Reports

- Nephrologists did not believe that reporting patient survey information to the public would be of value, and possibly might be misleading. Rather, they felt that reporting to facilities and providers for use in quality improvement efforts (nephrologist focus groups) would be useful. In contrast, patients and some network executive directors and facility administrators felt that survey results should be reported to all interested parties, including the general public (patient focus groups and interviews).
- Some chains produce and distribute performance reports comparing their member facilities to one another (interviews).

Domains and Item Content

The following are major subject areas that should be considered in the development of an ESRD CAHPS survey, identified by the four information sources.

- Communication with and education of patients (literature review, focus groups, TEP meeting summary). Doctors in particular mentioned that it was important for patients to understand their diagnosis and treatment options.
- Concern and helpfulness of staff (literature review, TEP meeting summary, focus groups, interviews). Possible items areas include listening, comfort, courtesy, respect, and dignity of treatment by staff. Also included in this domain is sensitivity of staff to the social relationships that exist among the patients.

Final ESRD Feasibility Report

- Patient involvement in care (literature review, interviews, TEP meeting summary). This area also includes such issues as flexibility of scheduling and waiting times.
- Coordination of care (literature review, nephrologist focus groups). Because of both the complexity of the disease itself, as well as the high proportion of patients with comorbidities, there is a wide range of staff involved in ESRD patient care. The issue of staff turnover at facilities is also relevant to this domain.
- Patient perception of staff proficiency (literature review, focus groups, interviews). Included in this domain are the technical expertise and professionalism of the staff. While patients felt able to judge some aspects of technical performance (e.g., venipuncture proficiency), some facility and network administrators did not believe patients capable of such judgments.
- Interpersonal relationships in the dialysis setting. This includes the continuity of providers and interactions with other patients.
- Patient safety (literature review, focus groups, interviews, TEP meeting summary). This area includes response to medical emergencies and the quality and maintenance of equipment.
- Facility amenities and environment (literature review, focus groups). This area includes patient comfort and the physical environment, such as room temperature, the availability of ice chips, noise level, comfortable chairs for family members, etc.
- Access and convenience of care including transportation (interviews, TEP meeting summary).
- Handling of grievances and complaints.

An additional issue to be considered is whether and to what extent a particular group of health professionals who serve ESRD patients and/or the facilities themselves are accountable for aspects of care in each domain. Nephrologists and some network executive directors and facility administrators were particularly concerned about the attribution of responsibility for quality of patient care in certain domains, especially if survey results were to be tied to financial compensation.

Methods and Survey Administration.

- There was recognition that the site of survey administration is a critical implementation issue for the ESRD population (interviews, nephrologist focus groups, TEP meeting summary).

Final ESRD Feasibility Report

On the one hand, facilities report being able to generate high response rates when the survey is administered on site. On the other hand, this results in potential biasing of responses (particularly when patients seek assistance from staff in completing surveys) and loss of confidentiality. Patients expressed fear of reprisals from staff if they rated their care as less than optimal, such as being labeled a “bad patient.”

- Low literacy levels, fatigue from comorbidities and the dialysis treatment itself, cognitive impairment, and poor vision are all serious obstacles to self-administration. TEP members recommended that surveys be geared to 4th grade reading level (literature review, interviews, TEP meeting summary).
- Patients indicated that they preferred either a mail or telephone survey to computer or Internet-administered surveys. Many stated a preference for being able to complete surveys at home (patient focus groups).
- There was agreement that surveys should be administered no more than once or twice a year (nephrologist focus groups, interviews, TEP), and that results should be reported back to the facility quickly (i.e., within weeks or months) to be useful for quality improvement.
- Some administrators expressed a desire for survey administration by an independent third party, like CMS, rather than allowing facilities to do so (interviews).
- Small numbers of patients at many facilities present special challenges. Not only do small numbers of dialysis patients make statistical comparison among facilities difficult, but they also introduce problems of patient confidentiality when publicly reporting results (nephrologist focus group).
- Frequent interaction of dialysis patients with one another and the staff creates a unique culture. Because of the high level of familiarity, patients are aware of staff communication and relationships with patients. TEP members noted that patients might want a survey to be administered to all patients at a facility so no patients would feel excluded or silenced, and so that the facilities ensure they have heard from as many patients as possible.

IV. Recommendations

This section examines the major issues identified in the report and provides recommendations to CMS concerning the purpose, content, use and implementation of an ESRD CAHPS survey. The main recommendations are presented below.

Main Recommendations

Final ESRD Feasibility Report

Recommendation 1:

CMS should develop a standardized survey, and in concert with AHRQ, take steps to ensure that the ESRD community is appropriately involved, so that stakeholder concerns are adequately addressed. Potential items generated for ESRD CAHPS should be reviewed by the TEP and other members of the renal community as the instrument is constructed.

Justification

While there is widespread recognition and even enthusiasm among some stakeholders for a standardized survey that could be used to compare facilities (patients, network executive directors and facility administrators, and nephrologists, with patients expressing the strongest support), there are also serious concerns. First, the validity and reliability of the survey must be firmly established, results available quickly, and specific action steps provided to guide quality improvement efforts. Patients, nephrologists and other stakeholders were united in their desire to have survey results used for quality improvement. Second, many facilities, particularly chains, have invested a great deal in the development and implementation of their own surveys, and fear that implementation of an ESRD CAHPS survey may present an additional burden, without providing the same valuable patient experience and quality improvement information. Use of patient data to determine reimbursement was not supported by either nephrologists or facilities.

The renal community has a solid record of successful collaboration with CMS in clinical quality improvement efforts. Because many facilities currently field their own surveys and some initiate quality improvement efforts based on those surveys, the community can offer valuable input to the survey development and reporting effort. The involvement and advice of the renal community in this effort is central in trying to construct an instrument that will be relevant and useful to providers, and minimize the imposition of additional burden.

Recommendation 2:

The new survey should focus on in-center hemodialysis patients and address public reporting and accountability needs as well as quality improvement. Both the survey and patient reports should be developed in both English and Spanish. An assessment should be conducted to determine the distribution of languages among non-English speaking dialysis populations. In addition, CMS should consider the development of surveys for other dialysis populations.

Justification

The research conducted for this report indicates that quality improvement and public reporting needs can be accommodated within one instrument. More specific and targeted questions can be asked of this patient population, due to their familiarity with particular

Final ESRD Feasibility Report

aspects of their care. It is likely that there is some significant overlap between patients' reports of their experience with care and quality improvement concerns.

The purpose of public reporting is to provide patients with reliable and valid comparative information on dialysis facilities to: 1) help them make more informed choices to the extent that they have a choice among facilities; 2) alert them to the comparative quality of the facility (facilities) where they receive treatment; 3) arm them with information that may be useful to them and their providers in discussions about their care and how it can be improved.

Recommendation 3:

CMS should carefully consider which items are and which items are not under the control of facilities when deciding how to publicly report and use survey results.

Justification

A number of TEP members noted that transportation was one of the suggested survey domains included in this report as an area of possible measurement, and protested that facilities do not control the availability of transportation. While areas not under facility control may not be appropriate for comparative performance reporting, such information may still be of interest to CMS, given the government's broad interest in the complete range of ESRD patient experience. Thus, CMS may have compelling program and/or policy reasons for the inclusion of survey items not under facility control; however, it should exercise caution in the use of such results.

Recommendation 4:

CMS should develop and test two separate reports of survey results: one targeted toward the provider audience and one targeted toward the ESRD patient audience.

Justification

There are significant differences in the information needs and characteristics of each audience. Providers want detailed information about topics such as sampling and response rates that may not be appropriate for inclusion in a patient report. Lower levels of literacy in the ESRD population make it advisable to target a consumer report at a lower reading level than may be acceptable for the provider population. In addition, providers need information that is more targeted toward quality improvement, whereas consumers need information that is presented in a way that allows them to gauge the differences in quality of care between facilities.

