

# **Dialysis Patient Transportation in Far West Texas**

## **Final Report to the Texas Department of Transportation (TxDOT) and the El Paso County Transportation Program**

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## **Executive Summary**

This report was prepared by the Center for Interdisciplinary Health Research and Evaluation (CIHRE) at the University of Texas at El Paso College of Health Sciences and it was undertaken as a joint collaborative effort between CIHRE and the El Paso County Transportation Program.

The study was designed to provide an overview of the current status of the transportation services for dialysis patients in Far West Texas including the following counties: El Paso, Presidio, Pecos, Hudspeth, Culberson, Reeves, Jeff Davis, and Brewster, and to examine how the main stakeholders— medical and transportation providers, as well as dialysis patients— viewed the transportation system and elicit from them suggestion for improvements.

The main motivation to conduct this study was the rising demand for dialysis treatment among the senior population of El Paso County caused primarily by chronic diseases, such as Type-2 diabetes and hypertension that affect kidney function and lead to End Stage Renal Disease (ESRD).

Dialysis treatment can be severely debilitating, especially immediately after treatment, thus precluding patients to regularly drive themselves to and from dialysis clinics. When not being transported by relatives, many dialysis patients in El Paso depend on licensed providers to transport them to and from dialysis clinics.

The growing number of dialysis patients nationwide puts a burden on transportation providers in terms of their capacity to provide timely services. It also puts a burden on the Center for Medicare Services (CMS) that since 1972 is required by law to cover the costs of dialysis to all ESRD patients regardless of their age (Section 2991 of Public law 92-603) and on the State of Texas for the cost for participants in the Medicaid program, which includes transportation to and from dialysis clinics.

### **Goals of the project**

The main goal of this study was to better understand dialysis related transportation issues and to investigate ways that transportation could be improved for patients currently undergoing hemodialysis in El Paso, Presidio, Pecos, Hudspeth, Culberson, Reeves, Jeff Davis, and Brewster Counties.

The study examines issues related to transportation and adequate treatment of dialysis patients and includes, but is not limited to, the following:

- Factors that influence dialysis clinic selection and referral
- Location of assigned dialysis clinics in relation to the patients' homes
- Number and availability of transportation providers
- Quality of service (driver courtesy toward patients, punctuality in picking them up from their homes, as well at clinics after the dialysis treatment)
- Distance covered on each trip to and from the patients' assigned dialysis clinics
- Time spent on each trip to and from the dialysis clinics
- Nephrologists' opinions on how to improve service for their patients
- Dialysis clinic personnel's opinion on how transportation may affect the adherence to dialysis treatment for the patients and the quality of life issues involved therein

- Transportation provider's personnel's opinions on how to provide better service to dialysis patients
- Patients' view of problems they encounter during their transportation to and from dialysis clinics and their suggestions on how to improve it

## **Project Design**

This study was based on qualitative data collection and analysis methodologies. It involved in-depth interviews with a convenience sample of 22 health providers (10 nephrologists, 6 dialysis clinic administrators, and 6 clinic social workers), 23 public and private transportation provider personnel (5 dispatchers, 12 drivers, and 6 managers), and 27 adult hemodialysis patients living in the El Paso, Presidio, Pecos, Hudspeth, Culberson, Reeves, Jeff Davis, and Brewster Counties.

CIHRE's Project Manager recruited all clinical and transportation providers' personnel for the interviews. Clinic nurses and social workers recruited the dialysis patients to participate in the study by handing them a pamphlet that explained the study and asked them to provide their name if interested in participating in the study. Only after the patient agreed to participate was the contact information given to the researcher responsible for data collection to set up an appointment and conduct the interview.

Before any data was collected all participants signed an informed consent form giving the researchers permission to conduct the interviews. UTEP's Institutional Review Board approved all instruments and procedures used in the study. Completed and transcribed interviews were analyzed using Atlas\*ti, a qualitative analysis software, to help codify the responses to the interviews in various themes that would allow the researchers to create a composite narrative of the opinions and suggestions of all participants.

Additionally, in an attempt to provide a better understanding of the increased costs of transportation of dialysis patients due to clinic assignment, the travel time of 287 dialysis patients (16% of the estimated 1,755 dialysis patients in El Paso in 2012) was plotted in a regional map using Geographical Information System (GIS) methodology to estimate the distance traveled by patients and the number of dialysis clinics bypassed during trips from the patients' residence to their assigned clinic.

## **Results**

The following is an overview of the analysis of the results of the interviews with clinical and transportation providers and patients describing the ESRD diagnosis, assignment to dialysis clinics, and the transportation process.

### *How patients are diagnosed with ESRD*

Nephrologists use the level of creatinine (a waste product of the body's protein metabolism) to determine the kidney glomerular filtration rate (GFR), which indicates how well the glomeruli (the tiny filters in the kidneys) are separating out waste products. When kidney function in general is 15% or less of the normal levels, a patient is referred to dialysis.

### How transportation to dialysis clinics is factored in clinical referrals

Upon diagnosis, the patient is assigned to a dialysis clinic by the nephrologist or a social worker. Nephrologists and dialysis clinic social workers reported that factors such as availability of transportation by the patient, the stage of ESRD, availability of seats in the clinic, distance from the patient's house to the clinic, are taken into consideration during the assignment process.

In El Paso County there are currently six main dialysis transportation providers: Sun Metro Lift, Project Amistad, Viba Transportation, BienVivir, Sun City Cab, and Dominion Ambulances.

### Actual role of the patient in dialysis clinic selection

Patients are usually given a list of dialysis clinics to choose from, but various factors may influence if the patient has the final say regarding the clinic assignment:

- There may be a clinic located near the patients' home, but it may be working at full capacity and unable to accept new patients.
- The patient's nephrologist may not work with the company that owns the dialysis clinic nearest the patients' home making treatment monitoring more difficult.
- The patients' clinic choice may be narrowed further because of the provisions of their health insurance or managed care organization.

### Issues impacting physician and patient selection of dialysis clinic

The main issue related to physician and patient selection of dialysis clinics is the nephrologist's association with available clinics. In most cases a nephrologist would be reluctant to send his or her patient to a clinic that is not owned by the company he or she works with, because it would make treatment monitoring more difficult. Under these circumstances patients may not want to change their nephrologist to attend a clinic located near their residence.

### Factors to consider when choosing a dialysis provider

Some of the most relevant questions to consider during the selection of a dialysis provider are as follows:

- Does the nephrologist vouch for the clinic treatment quality?
- Are there dialysis centers not far from the patient's home?
- Does the dialysis clinic offer diverse treatment options (peritoneal dialysis, home hemodialysis, in-center dialysis, in-center nocturnal dialysis, in-center self-care, etc.)?
- Does the clinic have a history of positive patient feedback about the clinic staff?
- Does the clinic offer additional support services for patients, such as emergency assistance transportation (especially in rural areas), insurance advisory, home medication delivery?
- Does the clinic offer resources to train patients and their caregivers to better manage their diet (dietitian meetings, recipes, nutrition / diet education)?

### Typical dialysis transportation experience

Patients are picked up from their homes, sometimes as early as 4:30 AM, depending on the shift assigned to them by the dialysis clinic. Patients receive treatment three times a week throughout the year. In urban areas, patients arrive at the dialysis clinic from 15 minutes to one and a half hours after being picked up, depending on the number of other patients or riders that have to be transported. In rural areas the trip may involve up to three hours each way. After the four-hour treatment is completed, patients board a van or bus and are taken home. Usually they are not taken directly home since the route taken by the driver varies daily depending on the addresses of other patients or riders being transported.

The distance travelled to and from a dialysis clinic would be shortened if patients were to be taken to the clinic nearest their residence. We estimate, based on a sample of 287 patients actual routes, that almost half (42%) of the patients bypass two or more dialysis clinics before they arrive at their assigned clinic. This extra mileage results in higher expenditures on fuel, extended driver's time, increased vehicle wear, and the decrease in the quality of life of the dialysis patients.