Recommendation 5:

CMS needs to support efforts to determine how most patients will use reports for choice, education, or advocating for improvements in their facilities and what

Final ESRD Feasibility Report

providers need from reports to guide their quality improvement efforts. This effort should include determining the best way to disseminate information to these groups (e.g., the use of information intermediaries to help the low literacy ESRD population; web-based tools for providers).

Justification

Sources were nearly unanimous in the view that patients did not have a choice among facilities, and therefore, comparative information to guide choice would be of little use to them. However, a number of patients did not agree and expressed great interest in using such information, although it is not clear how most will use the information. Providers need reports that are relevant, actionable, and timely, with detailed information about methodology (e.g., sampling and response rates); more information is needed from them to determine how to meet those reporting goals.

Recommendation 6:

To obtain the most comparable data across facilities, an independent third party is recommended for administration of the survey. This could be a set of licensed vendors (excluding chains themselves) or a vendor or vendors under contract to CMS. Analysis and reporting should be conducted by CMS or a vendor under contract to CMS.

Justification

Many facilities do not have the capability to conduct surveys and the Networks typically are not involved in this type of activity. A disadvantage of using the chains is that they have a vested interest in the outcomes of the survey and there likely would be the perception of potential bias if they were used to administer the survey. Furthermore, if the chains were used, a complementary system would have to be developed for facilities that are not part of chains. Thus, although using chains to administer surveys might be politically attractive, the research team thinks that having either a defined set of certified vendors (as are used to administer CAHPS for NCQA) or a vendor or vendors under contract to CMS would provide the most comparable data across facilities

Recommendation 7:

With respect to patient eligibility for the survey, CMS should evaluate, through field and cognitive testing, the impact of excluding patients hospitalized during the survey period. CMS should also evaluate whether patients who have been in treatment for a minimum of 3 months is sufficient for inclusion in the survey, or whether the prevailing standard of 6 months experience with a caregiver is appropriate.

Justification

Final ESRD Feasibility Report

Although there are no empirical studies that help define what a minimally adequate period is, health care surveys often require that a patient have had from 6 months to a year's experience at a facility. However, ESRD patients, due to their dialysis schedule, have much more experience with their facilities than most other patients, so 3 months exposure might be sufficient. A related issue has to do with the eligibility of patients who at the time of sampling are in a hospital (either receiving a transplant or because their health has deteriorated) or a rehabilitation facility (e.g., recovering from the amputation of a limb or adjusting to blindness.). There also are a small number of patients that are seasonal visitors to facilities. Generally, the decision about the inclusion or exclusion of such patients is made based on likely biases associated with inclusion or exclusion. For example, if poor treatment was related to an increased possibility of hospitalization or treatment in a rehabilitation facility, then excluding such patients could bias results. However, the team thinks that the link between the aspects of care measured in a CAHPS survey and treatment in other facilities is likely to be minimal. In addition, obtaining current contact information for patients in hospitals or rehabilitation centers is likely to be challenging, and response rates from such patients – even those who can be contacted – will likely be low.

Recommendation 8:

CMS should conduct a field test to examine two critical areas:

1. The mode effects and other important differences (i.e., costs, response rates) among the following:

- a-c. Telephone interviews**
- f. Interactive voice response (IVR) interviews**
- g. Mail surveys with telephone follow-up**
- h. Internet-based surveys**

2. Case-mix issues

The main strategies for surveying patients include in-person interviewing, telephone interviewing, and self-administered paper and Internet-based surveys. There are advantages and disadvantages to each of these approaches, including cost, typical response rate, and confidentiality. Because of the unique characteristics of the ESRD population, more information is needed about the optimal strategy to employ in survey implementation.

Recommendation 9:

More information is needed to resolve several analytic issues, including the number of patients that would be available to estimate a CAHPS score for a facility. Therefore, CMS should support analyses of available ESRD data to address this issue.

Recommendation 10:

**Final
ESRD Feasibility Report**

In general, we do not recommend that CMS allow proxy respondents to complete patient surveys. However, due to the many debilities ESRD patients suffer that may interfere with their ability to complete a survey without assistance, some help in completing the survey may be needed.

Final ESRD Feasibility Report

Appendix A. Summary of Research Findings

Details from each of the four sources: literature review, focus groups, interviews, and the TEP meeting summary are found below.

Literature Review

Method

The literature on patient assessments of quality of care in dialysis facilities was systematically reviewed by searching bibliographic databases yielding nearly 2,000 articles, reviewing public and private organizations' and services' websites related to ESRD, and analyzing sample instruments from proprietary and public domain sources.

Purpose and Use of Survey.

Overall, little information was available from the literature review on either surveys or reports of results from surveys and how to tailor such reports to specific audiences within the ESRD community.

Many dialysis facilities currently implement proprietary survey instruments among their patients, and some use the data for internal quality improvement. These instruments vary widely, are not often publicly available, and cannot be used to produce valid, "apples to apples" data for comparisons among facilities.

Domains and Item Content.

Based on the literature review and analysis of eleven ESRD patient surveys in the field, the following domains merit consideration as key areas of patient satisfaction with and perception of care.

- *Care, concern, and helpfulness of staff.* The interpersonal interactions of all staff with patients, including physicians, ancillary staff, technical staff and nurses were noted in ESRD patient satisfaction tools and articles. Descriptive items for this domain included listening, comfort, respect, courtesy, time spent with patients, and dignity of staff interactions.
- *Patient perception of staff proficiency.* Competence of both technical and professional staff is an issue that is important to patients. Patients sometimes may suffer through inexperienced, untrained staff's venipuncture technique, and some patients say they can evaluate skill through the level of pain and the number of venipuncture attempts. Additionally, some patients say that professional staff's role in achieving optimal therapy and fluid management can be evaluated by noting if machine settings are correctly adjusted and how they feel after the dialysis treatment.

Final ESRD Feasibility Report

- *Coordination of care.* ESRD patients require a multidisciplinary team of providers because of the disease itself and associated comorbid conditions. The patient's perception of care coordination was reflected in survey items describing communication among providers and referrals to other providers.
- *Patient education.* Data support that patients educated about dialysis and ESRD have better clinical outcomes. ESRD patients require education at many levels at different stages of the disease, ranging from their initial diagnosis and treatment choices, to the ongoing treatment stage where patients need education in dealing with diet, lab values, exercise, comorbid conditions and other aspects of long-term care, to managing emergency medical situations and infection control.
- *Shared decision-making and involvement in care.* Some patients feel a lack of control in their lives because of the nature of the disease and its treatment. Many patients cite the inability to hold a full-time job and the consequent effects on their financial status and personal relationships as one example of the loss of control entailed by ESRD. Thus, providing choice and control where possible takes on greater importance. The introduction of interventions designed to enhance patient involvement may enhance their emotional well-being and effectiveness of therapy.
- *Environment of the facility.* Because of the repeated routine visits to the dialysis facility, satisfaction with the facility's environment is routinely included as an important aspect of the patient's experience. Aspects of the facility environment suggested as important include but are not limited to: facility comfort, including temperature control, cleanliness, maintenance of machines and a pleasant milieu.
- *Time delays and flexibility of schedule.* Patients spend as many as 12 hours a week in treatment, which represents a significant time allocation for dialysis care. In addition to the amount of therapy time, dialysis care requires several processes of therapy that further affect time commitment for the patient and can add 6 or more hours per week to their dialysis schedule; for example, waiting for transportation, waiting for staff to weigh them before and after therapy, waiting to be put on the dialysis machine, etc. Reducing waiting time and control over scheduling treatments were items routinely found in ESRD satisfaction instruments.
- *Patient safety.* Issues surrounding patient safety were outlined in instruments reviewed. Items related to this area involved the response to medical emergencies—how quickly staff react to problems with the dialysis machines, (which a patient can evaluate from alarms), infection control/care/maintenance of the access site, (which a patient can evaluate by observing such things as provider hand washing and glove use) and through monitoring signs of infection of their vascular access site.

Final ESRD Feasibility Report

Methods and Survey Administration

Both the setting of care in which dialysis is provided and the type of therapy administered are issues that need to be considered in targeting the survey and selecting patients for inclusion.

- *Uniqueness of settings of care.* The setting of care, i.e., home dialysis versus in-facility dialysis, provides unique patient experiences, including the use of durable medical equipment companies, frequency of contact with the facility, educational needs, etc. Each setting requires different assessments. For example, an increasing number of patients in nursing homes are on dialysis.
- *Type of dialysis care.* Similarly, different therapies--hemodialysis and peritoneal dialysis--require unique assessments because the key concerns for each therapy may differ: e.g., relationships with dialysis staff, diet restrictions, dialysis dose, and self-care.

Focus Groups

Method

Separate focus groups were conducted with both patients and their family members, and with nephrologists. Four focus groups with hemodialysis patients were held, two each in Palo Alto, CA and Durham, NC. The California focus groups took place on May 3, 2003; the North Carolina focus groups took place three months later on August 7 and 8, 2003. A total of 30 patients participated, 17 in California and 13 in North Carolina. In addition, two focus groups with patient family members were conducted contemporaneously with the patient focus groups in California. Twenty-one family members participated. Finally, two focus groups were conducted with nephrologists: one in Washington, DC and one in California.

The Renal Physicians Association (RPA) 2003 annual meeting took place March 20-22 in Washington, D.C. Six nephrologists attending the meeting were recruited to participate in a focus group with the assistance of Dr. Richard Goldman, a nephrologist known to be knowledgeable about and active in quality improvement activities, who is chair of the Quality Patient Care Committee of the Renal Physicians Association. Dr. Goldman offered to notify a number of nephrologists attending the annual meeting of the focus group and its purpose, and encouraged their participation. The nephrologists who attended were from a wide range of practices.

A second focus group with nephrologists was held during the American Society of Nephrology (ASN) meeting on August 25, 2003. Ten nephrologists attending the meeting were recruited to participate in a focus group via announcement made verbally during the course of the conference. The participants represented seven states, rural and urban population centers, and large and small group practices (as well as one solo practice). Eight of the participants in group practice were still affiliated with dialysis

Final ESRD Feasibility Report

facilities that are owned or used by their medical group (the number of facilities serviced by the groups ranged from 2-45), one was working with an Indian population awaiting the construction of a dialysis center, and the solo practitioner had privileges at one dialysis center. Three participants were medical directors of dialysis units, including one person who was the medical director of a dialysis facility for children.

Purpose and Use of Survey.

Patients

Quality Improvement

In general, patients desired that their participation in a survey would result in improved quality of care. For example, one focus group was quite bitter about an effort they had participated in which feedback of survey results took months to receive and did not result in any noticeable improvements. An indirect impact of survey results on patient care is also likely to be appreciated. For example, one patient observed that consumer ratings of dialysis center care would lead to competition among dialysis centers for patients and this might motivate some centers to improve their services.

Choice

Overall, patients were enthusiastic about the opportunity to obtain data from other patients that would allow them to compare the quality of health care delivered in different dialysis facilities, and enable them to make a choice among facilities if such a choice should occur (e.g., when traveling). It is important to note that many facilities cannot accommodate traveling patients who wish to use their treatment center. While some participants cautioned that many dialysis patients do not have a choice of facilities, primarily because there is only one facility within commuting distance to them, the majority (20 of 30) had visited more than one dialysis facility (2 or more). A number of patients expressed an interest in finding a facility that delivered better care than they were currently receiving and moreover, indicated that if they knew of such a facility, they would try to go there.

Nephrologists

Quality Improvement

With respect to quality improvement, nephrologists were interested in unit-level information from the survey that could help them administer and manage the care given by the dialysis unit as a whole. They were also interested in information that could be used to guide quality improvement efforts. In addition, they felt that whether patients valued the survey would depend on whether the survey results were used to improve care.

Participants in the first nephrologist focus group welcomed the possibility of achieving a better tool to measure patients' experiences of care. Existing tools were seen as deficient

Final ESRD Feasibility Report

either because they did not assess aspects of care that matter most to patients and that are “actionable” for QI purposes; and/or, because they are too complicated and cumbersome for patients to complete. Participants in the second nephrologist focus group indicated that such surveys had the potential to be informative and educational; however, they cited concerns about the misuse of information, the accuracy and validity of patient feedback, specifically, concern over the ability of patients to objectively assess their care, and the need for case-mix adjustment of data.

Choice

Nephrologists felt that the ESRD CAHPS survey information would *not be useful* in informing patients’ *choices among dialysis facilities* because most patients do not have a choice among facilities. However, patients do have a choice among treatment options and modalities. Thus, the survey information could potentially be useful for consumer choice if the survey were structured to evaluate the experience of the patient with the type of treatment (e.g., modality) he or she receives.

Reports

In focus groups conducted with nephrologists, doctors did not think that information from the ESRD CAHPS should be reported to the public, citing concerns regarding data quality and patient confidentiality. Instead, they would like the data to be reported to the ESRD networks and to clinical staff.

Domains and Item Content

Patients

There was consensus among patients regarding the importance of the following domains to high quality dialysis care, which can be roughly separated into issues about the staff and issues about the facility itself:

- Highly trained, qualified and knowledgeable staff (for example, people felt that having nurses give all of the care, instead of technicians, would result in higher quality care)
- Staff that treat patients with kindness and respect
- Staff acknowledgement of social relationships among patients: e.g. allowing patients who have formed relationships to sit near one another during dialysis; informing patients when another patient has died
- Staff able and willing to educate patients and to assist new patients in orienting to dialysis
- Staff willing to communicate with patients regarding their treatment and progress
- Professional attire and demeanor on the part of staff

Final ESRD Feasibility Report

- Thorough communication among medical staff regarding patients' treatment and progress.³
- Patient control: ability to refuse care from technicians of proven incompetence; ability to reschedule dialysis appointments when necessary
- Patient safety issues, including maintenance of sanitary conditions and general cleanliness of the facility, hand washing, and use of masks, consistent monitoring of equipment on the part of staff during dialysis to ensure high quality treatment, and quality of the dialysis equipment; provision for emergency care: e.g. nearness to hospital, staff trained in CPR
- Provision for patient comfort: for example, comfortable chairs, ice chips when needed, food when needed to prevent sickness, warmth of room/blankets
- Location, transportation, and parking

When patients think of the care they receive in the dialysis unit from dialysis unit staff, they are unlikely to restrict their evaluations to care specifically and directly related to dialysis. We sought to obtain guidance from focus group patients with regard to the staff member that they perceived to be responsible for different aspects of care by asking them a series of questions. The reason assignment of responsibility is important in survey construction is because it is necessary to distinguish which health professional(s) should be the focus of particular questions. Nephrologists felt strongly that they were responsible for patients' overall health rather than specific processes of dialysis care. For quality improvement purposes, these distinctions are especially important because changes may need to be made, for example, by technicians, rather than the nursing staff. Responses are summarized below:

- *If the patient was really tired after a dialysis session and thought his or her dialysis treatment wasn't right*, most patients indicated that they would contact the head/charge nurse or nurse practitioner. Overall, responses indicated that patients would prefer to ask for help from someone they felt would hear their concerns, with whom they felt a personal connection, and had sufficient knowledge and experience to be able to help them.
- *If one of the technicians just couldn't insert needles without causing the patient lots of pain*, most patients said that they would ask the technician to stop and request that someone who is more skilled and/or who knows their access better.
- *If the patient had to reschedule a dialysis appointment because of a family emergency*, patients said that they would call the dialysis center and talk to the nurse or social worker to reschedule the appointment.
- *If the patient developed a painful rash*, most patients stated that they would talk to either the charge/head nurse or their doctor.