### Medical needs of the dialysis patients prior to and after dialysis treatment

Prior to the beginning of their dialysis treatment, patients should be informed about decisions and changes in life style that are required for a successful treatment. The first decision patients will have to make, jointly with their nephrologists, is what of the dialysis modalities (hemodialysis, peritoneal dialysis, at-home dialysis, etc.) is better suited to their medical condition and lifestyle. All patients in this study are under hemodialysis. Besides information about current prescribed medications, the patient or caregiver should also inform their physicians about their current use of herbal, vitamin and mineral supplements, which may, positively or negatively, influence the dialysis treatment outcome.

Explanations about changes in the patients' lifestyle to accommodate dialysis requirements should be described in detail. These adjustments will range from establishing a weekly pickup schedule to obligatory rest periods. Because dialysis is exhausting, patients should be informed about how to manage their energy expenditures before and after each treatment to avoid health complications.

Furthermore, a registered dietician should offer advice to patients about needed dietary change, food choices and meal portion size and in consultation with patient and caregiver design an individualized diet for each patient according to their particular health conditions and nutritional needs. Special attention should be given to maintaining adequate potassium, phosphorus, sodium and protein levels, throughout their treatment regimen.

Patients should be informed about all possible negative outcomes regarding poor nutrition and lack of exercise in order to avoid any complications with the dialysis treatment. Specifically, patients should be given information that fistula and graft sites need to be cleaned and assessed daily to avoid infection, and how to monitor changes in the skin's appearance, redness, bruising, localized swelling, or pustules. Because dialysis can have serious effects on the heart and other organs, it carries a significantly

high risk for sudden death and even minor complications should be dealt with immediately.

#### *Impact of transportation in worsening health conditions among dialysis patients*

The length of time spent trips to and from dialysis clinics is one of the most common issues affecting the patient's quality of life. Moreover, the interruption or modification of transportation schedules, lack of punctuality in picking up the patient at their homes or at the dialysis clinics after the treatment can lead to shortening of their dialysis time and have a negative effect upon compliance with the dialysis treatment, which negatively influences clinical outcomes.

#### *Description of dialysis clinics in the region*

Currently, 17 dialysis clinics serve the El Paso region. Of these, ten belong to DaVita, four to Fresenius (BMC), and the remaining three to DSI Renal. Inc. Presently, DaVita has two clinics that do not yet accept Medicaid insurance patients, but are expected to do so in the near future.

Dialysis clinics are not distributed evenly within the city. The majority of them are located in the central part of the city, and only a few located in the Far East and Northeast regions of El Paso. A map of El Paso showing the locations of the existing dialysis clinics is depicted in Figure 4.

Probably the growth rate of the dialysis patient population will require an expansion to the current facilities in El Paso. There is only one dialysis clinic in Pecos (Reeves County) and another in Ft. Stockton (Pecos County). These two clinics serve residents in Brewster, Culberson, Hudspeth, Jeff Davis and Presidio Counties, who have no local dialysis services. In rural areas the construction of clinics in remote and underserved areas in order to fulfill the increasing demand is a must.

#### *Estimation number of dialysis patients and dialysis clinic capacity 2012-2015*

Some clinics are expecting a growth of about 10-20% in the number of patients per year, while others have reported that they are expecting approximately the same number of patients, as new patients take the place of those who are deceased.

We estimate that the number of clinics will probably stay constant through 2015. Strategies to accommodate the increase in the number of patients include the addition of extra shifts, the utilization of unused space, or construction of additional space so more dialysis chairs can be installed.

These strategies are viable given that a linear projection of the growth of patients through 2015, based on the increase in the number of patients between 2002-2011, predicts an average growth of 94 patients a year (from 1,621 patients in 2011 to 1,998 in 2015) which means a manageable increase of 6 patients a year in each of the 17 existing clinics.

## Conclusions and Recommendations

The main problem mentioned by almost all participants, was the waiting time for transportation to and from dialysis clinics. Oftentimes patients have to wait for a long time to be picked up from their place of residence or at the dialysis clinics after finishing their dialysis treatment. This is compounded when both delays occur in the same day. The waiting time at the clinics was the most frequent complaint voiced by patients and also by dialysis clinic social workers. These delays may add from one to two hours to a patient's four hours dialysis treatment, in addition to the transportation time to and from the clinic.

Both dialysis patients and clinic personnel mentioned that some patients have to be transported for a long distance to the dialysis clinics to which they were admitted. If they are picked up late at their homes they will start treatment late at the clinic and run the risk of having their dialysis treatment time shortened. This situation places unnecessary pressure on the patients and on the dialysis clinic personnel, as treatment schedules have to be modified inconveniencing other patients and pushing back scheduled pickups.

Nephrologists and social workers stated that decreasing dialysis treatment time is a serious issue that negatively impacts the patients' health and may lead to a shorter life span. If this situation is repeated often, toxins are not removed adequately from the patients' system and will result in health complications that may lead to premature death. Some patients have complained that they sometimes miss complete dialysis treatments because they were not picked up at home at all, even if a pickup had been scheduled in advance,

Since the main concern voiced seems to be protracted waiting time, most of the recommendations by nephrologist, social workers, transportation staff and patients are centered on ways to shorten it, especially after the dialysis treatment is completed.

Since a dialysis patient's transportation is shared with others who are being taken to medical appointments, shopping malls, etc., it was suggested by some transportation providers staff, dialysis clinic personnel, and many patients that a certain number of vans or buses be used exclusively to transport dialysis patients. This would ensure a timely pickup and reduced travel time to and from dialysis clinics and would eliminate the possibility of shortened dialysis treatment times for patients. The impact of the above suggestions would be improved health outcomes and better quality of life for patients.

Participants in the study suggested that a committee be formed to achieve a better consensus on how to resolve various issues related to dialysis transportation and to improve services provided to the patients. This committee should include the El Paso County Transportation Program, as well as all the other transportation providers such as, Sun Metro, Viba, Project Amistad, Sun City Cab and BienVivir; and dialysis clinic personnel, nephrologists, and patients and their caretakers.

Some proposed solutions by van drivers and dialysis clinics' social workers were geared toward an improved scheduling system that would allow for constant communication

between drivers and dispatchers to decrease the pickup times at the patient's homes and clinics.

Social workers and dialysis clinic administrators commented that the various transportation providers should take into account that the dialysis treatment may have started late because of equipment problems, another patient's delay in completing the dialysis, late arrivals, etc., and that patients are not necessarily ready to be transported to their home immediately after the dialysis treatment. Moreover, there is always a short period of time when the clinics nurses have to check the patients to ensure that they are ready to be taken home.

### **CIHRE Recommendations**

We concur with the participants' recommendations and suggest some that are complementary to them.

As a buffer for unexpected waiting time, we suggest that an extra 10-15 minutes should be added to each pickup schedule from the clinics. The extra time that may be needed for patient to complete their dialysis and for stabilization is not currently being taken into account in the drivers' pickup schedule.

The communication among all stakeholders should be open and constant. It should involve the social workers at dialysis clinics, dispatchers and drivers at transportation companies, and patients to allow that any changes in schedules due to unforeseen circumstances be communicated easily among all the parties and thus decrease the frustration that patients experience when they have to wait without knowing when they will be picked up.

Given that sometimes delays are unavoidable, we suggest that all dialysis clinics provide at least a small snack for their patients when they have to wait for more than half hour to be picked up after their treatment. Many patients are diabetic and need to have some nourishment periodically to avoid hypoglycemia.

The use of Global Positioning System (GPS) should be mandatory in all transportation vans, to allow drivers to easily change routes in an unfamiliar part of town, when a traffic emergency arises, and to locate a new patient address. There are computer based systems using GPS in mobile units currently being used around the world, such as RouteMatch<sup>®</sup>, that are used to track transportation of patients, monitoring service adherence and allowing transportation managers/dispatchers the visibility and flexibility to better administer their fleet.

Every effort should be made to assign patients to the clinic nearest their residences. We propose that to expedite travel time transportation zones assigned to one single service provider be designed by mutual agreement among all transportation providers. This would minimize transportation costs, decrease the duration of travel time, and most important decrease the waiting time after treatment at the dialysis clinics, which directly will improve the patients' quality of life.