³ The term "staff" was not precisely defined; however, throughout the focus groups, participants suggested interaction with the following staff at the dialysis center: charge/head nurse, social workers, technicians, dietician/nutritionist, and physicians.

Final ESRD Feasibility Report

- *If one of the patients who had a dialysis appointment at the same time as the focus group participant was really being bothered by him or her, focus group participants said that they would either talk to that person directly or talk to the nurse about the problem.*
- *If the patient wanted to get more information about his or her diagnosis, treatment options or prognosis, most patients would talk to their doctor, nurse practitioner or nurse.*
- *Whose help would you seek if you were feeling depressed or anxious? A variety of answers were given to this question. Patients said they would speak with their doctor, a psychologist or psychiatrist, the social worker, or another patient. With one exception, none of the patients participated in a support group.*

Nephrologists

Nephrologists mentioned the following topics that they would like to know about with regard to their patients' care experiences:

- Do patients understand their diagnosis, treatment, and progress?
- Do patients understand their treatment options?
- What upsets or pleases patients about their care?
- Do they feel safe?
- Are patients getting the care they need?
- Do patients feel better as a result of their care?
- Do patients feel their nephrologists are accessible and aware of their care?
- Are patients receiving requested/needed referrals?
- Do patients feel any language barriers with the staff at the facility?
- Are patients satisfied with the physical environment at the dialysis unit?

Both of the nephrologist focus groups emphasized the importance of patient education, and the first group suggested that the survey should evaluate whether patients:

- understand their disease and diagnosis.
- understand their disease progress and prognosis.
- received an explanation of their treatment options.
- whether this explanation was clear and comprehensive enough to allow patients to participate in an informed choice of treatment options should they so desire.

Home dialysis is a case in point. Patients should understand that they need someone at home to assist them in the procedure. In addition, they need enough information about the procedure to determine whether this is something they really want to do and have the confidence to do.

Nephrologists mentioned the following dimensions of care as being particularly important to patients:

Final ESRD Feasibility Report

- Physical comfort directly related to the procedure (e.g. non-painful access, relief from itching)
- Physical comfort related to the environment (e.g. room temperature, seating, access to TVs and reading material, opportunity to snack)
- Social aspects of care with regard to caregivers (e.g. continuity of care)
- Social aspects of care with regard to other patients.

Methods and Survey Administration

Patients

A number of focus group patients could speak to issues regarding survey methodology because they had responded to previous surveys regarding the quality of dialysis care.

Most patients expressed a preference for filling out the survey at home for practical reasons (e.g. too much noise at the center or difficulty writing while hooked up to the dialysis equipment) and to ensure their confidentiality. Many expressed concern that their future care would be adversely affected if criticism of the care they received in the past could be linked to them.

When asked about preferred modality for completing a survey (e.g., mail, telephone, or Internet), most patients stated that they preferred to answer questions either on paper or by phone rather than by hand-held computer or over the Internet. While patients liked the paper surveys because they could view all of the questions and easily go back and forth through the survey, those with significant physical limitations (including the ability to write and read small print) viewed the phone as the more desirable option.

Physicians who participated in the first nephrologist focus group conducted at the end of March suggested that it might be difficult to obtain candid responses from patients. The physicians said that patients are vulnerable and very dependent on the dialysis center staff and would therefore be reluctant to be critical of the staff or the care they receive.⁴ To investigate this issue, we built into the patient focus group protocol questions regarding how patients felt or would feel about rating staff and physicians at their center.

While patients liked the idea of being able to give feedback to the nurses and technicians that work at their dialysis center, many expressed concerns about confidentiality, particularly if they were asked to put their names on the survey. Again, patients expressed fears of retaliation if staff found out that they had reported negative feedback. Patients stated that there is pressure not to become a “problem patient”. By contrast, no patients in either group expressed concerns over answering questions about their doctor; some even indicated that they “would love it”-- they felt that patients should be asked questions about their doctors. One woman said: “We are never asked questions about our doctors, and how we feel about our doctors.”

⁴ The second nephrologist focus group did not express concern over patients’ ability to be critical of staff but did express concern regarding the administration of the survey in the dialysis center, citing the patient’s physical difficulty in completing the survey (e.g., while connected to the dialysis machine).

Final ESRD Feasibility Report

Nephrologists

We learned from the nephrologist focus group conducted at the end of March (predating the patient focus groups) that not all aspects of care can be attributed to one particular clinician or staff member. For example, while one individual may be responsible for attaching the patient to the dialysis machine, the responsibility for patient education is shared among several staff members. The second focus group yielded similar responses; for example, one participant described the situation as a “point-of-service kind of model” where the focus of the patients is on the person serving them, and there is no perception that any one person is in control of the entire scope of their dialysis care. Furthermore, ESRD patients typically suffer from comorbid conditions and they spend a considerable amount of time with dialysis unit staff. Many clinicians see their job as treating the total patient and their focus of care is broader than dialysis.

There was consensus that if ESRD CAHPS data were to be used to provide incentives for performance, those data should meet high standards of reliability and validity.

Nephrologists suggested that data be collected longitudinally but not more than twice a year. In addition, they mentioned a number of challenges that we should anticipate in the design and administration of the ESRD survey (e.g., sample size—some dialysis centers might have relatively few patients from which to obtain data).

Both nephrologist groups indicated that some patients would not be able to complete the questionnaire due to interference from the dialysis equipment, fatigue, low literacy, blindness or other handicaps. The first group noted, however, that when staff members assist patients in completing the questionnaire, patients’ privacy is compromised. In addition, patients’ responses to the survey may be biased more favorably when they know that clinic staff will be aware of their individual responses. Participants emphasized that patients do not spontaneously discuss concerns about their care but must be encouraged to do so.

Interviews

Methods

A series of interviews were conducted to determine: (a) what surveys dialysis facilities are using to assess patient satisfaction, (b) staff evaluation of the surveys currently used, (c) how facilities are using the results of their surveys, and (d) whether and how staff think that facilities should be held accountable for the results of patient surveys.

Twelve interviews were conducted. Three were group interviews with network executive directors, three were individual interviews with network executive directors, five were individual interviews with dialysis facility staff, and one interview was with the Director of Renal Care for a non-profit HMO. The network executive directors interviewed represented 6 of the 18 End Stage Renal Disease Networks across the country. Dialysis

Final ESRD Feasibility Report

facility participants consisted of two clinic administrators and three social workers from four proprietary facilities. One of the staff members interviewed worked at a non-profit facility. The HMO has contracts for all 150 of its facilities with three for-profit chains. The staff interviewed represented facilities ranging in size from 16 stations to 80 stations that offered a variety of treatment options (e.g. hemodialysis, peritoneal, and home-hemodialysis training).

All interviews were conducted by telephone. The interviews lasted from 30 minutes to over an hour. All of the group interviews were slightly over an hour in length. Below we summarize the main findings from the interviews.

Purpose and Use of Survey

Most facilities use some type of patient survey, although use is affected by chain membership. All of the persons interviewed who are associated with national chains said that all the facilities in their chains conduct regular patient surveys. They administer surveys at least yearly with one facility on a quarterly schedule. The chains supply the instruments and in some cases specify the sampling period and protocol.