## Introduction

Given the need to better understand all the factors and issues that affect the transportation of dialysis patients, the El Paso County Transportation Program contracted with The University of Texas at El Paso's Center for Interdisciplinary Health Research and Evaluation (CIHRE) to conduct a study to examine ways to improve it.

The study was designed to provide recommendations to the Far West Texas/El Paso Regional Transportation Coordination Committee (WTEP) of the current status of the transportation services for dialysis patients in Far West Texas including the counties of El Paso, Presidio, Pecos, Hudspeth, Culberson, Reeves, Jeff Davis, and Brewster, and to examine how the main stakeholders— medical and transportation providers, as well as dialysis patients— viewed the transportation system and elicit from them suggestion for improvements. The main motivation to conduct this study was the rising demand for dialysis treatment among the senior population of El Paso County caused primarily by chronic diseases, such as Type-2 diabetes and hypertension that affect kidney function and lead to End Stage Renal Disease (ESRD).

The study findings and recommendations were based on qualitative data collected from interviews with medical and transportation providers and dialysis patients in El Paso County— the largest populated area in West Texas— and also in Fort Stockton, Texas to examine differences between a urban and a rural transportation issues

### Goals of the Project

The main goal of the project was to investigate a range of issues associated with dialysis patients transportation based on the analysis of interviews with patients and the medical, transportation and dialysis providers that serve them in the West Texas Counties of El Paso, Hudspeth, Presidio, Brewster, Jeff Davis, and Culberson.

The study examined current issues affecting patients' transportation to and from dialysis clinics and its effects upon the patients' quality of life. The study elicited recommendations from nephrologists, clinic and transportation personnel, dialysis patients, and from the CIHRE's staff on how to improve transportation services. It included, but was not limited to the following:

- Factors that influence dialysis clinic selection and referral
- Location of assigned dialysis clinics in relation to the patients' homes
- Number and availability of transportation providers
- Quality of service (driver courtesy toward patients, punctuality in picking them up from their homes, as well at clinics after the dialysis treatment)
- Distance covered on each trip to and from the patients' assigned dialysis clinics
- Time spent on each trip to and from the dialysis clinics
- Nephrologists' opinions on how to improve service for their patients
- Dialysis clinic personnel's opinion on how transportation may affect the adherence to dialysis treatment for the patients and the quality of life issues involved therein
- Transportation provider's personnel's opinions on how to provide better service to dialysis patients
- Patients' view of problems they encounter during the transportation service to and from dialysis clinics and their opinions on how to improve it

## Origin of the Project

The project started at the request of the Far West Texas/El Paso Regional Transportation Coordination Committee (WTEP) that wanted to ascertain the present situation and the various issues related to transportation services to dialysis patients from various public transportation providers. The project findings were to provide strategies to improve the transportation of patients to and from dialysis clinics with the ultimate goal of enhancing their quality of life. A secondary goal was to examine ways to decrease the costs of transportation while maintaining a high quality service. Finally, the project was intended to examine trends in dialysis treatment to better prepare for an anticipated rapid growth in needed transportation services.

The Far West Texas/El Paso Regional Transportation Coordination Committee (WTEP), a collaboration of health, human services and public and private transportation provider, formed in 2004 in response to Texas Transportation Code Section 461, became interested in this issue when transportation providers began to report a rapid growth in the percentage of trips to dialysis clinic locations and the very early departure times required of transportation providers to reach clinics for rural dialysis patients.

WTEP formed a workgroup to further explore and respond to dialysis transportation issues and to prepare for its expected growth. For example, Sun Metro and Project Amistad have reported that 30% and 49% of all their trips are respectively to dialysis clinic locations. Since both of these providers are operating at near capacity, the rapidly increasing number of dialysis trips that are requested raises real concerns for their future ability to meet demand. In fact, due to the high percentage of dialysis trips currently funded under the Older Americans Act, the Rio Grande Council of Governments' Area Agency on Aging (AAA) has been unable to provide funding for new requests for transportation assistance.

Dialysis treatment is a very debilitating procedure and it does not easily allow for self-transportation to and from clinics, and most patients require that some form of transportation services be provided. Many persons receiving dialysis treatment in the region use public or private transportation providers to travel to and from dialysis clinics. This arrangement can last for many months or even years, depending on the age and health status of the patients.

The demand for transportation to and from clinics is poised to increase in the near future to keep pace with the increased demand for dialysis. This increase could make transportation services unsustainable given the high investment related to vehicle acquisition, transportation personnel cost, vehicle maintenance, and rising fuel costs, and potential funding restrictions by the state of Texas.

With potential funding changes in the State of Texas Medical Transportation Program (MTP) and other funding sources related to Medicaid in Texas, it is vitally important for all stakeholders involved — transportation providers, dialysis clinic administrators, the WTEP, and of course, the patients themselves — to fully understand the financial and logistic issues associated with dialysis transportation and develop a strategy to most efficiently use existing transit resources and identify additional resources to satisfy the growing demand.

The Far West Texas/El Paso Regional Transportation Coordination Committee (WTEP) included these concerns in the updated Regional Transportation Coordination Plan. The Regional Transportation “Priorities, Recommendations and Actions” section includes as a goal to “Fill unacceptable gaps in service especially for transit dependent populations through the continuous identification and assessment of changing mobility needs. Expansion of financial support, increased efficiency, redeployment of resources and services innovation” with a prominent implementing objective to “Create a workgroup to study current and future transportation needs and resources for dialysis patients and providers to maximize coordination and efficient use of funds.”

The updated Regional Transportation Coordination Plan also acknowledges that the rapidly increasing use of various forms of demand-response public transportation for dialysis trips is a significant contributor to transportation providers operating at near capacity. This means that potentially other trips are being denied, in some cases for medical services that could prevent or forestall the need for dialysis. If the unavailability of transportation prevents a patient from attending a dialysis session, if delays result in a decrease in the time of dialysis, or if unreliable transportation forces the patient to wait for a long time at the clinic after a 4 -hour dialysis treatment session, this can seriously affect the health status and the overall quality of life of patients. The Regional Plan also states that the “lack of coordination between providers renders the system incoherent and redundant.”

It is important for regional dialysis and transportation stakeholders to act quickly to re-deploy existing resources in a more efficient manner and identify new resources to meet documented increases in demand in dialysis patients’ transportation. Additionally, the possible conversion of the MTP by the Texas Health and Human Services Commission from a per-use funding mechanism to a capitated system that awards MTP funding on the basis of the Medicaid population raises serious concerns, since a region that has a high percentage of dialysis patients that must travel to receive care three days each week will have much higher transportation costs compared to a region with few dialysis patients who may travel to medical care only a few times each year.

## **Background**

To better understand the transportation needs of dialysis patients, it is necessary to examine the etiology and natural history of Chronic Kidney Disease (CKD) and its evolution to End Stage Renal Disease (ESRD), with the attendant need for dialysis. Although chronic kidney disease sometimes results from primary diseases of the kidneys themselves or other conditions (prolonged use of certain medications, HIV infection, enlarged prostate, atherosclerosis, the major causes of CKD are Diabetes Mellitus (diabetic nephropathy) and hypertension — medical conditions that are present alone or together in 65% of an ESRD diagnosis <sup>1</sup>.

### **How Patients are Diagnosed for and Referred to Dialysis Treatment**

During the routine examinations of patients diagnosed with CKD, nephrologists measure the level of creatinine (a waste product of the body’s protein metabolism) with a simple blood test. A normal adult creatinine blood levels is about 0.6 to 1.2 milligrams

(mg) per deciliter (dL) in adult males and 0.5 to 1.1 milligrams per deciliter in adult females. Nephrologists use the level of creatinine to determine the glomerular filtration rate (GFR) to determine how well the glomeruli (the tiny filters in the kidneys) are filtering out waste products. The higher the GFR, the better the kidney is functioning. Most patients do not show symptoms of decreased kidney function until the GFR is .20mg/dL or less, and some people don't feel sick until the GFR is as low as .10 mg/dL. When kidney function is .15 mg/dL or less ESRD is diagnosed, and a patient should be referred to dialysis as soon as possible <sup>2</sup>.

Individuals diagnosed with ESRD require either dialysis or kidney transplantation to survive. In 1972, the Social Security Act extended all Medicare Part A and Part B benefits to individuals with ESRD who are entitled to receive Social Security benefits. This entitlement is nearly universal, covering about 90 percent of all people with ESRD in the United States.

Chronic renal failure, or ESRD, impacts more than 2 million patients worldwide, including 571,414 in the U.S. – a number growing by 3.8% annually. Annual care costs in the U.S. approach \$82,000 per patient, for a total cost exceeding \$42.5 billion <sup>3</sup>. Yet the dialysis treatment itself represents less than one-third of this cost <sup>1</sup>.

### **Factors Determining Dialysis Modality and Clinic Selection**

Upon diagnosis of End Stage Renal Disease (ESRD), patients are offered information on dialysis modality choices available, most frequently hemodialysis or peritoneal dialysis at home or in a clinic is recommended. Disease-related stressors and coping behaviors can also have an important influence upon dialysis selection, and the patient's nephrologist is the best-indicated person to help with this decision. Figure 1 depicts the actors involved in the ESRD diagnosis, referral to a dialysis clinic, and the transportation of patients to and from a dialysis clinic. The diagram in figure 2 illustrates the transportation process to and from dialysis clinics in more detail <sup>4</sup>.

Patients about to start dialysis can also choose their dialysis provider and treatment facility. Although the patients' options may be narrowed because of the provisions of their health insurance or managed care organization, it's important for the patient to be aware of other factors to consider in the selection of a dialysis clinic. These include the friendliness and knowledge of the clinic personnel and the availability of a convenient hour for dialysis. The main factor that affects the patients' quality of life (QOL) on a daily basis is the distance from the patients' residence to the dialysis clinics which is directly related to the time spent being taken from their home to the clinic and back <sup>5</sup>.

The number of clinics that are available to dialysis patients in El Paso is comparable to urban regions of the same size and density, although clinics are more concentrated in Central and East El Paso with only one clinic on the West Side and the Northeast.

Table 1 shows all 20 dialysis clinics available in the City of El Paso in 2012 serving about 1,621 patients, these include one (Beaumont) that is run by the U.S. Army.

Table 1. List of all Dialysis Clinics in the City of El Paso (2012).

License Number	Facility Name	Zip
007906	Davita -Mission Hills Dialysis	79902
007894	Davita - Central City Dialysis Center	79902
000242	Davita Mesa Vista Dialysis	79902
008148	Davita Sun City Dialysis Center	79902
000128	Fresenius Medical Care - El Paso Cliff View	79902
110125	DSI El Paso West	79902
110092	DSI South	79927
007895	Davita West	79905
007893	Davita Cielo Vista Dialysis	79915
Not Available	William Beaumont (ARMY)	79920
008120	Davita Transmountain Dialysis	79924
007174	Fresenius Medical Care -Vista Del Sol	79925
008479	Upper Valley Dialysis	79932
000649	Davita - Loma Vista Dialysis	79935
000111	Fresenius Medical Care - El Paso Gateway	79935
006358	DSI- El Paso East	79935
008500	Fresenius Medical Care Horizon Dialysis	79936
008408	Davita East Dialysis	79936
110021	Access Care-Fort Stockton	79735
008098	Reeves County Hospital Dialysis	79772

Ten of the dialysis clinics serving the general population of the City of El Paso belong to DaVita, four to Fresenius (BMC), and the remaining three to DSI. The DaVita Loma Vista clinic in East El Paso is by far the largest in the region.

Most clinics have about 20 chairs and three shifts which accommodate approximately 60 patients a day. Patients are seen three times a week, either on Mondays, Wednesdays and Fridays; or Tuesdays, Thursdays and Saturdays. Only one clinic offers night dialysis treatments, although four clinics will be expanding to four shifts in the near future to accommodate the increase in demand. Table 2 shows the projections for expansion between 2013 and 2015 by 14 clinics in El Paso.

Table 2. Selected Dialysis Clinic Capacity Projections 2013- 2015.

Name of clinic	Projection (2013)	Projection (2014)	Projection (2015)
Da Vita East	112 (18 chairs- 4 shifts)	111	117
Da Vita Mesa Vista	118 (24 chairs- 4 shifts)	120	120
Da Vita Central City	116	120	120
Da Vita West Texas	120	120	120
Da Vita Loma Vista	279 (4 shifts)	288 (24 chairs- 4 shifts)	288
Da Vita Sun City	120 (3 shifts)	120	120
Da Vita Transmountain	146 (24 chairs)	165 (36 chairs)	185
Fresenius-Cliff	83	93	103
Fresenius - Gateway	60 (24 chairs)	60	60
Fresenius- Vista del Sol	93	103	123
Fresenius-Horizon	93	103	123
DSI	112 (18 chairs- 4 shifts)	132	150
DSI East	105 (18 chairs)	111	117
DSI West	55	61	67

### **How transportation to dialysis clinics is factored in clinic referrals**

Nephrologists and social workers attempt to assign dialysis patients to the clinic nearest the patient's place of residence. This is not always possible given the availability of seats in a specific clinic, and the referral is most times made to the nearest clinic with an available chair, even though the clinic may be many miles from the patient's residence.

The dialysis clinics' social workers provide a list of options for new patients regarding transportation options and providers, according to the benefits they may have. For example, patients covered under Medicaid can receive no-cost transportation from the local Medical Transportation Program (MTP) provider and calls the statewide MTP call center to schedule dialysis trips. Those covered only under Medicare, which does not automatically pay for transportation, may qualify to use Sun Metro's ADA-paratransit LIFT service for a fee and contacts Sun Metro directly in order to schedule the first and subsequent trips to the dialysis clinic.

### **Actual role of the patient in dialysis clinic selection**

The study revealed that patients are usually given a list of dialysis clinics to choose from, but other factors are involved that may prevent the patient having the final say regarding actual clinic assignment. The main factor is related to the number of available dialysis chairs in the clinic that is nearest to the patient's home, which may be working at full capacity and unable to accept another patient. Moreover, the patient may choose not to select a particular clinic even though it may be located near their home to keep seeing their own nephrologist. The patient's nephrologist may not work with the company that owns the clinic nearest the patients' home making treatment monitoring more difficult. Because nephrologists are required to visit the patients at the clinic at least once a month to assess their health status, in most cases a nephrologist would be reluctant to send the patient to a clinic that may not give them access to the patient at the dialysis clinic. The patients' options may be narrowed further because of the provisions of their health insurance or managed care organization.

### **Typical dialysis transportation experience**

After the initial assignment is made to a particular clinic, the patient starts a regular dialysis regimen, which consists of treatments three times a week throughout the year. The patients interviewed in the study mentioned that they are usually picked up at their homes by a van at a pre-determined time and arrive at the dialysis clinic from 15 minutes to one and a half hours after being picked up. In rural areas the trip to a clinic may take up to three hours each way. The typical treatment lasts four hours. After treatment, patients board a van or bus and are taken home. Usually the route taken by the driver to and from a dialysis clinic varies daily depending on other dialysis patients being transported, and other passengers that may be going to other appointments not related to dialysis.

The distance travelled to and from dialysis clinics can be shortened if patients were to be taken to the clinic nearest to their residence. We estimate, based on a sample of 287 patients, that almost half (42%) of the patients bypass two or more dialysis clinics

before they arrive at their assigned clinic. This implies added costs for extra fuel, driver's time, vehicle wear, and a decrease in the quality of life of the patients.

### The Diagnostic, Referral and Transportation Process

In figure 1, the path from diagnose to dialysis treatment is shown in red. A primary care doctor diagnoses CKD and refers the patient to a nephrologist who works with the patient to manage the disease. Depending on the course of the disease, the patient may be diagnosed with End Stage Renal Disease (ESRD), which requires dialysis.

The patient and the social work decide on the clinic to which the patient should be assigned and also the transportation provider that is better suited to the patient, given the constraints discussed previously.