The Networks are not involved in the administration of patient surveys and do not analyze the data. Often they only get involved if there are a number of complaints about a specific location. For example, in one of the Networks, when complaints are lodged, they encourage the facility to evaluate the situation more systematically and the network then sends them a copy of a survey instrument used in other facilities in that network.

Quality Improvement

Although most facilities collect information on patient satisfaction, often very little is done with the survey results. Some facilities have used the information to stimulate improvements in areas such as comfort levels of patients, social worker availability, services, and other staff issues. Another area in which facilities have attempted to improve processes related to patients who miss treatments.

In many of the chain facilities, the survey results are presented in reports that compare the facilities with other facilities owned by the chain locally and sometimes nationally. In facilities that are not owned by chains, comparative data is rarely presented.

Dialysis facilities have had varying degrees of success using information from patient surveys for quality improvement. One person reported talking with staff about the results, but did not think it affected process improvement activities. One facility made a decision to move staff to another facility, based on survey information, but did not directly address the staff problem. When asked why facilities did not use information obtained from patient satisfaction surveys more, many interviewees said that the data are not presented in a meaningful or useful way.

Final ESRD Feasibility Report

Thus, relatively little use is made of the data collected for quality improvement activities. Some of the networks conduct quality improvement activities but may need more assistance collecting and analyzing data, as well as applying the results to quality improvement strategies. Regular information collected from patients may enable the networks to focus on improvement and not just get involved only when there is a grievance.

However, many of those interviewed were concerned about the ways in which patient responses would be used. Many do not think they have control over some of the issues currently assessed, such as aspects of the treatment experience determined by chain policies, or things that are not under their control, such as transportation. Most were apprehensive about the prospect of having reimbursement determined by survey performance. Furthermore, many said that the data are not currently presented in a way that is useful for quality improvement efforts.

Choice

Opinions varied as to the usefulness of survey data for influencing patient choice. Although many thought that information should be released to stimulate facility response, it is not clear how useful such information would be to patients. Many of the network executive directors reported that patients usually do not change facilities, even when they are presented with such information. For many patients, changing facilities does not seem to be an option (e.g. contracts do not permit the change, few facilities offer that type of treatment, or the facility does not offer late shifts), and for others, it is too much of an inconvenience (e.g. too far from home or work). The staff interviewed consistently rated comparative information about other facilities as less important to patients than information about their direct experience of safety, courtesy of staff, and keeping on schedule

Reports

Interviewees were asked which groups should have access to dialysis facility reports on patient satisfaction. Some people felt that the reports should be given to the general public because that would get the attention of the facility. Others felt that it should go to all groups asked about, including other dialysis facilities, the regional ESRD Network, nephrologists, insurance companies, CMS, the public and corporate organizations of dialysis chains. Still others felt that patients in the facility, but not necessarily the general public should have the information. One person felt it was important to share the information with the facility staff as well.

Domains and Item Content

Most of the domains asked about in the interview, such as ease of appointment scheduling, interactions with physicians, technicians, and administrative staff and feeling safe during treatment were rated as important or very important by those interviewed. Interviewees thought that other issues such as the technical skill of physicians and

Final ESRD Feasibility Report

technicians were important but did not think that patients could assess those types of issues accurately.

Many problems that lead to grievances result from staff behavior. These problems include not explaining delays in treatment and waiting times and not appearing to care. Other common complaints about the staff include a lack of professionalism, a lack of sensitivity, and the doctor not having enough time for the patient. Another factor related to the staff that results in negative patient satisfaction ratings is staff turnover. Many of the surveys used distinguish between medical and administrative staff, but not other members of the patient care team (e.g. nutritionists, social workers, or technicians).

Most of the surveys used include questions about facility characteristics such as the temperature, how comfortable the chairs are, and whether there are working televisions. Some facilities do not feel these are issues within their control because a chain may have a policy concerning these amenities. For example, one person said that the chain specified what the facility temperature should be because there were so many complaints about the temperature. Transportation is another example of an issue patients often complain about, which facilities do not feel is under their control.

Methods and Survey Administration

Methodological issues raised included administration protocol, the types of dialysis patients that would be included, and developing an instrument that could be understood and completed by the majority of patients.

The majority of staff said that surveys are distributed at the facility, and patients are encouraged to complete the survey while receiving treatment. Several respondents think that passing the survey out in the facility and telling patients how meaningful it is can increase response rates. Many of the chains suggest that the surveys be completed in the facility to ensure a higher response rate. Several people, however, thought that having patients complete the survey in the facility might bias responses. Patients may be afraid of getting the staff in trouble or worried that they will receive worse treatment if they report problems. This is particularly a problem in some of the smaller facilities.

There was not a consensus among respondents about who should administer the surveys, although all agreed that they should not be conducted by the facilities. Options endorsed by respondents included having the surveys administered by an independent vendor, CMS, or the Network in conjunction with CMS. A point in favor of having CMS do it is that CMS is perceived as more legitimate than the network or an independent vendor.

Technical Expert Panel Meeting

Purpose and Use of Survey

Discussion focused on the potential value of a public domain standardized survey. Specifically, TEP members expressed concerns about a survey replacing what they are

Final ESRD Feasibility Report

already doing since most of the dialysis facilities and proprietary chains already have their own tools and administrative processes for surveying patients. They expressed concerns about both the costs involved and the loss of the ability to trend years of longitudinal performance data. Similarly, they want to be able to get answers to their own questions and fear that they will have to ask questions that are not relevant to them. Some participants noted that they currently use the results of their surveys for marketing and branding purposes, and expressed concern that a CAHPS survey would not meet that need.

There was much debate at the TEP meeting about the purpose of surveying ESRD patients. The TEP members were particularly concerned that one survey could not address the broad needs of multiple audiences; for example, addressing CMS's oversight to Congress as well as facilitating quality improvement. They also expressed concern about the correspondence of patient satisfaction data to patients' actual experiences of care at dialysis facilities. Lastly, TEP members voiced concern over the potential use by CMS of the results for disciplinary enforcement, including reduced funding.

Yet TEP members did acknowledge the benefits of a scientifically-validated and well tested instrument: reporting comparable results across dialysis facilities, providers, ESRD Networks, and geographic regions, and providing the research community data to generate a better understanding of the quality of care for ESRD patients.

TEP members expressed interest in the following benefits for the survey:

- Providing patients a platform to voice concerns;
- Investigating links between patients' experiences and clinical outcomes;
- Rewarding good quality in the context of a balanced scorecard;
- Educating patients about how facilities address patient concerns; and
- Identifying ways to evaluate the effectiveness of patient education.

Quality Improvement

The TEP members wanted the ability to add supplemental items to meet their own needs and assurance that the data would provide them a basis to institute improvements.

Choice

TEP members noted that ESRD patients have little if any choice of dialysis facilities because of factors beyond their control (e.g., insurance, physician's formal contractual relationship with the facility, location). Those dialysis facilities and proprietary chains that conduct surveys primarily use the results to help monitor/improve quality of care at the facility level.

Reports

Since few of the representative dialysis facilities seemed to be sharing survey results with patients, they expressed concern over what information actually will be reported to

Final ESRD Feasibility Report

patients and in what format. Also, TEP members questioned how data would be reported at the facility level. They noted that while they currently use their data to improve care, they also review and respond to patients' comments. The concern was that they might no longer have access to them.

Several participants noted that the results have to be reported at the facility level if they are to have any value for the patient. The facilities indicated that they use individual measures for quality improvement purposes; in general, they do not combine them into categories (or domains). Some expressed interest in rolling up items by discipline, area/facility, ESRD Network organizational region, and/or geographic area. They recommend providing some analysis with the data, including a discussion of their strengths and areas for improvement. Further, they requested that CMS explore the possibility of generating longitudinal data. For patient reports, they suggested that each facility could use the results to outline strengths and areas for improvement in patient newsletters or posters.