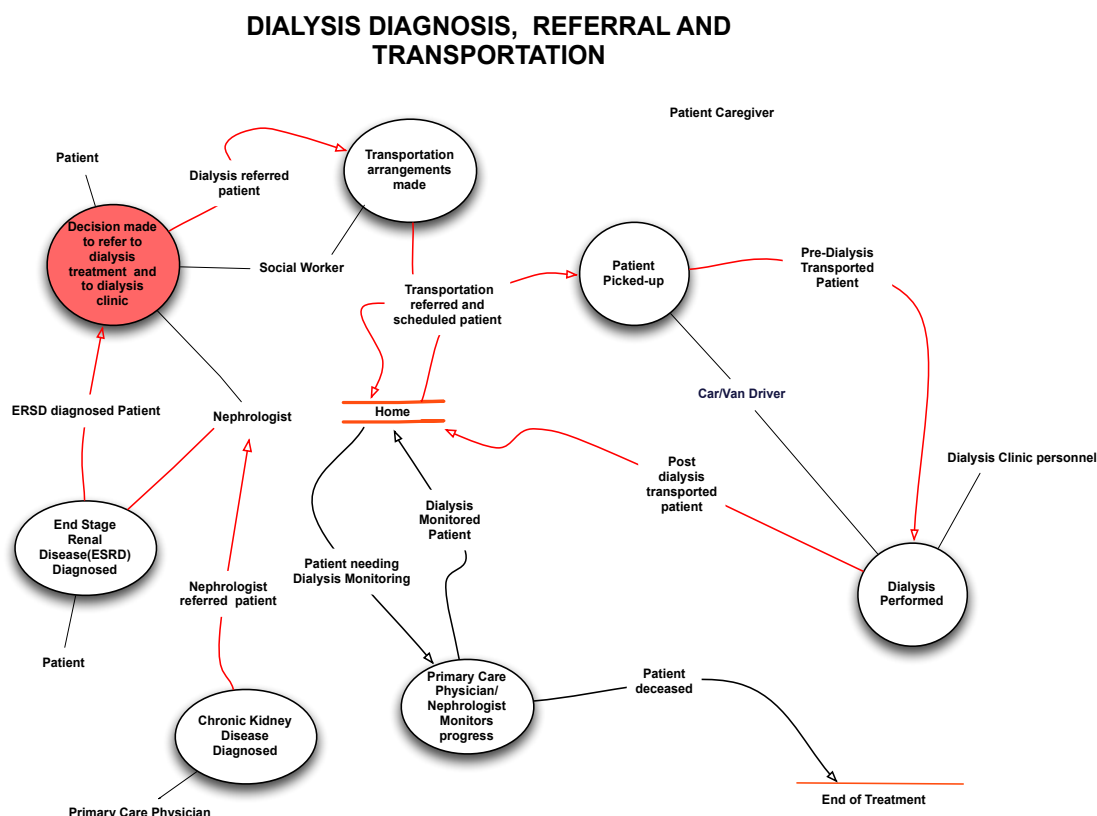


Figure 1. Diagram complete diagnostic, referral and transportation process- main path in red.

Figure 2 depicts the dialysis transportation process. After the transportation scheduling staff, the transportation dispatcher and the patient or the caregiver decide on the schedule for the three times a week dialysis treatment, the transportation process starts. The patients are picked up at their homes at an established time there times a week, and transported to the dialysis clinic. At the clinic, the patients are connected to the dialysis machine and for four hours the dialysis is performed. After being examined by the clinic nurse, and discharged, the patient sits in a waiting area until the bus arrives and is taken home. The process is simple, and should proceed smoothly, but for the problems that are generated by delays at each end of the transportation process.

## Dialysis Transportation Provider

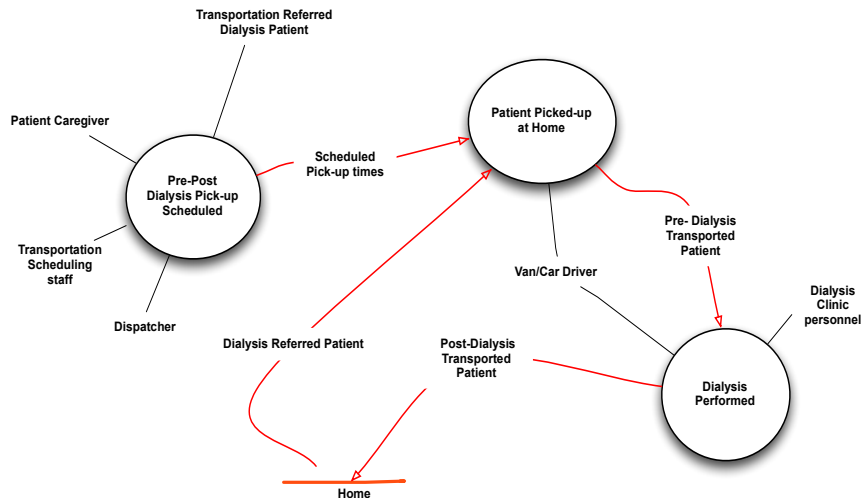


Figure 2. Diagram of the dialysis transportation provider process – main path in red.

## Study Methodology

### Project Design

The study was designed to better understand and suggest ways to improve transportation services for hemodialysis patients in El Paso and the rural counties of Hudspeth, Presidio, Brewster, Jeff Davis, and Culberson, with regard to clinic selection and assignment; the quality of service, safety, and punctuality of the transportation services; and to evaluate if the transportation routes to and from the patients' homes were the shortest possible in order to decrease transit time to and from the dialysis clinics.

The study was planned as a research project based on grounded theory<sup>\*</sup> methodologies consisting of in-depth interviews and qualitative analysis methodologies. It involved 72 individual interviews with dialysis patients, and medical and transportation providers in El Paso and Presidio Counties.

As shown in Table 3, the study involved a convenience sample involving 22 health providers (10 nephrologists, 6 dialysis clinic administrators, and 6 clinic social workers), 23 public and private transportation provider personnel (5 dispatchers, 12 drivers, and 6 managers), and 27 male and female patients, 55 years of age or older who were undergoing hemodialysis in the cities of El Paso and Marfa.

Although in the original protocol the researchers had suggested that two focus groups were to be held with dialysis patients enrolled in the study; further consultation with the

<sup>\*</sup>Grounded theory method is a research method in which data is collected through a variety of methods and coded for meaning extracted from the text, grouped into concepts from which *categories* are created.

nephrologists, dialysis clinic managers, transportation supervisors, and patients, made it clear that the logistics of having patients transported to a central location for the focus group was not feasible and detrimental to their health. Most patients want to rest on the days they do not have to go to the clinic and the prospect of being transported again was daunting. It was decided, in consultation with the project funders, that the focus groups were not to be conducted.

Table 3. Number of Study Participants.

Categories	Number of Participants
Patients	27
Nephrologists	10
Social Workers	6
Dispatchers	5
Drivers	12
Clinic Administrators	6
Transportation Managers	6
<b>Total</b>	<b>72</b>

To be eligible to participate in the study, medical providers to be interviewed had to be directly involved in the process of referral of one or more patients to a dialysis clinic due to end-stage renal disease (ERSRD) in the past year. In order to be included in the study, transportation provider personnel as well as the dialysis clinic personnel had to have been in their current position at least six months prior to the date of the interview. Male and female patients 18 years of age or older undergoing hemodialysis were included in the study. The study participants were also non-institutionalized, at least partially ambulatory (including wheelchairs, walkers, and similar devices) and had been provided transportation services for a minimum of six-months prior to the date of the interview. All participants were also able to understand the contents of and to provide a signed informed consent form prior to the beginning of the interviews. Those individuals who did not meet the above inclusion criteria were not able to participate in the study.

### ***Privacy and confidentiality of participants***

All study participants had complete control over the extent, timing, and circumstances of participating in the interviews. They were informed twice (verbally and in the informed consent) about their right to refuse to participate or leave the study at any time, for whatever reason, which did not have to be disclosed unless desired. All participants were requested not to mention their name during the interview. No personal questions about a participant's sexual orientation, drug use, sexual behavior, previous convictions, or health status were asked of participants. The only information available to researchers, given the subject matter of the study, was that patients were diagnosed with ESRD and were receiving dialysis treatment and that all medical and transportation providers were employed fulfilling a needed role in the dialysis process.