Domains and Item Content

TEP members mentioned several domains that they considered important: accessibility of care, acceptability of care, the patient physician relationship, the process of care, safety, respect, flexibility and convenience of scheduling, education, transportation, sense of control, facility culture and atmosphere, turnover, and billing issues.

Based on their knowledge and experience of the patient population, they suggested wording the questions from the patient perspective, using a 4th grade reading level, providing a comment field, researching the expectations of patients and families to understand domains that are important to them, and reviewing existing instruments for ideas. Also, they recommended distinguishing patient experiences with facility staff from those of physicians.

Methods and Survey Administration

Participants voiced concern over the financial and time burden on patients and facilities, especially if the facility continued to use their own instrument. They noted that response rates are often dependent on staff's encouragement, and that a third party vendor might be regarded as too remote. Also, they thought that a survey completed at the facility yielded a better response, although the patients may respond differently if they had just been dialyzed.

According to TEP members, an average of 15-20 percent of patients need assistance, in which staff strives to prevent biased responses. They voiced concern about collecting the responses and maintaining confidentiality. Since dialysis facilities tend to be small, with many serving fewer than 50 patients at any given time, TEP members were concerned that the response rates would not be useful at the facility level. Since many patients have cognitive impairments, language and literacy barriers, TEP members voiced concern that the responses would not be representative of the population.

There was consensus that a brief, simple survey, requiring approximately 15 minutes to complete was best, and that the instrument should be offered in Spanish and English.

Final ESRD Feasibility Report

They cautioned against using the skip format, font size and variety of scale responses in CAHPS surveys. Establishing a simple, clear, uniform process for administering the survey would yield comparable results and minimize staff burden. Because timely data is critical for quality improvement, they suggested that results must have a quick turnaround back to the facility (weeks or months).

They also counseled developers to be mindful when administering the survey because patients are tired during the treatment or immediately after; also, surveying mid-week may provide the best time for patient responses. Patients' experiences also depend on the kind of dialysis treatment they receive (hemodialysis vs. peritoneal) and would require different instruments. Other factors that affect the patient experience include when they are treated (day or evening shift), how long they have received treatment, their comorbidities, and demographic factors, such as age and geographic area.

Because ESRD patients spend time waiting for and getting dialysis treatments, they tend to develop close relationships with other patients. According to TEP members, this has implications for singling out only a sample of patients for the survey because patients will know who received the survey and who did not. TEP members suggested conducting the survey once a year. They also suggested using telephone administration to prevent barriers for patients who cannot self-administer the survey, but cautioned against using online survey administration.

Communicating with patients by cover letter to introduce the survey or using existing vehicles such as newsletter to disseminate the questionnaire may enhance the visibility of the tool and the patients' understanding of its importance.

Final ESRD Feasibility Report

Appendix B. Discussion of Recommendations

The following sections explore in more detail the recommendations made above.

Purpose and Use of Survey: Discussion and Recommendations

In this section we use the information presented above to answer the questions:

1. Use: Is there a demand for information provided by an ESRD hemodialysis patient experience of care survey?
2. Application: How might this information be used?

We will describe consensus across information sources regarding the answers to these questions as well as discrepant viewpoints.

Interviews with network executive directors administrators and dialysis facility staff (key informant interviews) support findings from the literature that many dialysis facilities (especially those affiliated with national chains) conduct regular surveys of patient experience. However, many focus group (FG) patients reported that they had never participated in an experience of care survey. In addition, there was consensus across literature review, key informant interviews and the Technical Expert Panel (TEP) that patient experience surveys currently in use vary widely and there is no accepted standard of measurement in this arena. This prevents comparisons of patient experiences of care across chains. Many key informants and patient focus group participants were enthusiastic about the prospect of a standard instrument to assess patient experience that could be used nationally and across facilities. In contrast, the TEP expressed reservations because they were concerned about inefficiencies that would occur were they required to switch to a new instrument. Many TEP members were organizationally responsible for surveying dialysis patient satisfaction. Thus, they were expert in the use and interpretation of a particular survey. This expertise, as well as the infrastructure for managing, analyzing and reporting the survey data, takes years to develop. Also, participants in the second nephrologist focus group expressed strong doubts about the validity and hence usefulness of data that would come from patient reports.

Recommendation:

There is some controversy surrounding the desirability of an ESRD CAHPS survey. To increase the chances of success for such an initiative, a strong effort might be made to incorporate network executive directors, dialysis facility staff, TEP members and the community of nephrologists into the design and development of the survey administration procedures, the survey itself, and methods for analyzing, presenting and interpreting the survey data. The work done to support this feasibility report, including key informant interviews, nephrologists focus groups and the Technical Expert Panel meeting represents an example of the kind of activity required to build consensus and a coalition behind the CAHPS ESRD survey effort.

Final ESRD Feasibility Report

Consumer choice

Sources were nearly unanimous in supporting the view that patients did not have a choice in the dialysis facility that they attended, so this information would not be useful for informing patients about where to go to get the best care. This was decidedly not the view of a number of participants in the dialysis patient focus groups, however. These patients expressed great interest in using such information to choose between facilities or to select a facility when traveling. The discrepancy between the views of these patients and the literature review and key informant interview results as well as the opinion expressed by the TEP and nephrologists focus group participants, may be due to the composition of the patient focus groups. The focus groups took place in urban areas and the participants were at least well enough to participate. Their health and location may have afforded them options not available to the majority of patients.

Quality improvement

Key informant interviews and the TEP meeting revealed that while these data are sometimes used for quality improvement, there is no consistency across the different survey efforts in what are the paths from the data to the particular QI action. Further, the need to maintain patient confidentiality should the data be used to guide improvements in care was emphasized by both the TEP and the patient and nephrologist focus groups. On the other hand, despite worries about staff retaliation, patients felt strongly that they should not be asked to participate in a survey if the information were not used to improve their care in the near term.

Compensation and Reimbursement

The literature review and patient focus groups were silent on the issue of linking physician compensation or facility reimbursement to patient experience data. By contrast the consensus among the TEP, key informant interviews, and one of the nephrologist focus groups was that patient experience data should not have financial consequences for providers. The most common reason given was that 1) those data were not reliable or valid and 2) the aspects of care included in patient surveys are not “actionable” by providers; that is, providers are not responsible for those aspects of care.

Recommendation:

The view of focus group patients that they could use patient survey data to inform decisions about where to receive care, conflicts with other sources which say that dialysis patients really have no choice in facilities. More information needs to be obtained to resolve this issue. Stakeholders were unanimous in their belief that these data can and should be used to guide quality improvement efforts, but that patient confidentiality must be maintained. The success of QI efforts based on these data will be influenced by how quickly the data are provided to the facilities and the provision of clear guidance regarding the QI actions that should be taken to achieve improvements based on the data.

Final ESRD Feasibility Report

Mechanisms should be put in place to enable “quick turnaround” of the survey data and “action steps” should be suggested for different ranges of scores. The use of these data to determine physician compensation or reimbursement of facilities would be very controversial and is unlikely to be acceptable to most stakeholders under any circumstances.

Reports

Although not an exhaustive list, some key questions related to reporting ESRD CAHPS information include:

1. Who are the target audiences (including characteristics of potential audience segments)? In addition, for each target audience critical questions include:
 - What is the context in which the information will be used (e.g., quality improvement by providers, potential patient use, any competing efforts to influence behavior, etc.)?
 - What are the hoped for outcomes of the use of information?
2. How can we best raise the salience and facilitate use of the information?
3. What should be the unit of assessment reported (e.g., dialysis facility, chain of facilities) and what level of information detail is most useful/appropriate for each target audience?
4. What is the most appropriate reporting media (e.g., paper or web-based) and dissemination strategy for each target audience?

Target audiences

As defined by CMS, the two main, and quite distinct, target audiences for ESRD CAHPS reporting are consumers (i.e., ESRD patients) and providers (i.e., nephrologists, dialysis facilities and networks).

The characteristics and context for the use of information are significantly different for the two main audiences, as are the goals for providing the information. As such, the information needs of both consumers and providers also differ. For example, the immediate goal of providing information to providers is use of the information in quality improvement efforts. The ultimate outcome should be to improve the quality of care delivered. Providers indicate they want detailed information on the measures and about topics such as sampling and response rates. In contrast, the type and extent of information that would be appropriate for providers is not likely to be appropriate for inclusion in a patient report. In addition, lower levels of literacy in the ESRD population make it advisable to target a report at a lower reading level than may be acceptable for the provider population. However, both providers and ESRD patients are likely interested in the quality of care within and between ESRD facilities, but for different purposes.

Recommendation: Develop and test separate reports for providers and ESRD patients. Patient reports also should be developed in both English and Spanish.

Final ESRD Feasibility Report

Developing and testing reports to facilitate use by the target audience

As noted above, the proposed uses of the information from the survey of ESRD patients are two-fold: to provide patients with information about the differences in quality of care between dialysis facilities, and to provide dialysis facilities and networks with information that motivates and facilitates quality improvement.

Results from the patient focus groups indicate that they are enthusiastic about seeing information from patient surveys. The groups also provided insight into the information that patients want from other patients. Less clear is how they would use this information.

With regard to providers, although many facilities already are engaged in patient surveying and reporting efforts, administrators and dialysis facility staff indicate that these reports often are not useful for quality improvement. For a report to be useful, it is most important that it be:

1. Relevant: The report should contain information that feeds into the facility's quality improvement plan. Providers feel that information about direct patient quality of care experiences is most relevant for QI purposes.
2. Actionable: Because many facilities do not have extensive QI resources, the report needs to outline next steps or make clear areas for improvement. In addition, the areas for improvement should be within the facility's control—or, if not within the facility's control (e.g., patient complaints about policies that are set at the network level), then this issue needs to be addressed at the appropriate level.
3. Timely: Outdated information is not useful for quality improvement purposes and is likely to be ignored.

Recommendation: The goal of reporting quality information to ESRD patients must be defined more clearly, by addressing the question of how patients are likely to use the information from a survey of ESRD patients' experiences with their care. In addition, given that patients may not have much choice of a dialysis facility, should reports for patients be designed to provide them with information to gauge the performance of their dialysis facility against other facilities with the goal of having patients advocate for change at lower-performing facilities?

More input from the provider community about what information would be most useful to them in their quality improvement efforts and how they would like to see information presented is also necessary.

Information presentation—unit of assessment, level of detail reported

All the data collected for this feasibility report (i.e., literature review, focus groups, interviews, and TEP meeting) suggests that information should be reported to patients and providers at the dialysis facility unit, not the chain of facilities or the ESRD Network level.

Final ESRD Feasibility Report

The characteristics of the audience, context for use of the information, and goals should also drive the detail level of the information to be reported to the two main audiences. For example, in addition to different content (e.g., information about survey methodology to demonstrate and support the report's validity and reliability) providers want information reported at the individual item level. Yet for consumers, item level reporting can result in an overwhelming amount of information that can be misinterpreted and is unlikely to be meaningful.

Recommendation: Initiate discussions with CMS and other stakeholders regarding optimal reporting strategies.

Media and Dissemination Strategy

Electronic or web-based reports likely will not be useful for the ESRD patient population due to their limited access to the Internet. However, paper-based reports may also be problematic due to vision impairments in a number of ESRD patients. Therefore, for some patients, it may be most useful to involve information intermediaries. Any dissemination strategy for ESRD patients should include the use of established information networks (e.g., patient newsletters).

On the other hand, electronic and web-based dissemination of information to providers is often ideal. We know from previous work that many providers value specificity and flexibility (e.g., the ability to customize reports at the appropriate level of detail). The optimal amount of detail and approach to making reports flexible (e.g., various pre-specified reports or output versus user defined reports) must still be determined in concert with providers. We also need to address basic dissemination questions such as who should receive the reports or notification that the reports are available (e.g., the individual dialysis facility, chain administrator, regional network executive director).

Recommendation: The patient focus groups only address what information was most salient to consumers and to whom they attribute responsibility for various types of care in ESRD facilities. The method cannot address how best to provide information to the patient audience (e.g., presentation formats, how to label data, media and dissemination strategies, etc.). This is an area for further investigation. In addition, we need to develop a better understanding of the information needs of the provider community in order to determine the most effective design and dissemination strategies.

To obtain buy-in from the provider community, it will be critical to demonstrate that we understand and have addressed their concerns. Continued consultation and information sharing with the provider community will be important.

Content of Survey—Domains and Individual Items for Both Quality Improvement and Consumer Reporting

Final ESRD Feasibility Report

The review of the literature, focus groups, and interviews revealed several important domains that may be relevant for quality improvement (QI) and reporting to consumers. The domains identified included:

- 1) communication with and education of patients;
- 2) concern and helpfulness of staff;
- 3) patient involvement in care;
- 4) coordination of care;
- 5) patient perception of staff proficiency;
- 6) interpersonal relations in the dialysis setting;
- 7) patient safety;
- 8) facility environment;
- 9) access/convenience of care
- 10) handling of grievances and complaints.

Because of the limited choice of facilities for ESRD patients, survey data may not end up being used for consumer choice but rather for QI and stimulating positive change in delivering care.

One of the design principles that guided the CAHPS survey development was to ask consumers only those questions to which they could give meaningful answers. The interviews conducted with network administrators, dialysis facility staff, and a Director of Renal Care indicated an acknowledgement of the importance of the technical skill of physicians and technicians but concern about the accuracy of patients' perceptions. In developing items to represent technical quality of providers it will be important to restrict items to those that consumers are the most appropriate source of information. For example, a candidate item might ask about the extent to which providers minimize discomfort when hooking up the patient to the equipment at the start of dialysis.

A listing of some potential item content falling within the 10 domains noted above is as follows:

- communication with and education of patients
 - how well physicians, nurses, and ancillary staff listen to the patient
 - how well staff explain aspects of treatment and self-care (diet, exercise)
 - enough time spent with patients
- concern and helpfulness of staff
 - comfort provided
 - courtesy, respect and dignity
- patient involvement in care
 - able to refuse care from some staff
 - patients involved in care decisions as much as wanted

Final ESRD Feasibility Report

- coordination of care
 - physicians and nurses are aware of what other staff have done
- patient perception of staff proficiency
 - minimizing discomfort during venipuncture and when administering treatment
 - machines are correctly adjusted
 - dialysis equipment perceived to be modern and well-maintained
- interpersonal relations in the dialysis setting
 - continuity of providers
 - patient interactions facilitated
 - pleasant social milieu
- patient safety
 - provision for emergency care
 - whether staff respond soon enough to problems with dialysis machines
 - proper maintenance of the access site
- facility environment
 - comfort
 - cleanliness
 - sanitation
 - temperature control
 - site (hand washing, use of gloves)
- access/convenience of care
 - transportation
 - parking
 - location
- handling of grievances and complaints
 - how quickly respond to grievances/complaints
 - whether resolution of grievances/complaints was satisfactory

Particular attention needs to be given to the potential distinction between items for public reporting versus quality improvement. This team will also entertain plans for the planned cognitive testing of the item set this winter in preparation for the Spring 2004 pilot test.