Only the main researcher had access to the data files that contain the contact information of participants to facilitate the scheduling of interviews. The researcher scheduling the interviews was provided only the necessary information to contact participants. All data were coded and no personal identifiers were made available.

The interview transcriber only had access to digitally recorded interviews. Only a code number was part of the transcribed file name, identifying the participant category. All data were removed from the CIHRE computer upon completion of the transcription.

All data analysis results were aggregated and thus reported. No names, pseudonyms, or codes were used to identify any quotes obtained verbatim from the digital recording and will be identified in presentations or publications only by sex and age of the participant being quoted.

### ***Data collection procedures***

The recruitment of health providers, dialysis clinic and transportation personnel was facilitated by the respective administrators and managers. Dialysis clinic and transportation personnel were approached by the administrator or manager and explained that researchers from CIHRE were interested in interviewing them confidentially and that management had agreed that the interviews be conducted. Permission was sought and obtained from management for CIHRE researchers to conduct interviews with their personnel in-situ and to help in the recruitment of dialysis patients to be interviewed.

After preliminary discussions with clinic personnel, it was decided that the most efficient way to contact patients while maintaining their anonymity during the recruitment phase, was to have the clinic social workers approach them while they were at the dialysis clinic and ask if they would be willing to participate in a study to examine issues relevant to their transportation to and from the dialysis clinics.

Patients were told that they would receive a compensation for the one-hour interview and that the interview would be conducted in a place of their choosing — most likely their homes. A bilingual (English-Spanish) pamphlet explaining the project was given to the patients for perusal during the dialysis treatment (please see Appendix 1). After the patient had read it, the social worker took the name and phone number of the patients who consented in being contacted and forwarded it to the CIHRE Dialysis Project Manager. This procedure took a minimal amount of time from the social worker's duties and did not interfere with the dialysis clinic workflow.

Only after the client gave permission for the interviewer to call them, they were contacted to set up an appointment for the interview. No names were written down during the interview and the only link between the patient name, address and phone number was a master list that the main researcher kept under double lock and key in the CIHRE office. This list will be kept for three years after the end of the project, and destroyed afterwards.

A semi-structured interview guide tailored to each of the three provider categories (medical, dialysis clinic or transportation personnel) and to dialysis patients was used. The guide contained questions that probed the perceptions and opinions of the

participants related to the dialysis process. They ranged from the assignment to a dialysis clinic to the transportation to and from the patients' residence, to the nephrologists' follow-up visits. A copy of each of the interview guides is included in Appendix 2.

All interviews were conducted in places that protected the privacy and confidentiality of the study participants in a venue that was comfortable to the patient. In most instances, the interview was conducted at their place of residence or at a relative's residence. A signed informed consent was obtained for each participant prior to initiation of each interview. These informed consent forms in English and Spanish are included in Appendix 3. Before signing the informed consent form, participants were asked to read it completely and asked if they understood its contents and if they had any questions. The informed consent included explanations about the reason for the study, and the risks and benefits that may accrue to participants by taking part in the voluntary and confidential study. All interviewers were bi-lingual and interviews were conducted in English and Spanish depending on the participant's choice of language.

No names were required and only the participant signature and the assigned code numbers for analysis appeared in the consent form. The signed informed consent forms were transported to the CIHRE's offices and kept in file cabinets under double lock and key on the same day they are signed or during the next workday.

All individual interviews lasted approximately 90 minutes, and, with the participant's consent, were recorded using two digital recorders. At the beginning of the recording, the interviewer identified himself/herself and stated the daytime and location of the interview and asked each participant to state if he/she understood the informed consent form and had granted permission for the taping of the interview and note taking. Using an interview guide the interviewer then proceeded to ask questions and probe for more explanations whenever necessary.

To compensate for their time, at the end of each interview a \$25 incentive was offered to participants in the form of a gift certificate. Receipts for each gift card were signed by the participant and will be treated as confidential information and will be kept under double lock and key at the CIHRE offices.

### ***Constraints under which the research was conducted***

Initially, three major companies that provide dialysis treatment in El Paso County: Da Vita, DSI, and Fresenius Medical Care (FMC) were contacted by the researchers to obtain access to their facilities either to interview staff or to obtain confidential access to their patients.

The response from the three companies was slow, since none of the major corporate offices are located in Texas and the researchers were directed to various levels of the corporate structure to obtain permission to access the clinic personnel and to recruit patients for the study. After 8 weeks of delayed responses, Da Vita agreed to participate in the study and to permit the researchers to interview their patients and clinic personnel (administrator and social workers) in 6 clinics located in diverse areas within the City of El Paso. There was still a slight delay while the corporate offices communicated with each of the clinic managers to inform them of the agreement.

Unfortunately, after more than three months of delay the two remaining dialysis companies, Fresenius and DSI, declined to participate in the study, citing conflicts between the study aims and corporate policies on research. DSI explained that they were occupied in the expansion of other clinics throughout the country and therefore they could not participate at that time. Documents received from Fresenius stated that they required 10% of the study budget as payment in order to participate in the research. Additionally, Fresenius did not agree with their clinic personnel recruiting the patients with a pamphlet that mentioned that a monetary compensation would be offered to the participants. The company further stated that they did not want anyone to think that it was Fresenius offering the compensation, even though it was clearly stated in the pamphlet that it was the CIHRE who was offering the compensation for voluntary patient participation.

For these reasons, it was decided to work only with the Da Vita clinics, which have the largest number of clinics in El Paso County, and could thus provide the geographical diversity of patients the study required.

## **Training**

All CIHRE personnel who participated in the interviews had previously obtained training and certification by the UTEP Institutional Review Board (IRB), as well as briefing before the project started by the principal investigator and the project administrator.

## **Data collection Personnel**

The data was collected and organized by the following individuals:

- Principal investigator
- Project coordinator
- GIS doctoral student
- Undergraduate and graduate student assistants
- Contractor Interviewer

A timeline for the whole project can be found in Appendix 6.

## **Measures and Instruments**

All interviews were transcribed by a professional bi-lingual transcriber and exported into MSWord files: one file for each interview and categorized by date and place. The MSWord files were uploaded into a qualitative analysis program, Atlas•ti, where each participant's responses were coded into categories that describe underlying themes. This coding was done by at least two researchers and their interpretations were reconciled in data meetings. This was an iterative process, which involved the development of a coding schema, which \*was modified as the interviews evolved.

Please see Appendix 4 for the final coding scheme used for each of the participants' categories.

The instruments employed in this study included the following:

- Pamphlets in English or Spanish briefly outlining the nature and importance of the project and requesting patients' voluntary participation (Appendix 1)

- Scripts for patient interviews in English or Spanish (Appendix 2)
- Scripts for transportation providers interviews (managers, dispatchers, and drivers) interviews in English or Spanish (Appendix 2)
- Scripts for dialysis clinic personnel interviews (Appendix 2) Scripts for interviews with nephrologists (Appendix 2)
- Informed Consent in English and Spanish (Appendix 3)

### **Confidentiality of the research data**

All data collected in digital or paper formats were brought physically to the CIHRE office. Digital files were downloaded to the CIHRE encrypted database created specifically for the project. At the completion of the project, all hard copies of the data were scanned and together with the electronic files were encrypted and saved on DVDs, which will be kept for three years at the CIHRE office under double lock and key. All data will be accessible only on a need to use basis and authorized by the main researcher.

Only the data analyst had access to the electronic files and was responsible to ensure that all data was backed up and that work is only done in a copy of the original data. A continuous backup program to the CIHE server was used to prevent data loss due to computer malfunction or human error.

### **Data Analysis**

Interviews were transcribed into an MSWord file by bilingual transcribers/translators. Transcribers were not given respondents' specific identifying information and if specific names of people or places arose during the interviews, they were omitted from the transcribed file. Interviewer's brief notes on the participants' responses and observed behavior were used to supplement the transcript. All this information was compiled and used in the analysis of the individual interviews.