C. Methods and Survey Administration

One of the first issues to be addressed in the development of a standardized ESRD CAHPS survey is the way in which survey administration and analyses should be managed. There are several entities that could administer such surveys, including

Final ESRD Feasibility Report

treatment facilities, ESRD Networks, proprietary chains, an independent vendor or vendors approved by CMS, and/or an independent vendor under contract to CMS (as is currently done with Medicare CAHPS).

It is apparent from the work done as part of this study that many facilities do not have the capability to conduct surveys, and the Networks typically are not involved in this type of activity. All of the chains interviewed currently have a system in place for interviewing patients and presumably would be able to administer a standardized instrument using a prescribed protocol. A disadvantage of using the chains is that they have a vested interest in the outcomes of the survey, and there likely would be the perception of potential bias if they were used to administer the survey. Furthermore, if the chains were used, a complementary system would have to be developed for facilities that are not part of chains. Thus, although using chains to administer surveys might be politically attractive, the research team thinks that having either a defined set of certified vendors (as are used to administer CAHPS for NCQA) or a vendor or vendors under contract to CMS would provide the most comparable data across facilities.

Confidentiality is both an increasing concern among patients and now is strictly governed by the Health Insurance Portability and Accountability Act (HIPAA). Both the actual and perceived protection of confidentiality would be enhanced if CMS or a single vendor under contract to CMS were to administer the survey. In general, the comparability of survey results is enhanced if a centralized group does the analysis and reporting. However, there may be resistance to this type of approach from chains and facilities that have invested considerable resources into developing survey administration and analysis operations.

Recommendation:

To obtain the most comparable data across facilities, a set of licensed vendors (excluding chains themselves) or a vendor or vendors under contract to CMS should be used. Analysis and reporting should be conducted by CMS or a vendor under contract to CMS.

Sampling

Capacity of dialysis facilities to provide patient lists.

Interviews with administrators of dialysis facilities indicated that most currently conduct some type of patient satisfaction survey. While some facilities survey samples of their patients, others, including all of those interviewed, survey their entire patient population. According to the TEP members, this is in part a reflection of the camaraderie felt by the patients; the facilities survey all patients so that none will feel excluded and so that the facilities ensure they have heard from as many patients as possible. Having current patient lists in electronic form would facilitate sampling. We assume that at least those facilities that utilize sampling procedures have patient records in an electronic database format.

Final ESRD Feasibility Report

An assessment needs to be done of all dialysis facilities' capacity to provide high quality electronic lists of current patients.

Patient eligibility

The literature review, focus groups, and interviews with administrators revealed several issues that need to be considered when determining the eligibility criteria for an ESRD CAHPS survey. The first is the minimal experience with a facility. Although there are no empirical studies that help define what a minimally adequate period is, health care surveys often require that a patient have had from 6 months to a year's experience at a facility.

A related issue has to do with the eligibility of patients who at the time of sampling are in a hospital (either receiving a transplant or because their health has deteriorated) or a rehabilitation facility (e.g., recovering from the amputation of a limb or adjusting to blindness.). There also are a small number of patients that are seasonal visitors to facilities. Generally, the decision about the inclusion or exclusion of such patients is made based on likely biases associated with inclusion or exclusion. For example, if poor treatment was related to an increased possibility of hospitalization or treatment in a rehabilitation facility, then excluding such patients could bias results. However, the team thinks that the link between the aspects of care measured in a CAHPS survey and treatment in other facilities is likely to be minimal. In addition, obtaining current contact information for patients in hospitals or rehabilitation centers is likely to be challenging, and response rates from such patients – even those who can be contacted – will likely be low.

Recommendation:

Patient eligibility and inclusion criterion: Patient has been in treatment at facility for at least 6 months, although 3 months of treatment might be enough experience for patients to provide valuable information. Exclusion criterion: Patient is in or has been in (within the month) a hospital or rehabilitation facility.

Data collection

Mode of data collection

The main strategies for surveying patients include in-person interviewing, telephone interviewing, and self-administered paper and Internet-based surveys.

1. In-person administration

The advantages of in-person interviews include the ability to administer the survey to patients with low literacy levels and disabilities that preclude other methods (e.g., blindness). The main disadvantage is cost. The only practical way to conduct such a survey would be to use facility personnel, which would raise the

Final ESRD Feasibility Report

possibility that results could be biased by unstandardized and potentially biased administration of the survey. Thus, the team does not think that in-person interviewing is a feasible alternative.

2. Telephone Interviewing

Telephone interviewing would have many of the advantages of in-person interviewing, but could be conducted at much lower cost. This strategy would still cost substantially more than mailed questionnaires, however.

A strategy that has been used increasingly in recent years is Interactive Voice Response [IVR] technology. In this approach, a live interviewer will contact a patient and answer any questions, but then the interview is conducted primarily using voice recognition programs.

3. Self-administered questionnaires

Self-administered questionnaires are typically the least expensive way to administer surveys, but challenges to self-administration include the relatively high number of ESRD patients who are blind as a result of their renal disease. The feasibility of mail administration is directly related to the quality of the contact information that the facilities can provide.

An efficient way to distribute and collect surveys is to distribute them at treatment facilities. This is a strategy currently used by many facilities. In addition to the ease of distribution, this approach allows facility personnel to help patients complete the surveys. A disadvantage of completing surveys in facilities is that many survey researchers think that completing surveys within a treatment facility can seriously bias the results because patients are reluctant to make negative comments while they are in a facility receiving care. Allowing facility personnel to help patients complete questionnaires can also introduce serious biases and potentially jeopardize patient confidentiality.

4. Internet based surveys

Internet surveys are relatively low cost, but most field trials to date have resulted in very low response rates. Internet-based surveys are only appropriate in populations where all members have computer access and a known email address.

Recommendation:

CMS should conduct a field trial to compare the costs, response rates, and mode effects of:

- Telephone interviews
- IVR interviews
- Mail surveys with phone follow-up

Final ESRD Feasibility Report

Determine whether proxy or assisted interviews are acceptable.

The literature on proxy interviews indicates that the responses of proxy respondents often differ substantially from those of patients, and that the difference varies depending on the subject matter. Differences tend to be largest for aspects of care that are not directly observed by the proxy respondent. The only persons who routinely observe the care of dialysis patients are facility staff, and they are likely to be biased respondents. Thus, using proxies is not recommended. For similar reasons, allowing patient respondents to get assistance is not optimal but usually cannot be avoided, particularly with self-administered mail surveys.

Recommendation:

Patients should be encouraged to complete the survey themselves. The survey should include the question used on the CAHPS survey that asks if anyone helped the patient complete the survey. This variable can be used to case-mix adjust results, as is done with the Medicare CAHPS surveys. Surveys completed completely or in part by facility personnel should be excluded.

Data analysis

The literature review, focus groups, and interviews revealed several analytic issues that need to be resolved before final decision are made about a national ESRD survey. The first is the number of patients that would be available to estimate a CAHPS score both for an entire facility and for subsets of patients (e.g., home dialysis patients). A second is the need to adjust CAHPS scores for differences among facilities in the types of patients treated.

Action steps

Conduct analysis of the distribution of patients at different facilities.

Obtain data from a large administrator of ESRD surveys (e.g., a national chain) and conduct preliminary analyses of potential case-mix adjustment models, such as those used for Medicare CAHPS.

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¹ NKF

² NKF/DOQI

³ USRDS 2002

⁴ USRDS 2002

⁵ Ragson

⁶ Sehgal 1997

Final ESRD Feasibility Report

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⁸ Powe 2001.

⁹ Christensen 1994.

¹⁰ USRDS 2002

¹¹ USRDS 2002