One file was created for each interview categorized by date and place. Each of the participants' statements for each question was dynamically coded into categories that described underlying themes. The interviewers helped generate the codes jointly with the researchers. This coding was done by at least two researchers and their interpretations were reconciled during data meetings to ensure consistency.

The combined individual data was analyzed to synthesize their content into "meaning units" that created a composite description of the participants' perceptions and opinions about how the patient dialysis transportation system functions and how it can be improved. The final data analysis was designed to retrieve information to be used in developing participants' recommendations to the Far West Texas/El Paso Regional Transportation Coordination Committee (WTEP) on how the transportation system for dialysis patients can be improved and made less costly.

Examples of the transcribed interviews can be found in Appendix 5.

## Results

The following discussion and suggestions were derived from the cross-analysis of the interview responses of nephrologists, clinical and transportation providers, and dialysis patients.

### *Unnecessary delays*

Nephrologists who participated in the study were not very knowledgeable about the transportation process, unless they were directly involved with a particular clinic. In this case, they were cognizant of the waiting time that patients sometimes had to endure and saw it as the main problem in the transportation process. Dialysis clinic staff voiced the same concern about delays.

Patients complained that after finishing their treatment at the dialysis clinics they often had to wait for a very long time to be taken home. Although they recognized that sometimes patients were not ready to be picked up at the dialysis clinic many times the drivers were late in arriving.

Transportation provider personnel were also sympathetic to the length of the trips that patients had to undergo, but they also mentioned that sometimes drivers had to wait to pick up patients at her homes and more frequently at the clinics, and that the constant need to change schedules on the fly to accommodate delays increase the duration of the trips to all. This was commonly a result of the dialysis being started late, or medical complications having developed that did not allow the clinic staff to release the patient to the care of the transportation provider.

If for some reason patients have to overstay at the dialysis clinic, it is difficult for the drivers to wait for them long, since that causes delays in the transportation flow and inconveniences other patients that are ready to be transported. Some drivers wait only about 5-10 minutes after the scheduled time for after treatment pick up. In these instances, drivers leave the patients that were not ready to be transported who must then wait for another van or bus to pick them up, sometimes much later.

Overall, patients are satisfied with their experience at the dialysis clinics, with their doctors, with the care they receive from the clinical staff, and with the large majority of the drivers. Some complaints were explicitly aimed at the transportation providers' dispatchers, who are perceived as making wrong assignments and creating backlogs and unnecessary delays.

On the other hand, the transportation provider dispatchers mentioned that some non-dialysis patients wait until the last minute to change their appointments and that it results on having to adapt their already tight schedules to comply with their priority to transport dialysis patients to the clinics.

Most complaints directed at the dispatchers are a reflection of the main grievance voiced by almost all participants, including dialysis clinic personnel, and even some transportation provider dispatchers themselves — the length of time it takes for the patient to be transported from their homes to the clinic and back.

### ***Length of trips***

Besides the complaints about waiting time the patients added criticisms about the long distances they were driven, the length of time it took to transport them to and from the dialysis clinics, and the change of transportation routes almost on a daily basis. These route changes make patients anxious about being late for the dialysis and uncertain about the time they will get home after a debilitating dialysis session.

The long routes are a direct result of the initial clinic assignment and the lack of any mechanism to subsequently reassign patients to a closer clinic, the need to adjust routes to the daily demand of different users of the transportation system, and the need to adapt to delays caused by other passengers and by dialysis patients being late or not being ready to be picked up at the end of their treatment.

The long distances that patients have to travel to the dialysis clinics may result in their treatment being started late, if they are late arriving at the clinic. This situation creates anxiety for the patients and places excessive pressure on the clinic personnel as dialysis treatment schedules have to be adapted to accommodate late patients. In some instances the quality of treatment may suffer when the dialysis treatment time is shortened. Shortening and skipping hemodialysis treatments occur commonly and are associated with inadequate dialysis and increased mortality. Studies have revealed that one of the most common reasons for missing hemodialysis treatment was related to transportation issues, specifically the length of the trip to and from the clinic.<sup>5, 6, 7</sup> In addition, there is evidence that longer post dialysis treatment travel times are over time associated with poor health outcomes and increased mortality.<sup>5</sup>

### ***Shorter treatment time***

Decreased dialysis treatment time is a serious issue that directly and negatively impacts the patients' health and may lead to a shorter life span. If this situation is repetitive, the toxins are not removed adequately from the patients' system and can lead to various afflictions, which will ultimately result in health complications that may lead to premature death.<sup>5, 8</sup> In addition, some patients have complained that they have missed complete dialysis treatment days because the drivers did not pick them up at home, even though the patients claim to have called the transportation provider in advance to schedule a pickup day and time.

Social workers expressed their concern for the patients' quality of life and health outcomes, because on some occasions patients ask to be removed from the dialysis machine before their allotted time so as to not miss the transportation van. It was also mentioned by the clinic social workers that drivers do not wait long. If the patient is not ready they will leave, arguing that they are too busy to wait and have many other patients to pick up elsewhere.

### ***Lack of nourishment***

Most dialysis patients are 65 years of age or older and may suffer from various co-morbidities related to kidney dysfunction such as type-2 diabetes and hypertension. Any unexpected increase in the length of the trips and in the waiting time places undue

stress on dialysis patients. Delays may also cause patients to become very hungry if they do not have access to any nourishment during their waiting time at the dialysis clinic.

Most patients prepare a snack for the time they know they will have to wait, but when made to wait for unanticipated extended periods of time, they become hungry. This is particularly worrisome for those patients who are diabetic and may experience hypoglycemic episodes that may lead to serious complications and in extreme cases be fatal.<sup>9, 10</sup> Only one of the clinics visited provides patients who are left to wait for a long time with a cup of soup or tea. The rest of the clinics stated that they neither have the resources nor the permission to serve any type of food or drink for the patients.

### ***Communication issues***

According to dialysis clinic administrators, the transportation managers and dispatchers may not be aware that sometimes patients need extra time before being allowed to leave the clinic. After finishing dialysis, patients have to be examined to ensure that no bleeding is occurring and that they are ready to be transported, and it may be hard to predict at all times when patients will be ready to be released. These unpredictable delays should be taken into account and more waiting time by the drivers should be allowed when scheduling pickups from the clinics.

Both social workers and dialysis clinic administrators have stated that many problems would be solved, if better and more constant communication between the transportation providers and the clinics existed. This is especially true of the communication between dispatchers and the dialysis clinic social workers, to create a better understanding of the patients' needs and to develop a mutually acceptable procedure to improve the scheduling for the patients' pickups at the clinics.

### **Further Analysis**

#### ***Estimated number of dialysis patients and dialysis clinic capacity 2002-2015***

Since nationwide the number of patients with Chronic Kidney Disease (CKD) has been increasing among Hispanics, and given that Hispanics are over 80% of El Paso residents, there is a concern that the existing clinic capacity would be overwhelmed by the influx of patients who had progressed to End Stage Renal Disease (ESRD) and require dialysis treatment.

Some clinics that were contacted for this study reported that they are expecting a growth of about 10-20% of patients per year, while others have reported that they are expecting approximately the same number of patients, as patients who die are replaced by new patients.

Table 4 depicts the growth in the number of El Paso dialysis patients between 2000-11.

To predict the approximate number of patients expected until the year 2015, a linear projection of the growth of patients predicts an average growth of 94 patients a year (from 1,621 patients in 2011 to 1,998 in 2015), which means an increase of 6 patients a

year per each of the 17 existing clinics, which is manageable by an increase in the number of shifts or seats, without further clinics being built.

Figure 3 plots the graphical representation of this projection and the growth of dialysis patients in El Paso until 2015.

Table 4. Number of Living Hemodialysis Patients by Dialysis Facility (2002-2011).

Dialysis Clinic	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011
FMC - Gateway	48	48	54	52	56	55	52	59	59	56
Davita - Central City	114	94	113	89	98	89	96	101	92	97
FMC - Cliff	92	88	77	76	70	75	70	63	69	70
Cielo Vista Dialysis	104	99	105	109	112	113	115	115	115	114
Davita West	102	100	101	89	99	87	94	94	89	97
Davita - Loma Vista	177	196	219	230	225	220	223	234	228	232
NRI-East	97	101	102	103	103	97	110	107	106	105
Davita Mesa Vista	111	104	99	117	112	97	117	117	95	103
NRI- West	50	67	74	70	64	61	56	59	82	65
FMC Vista Del Sol	69	69	76	93	101	70	77	92	92	81
Davita -Mission Hills	0	46	52	61	63	64	55	59	68	66
DaVita-Transmountain	#	#	#	48	77	97	114	108	113	126
Davita Sun City	#	#	#	56	55	60	67	86	113	114
Upper Valley Dialysis	#	#	#	#	35	51	69	82	91	96
Davita East	#	#	#	#	#	90	116	121	139	143
FMC Horizon	#	#	#	#	#	16	36	48	59	56
<b>Total /Year</b>	<b>964</b>	<b>1012</b>	<b>1072</b>	<b>1193</b>	<b>1270</b>	<b>1342</b>	<b>1467</b>	<b>1545</b>	<b>1610</b>	<b>1621</b>

# =Clinics not operational at the particular year.

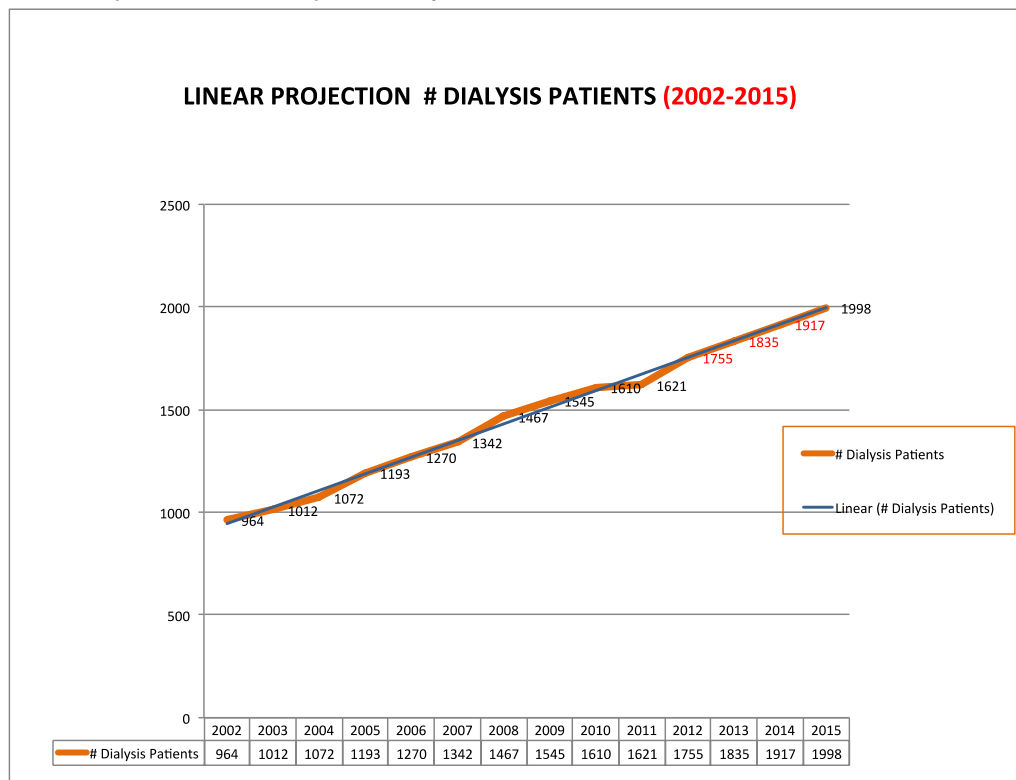


Figure 3. Linear projection of the number of dialysis patients in 2002-2015

### ***GIS mapping***

Since the most frequent complaint from patients was the long duration of transportation to and from dialysis clinics and that they would prefer to be at a clinic closer to their homes, it was observed that many dialysis clinics were by-passed during the transportation of patients to their assigned clinics.

Using spatial analysis, the researchers decide to document how many clinics actually were by-passed during the transportation route for a sample of dialysis patients.

Sun Metro lift volunteered to provide access to their trip log and provided the researchers with a listing of 14,776 patient pick-up and drop off addresses. The provided lists were cleaned and sorted according to the clinic address. From the home addresses (rounded to the nearest hundred protect the patient's identity), a route was mapped to the dialysis clinics assigned to the patient. This resulted in 287 unduplicated routes from a patient's home to a dialysis clinic.

The ArcGIS v.10.0 software was used to map patients' and dialysis clinics' addresses in a process called geocoding. During this process, an address locator for the El Paso region was established and then using the patient and clinic addresses matched to the regional map.

Figure 4 shows the location of each El Paso dialysis clinic that was mapped according to census tracts. We utilized shapefiles™ (a non-topological format for storing geometric locations and associated information) from the 2010, U.S. Census Bureau to illustrate the 126 census tracts for El Paso County. Figure 5 shows the same information overlaid on the El Paso street map

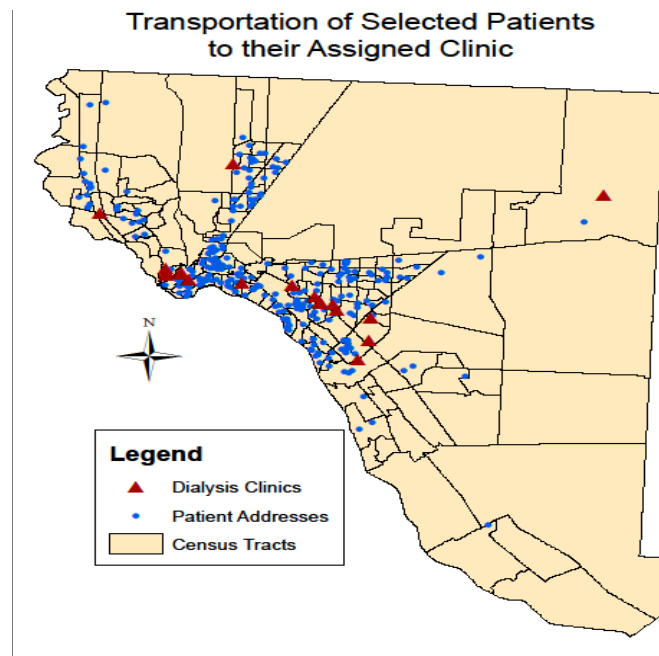


Figure 4. Map of El Paso dialysis clinic locations with census tracts.

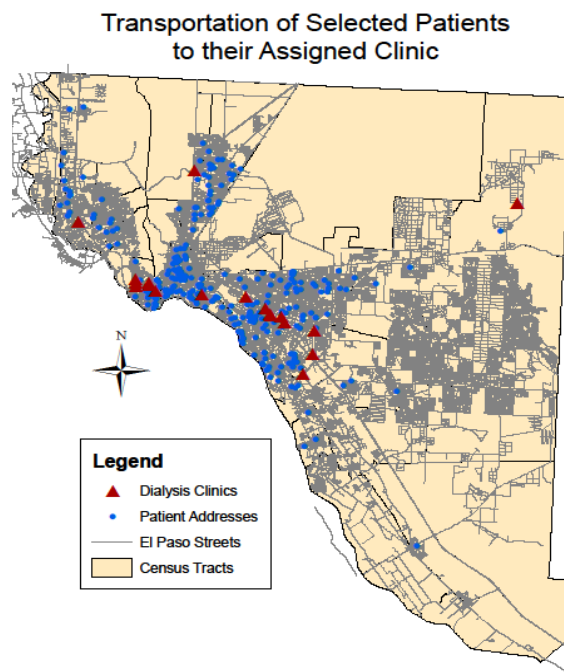


Figure 5. Map of El Paso Dialysis clinic locations with El Paso streets

Figure 6 shows an example of dialysis transportation trips where patients are bypassing 3-5 clinics. The transportation routes bypass a number of clinics, even though there are other clinics much closer to the patients' addresses.

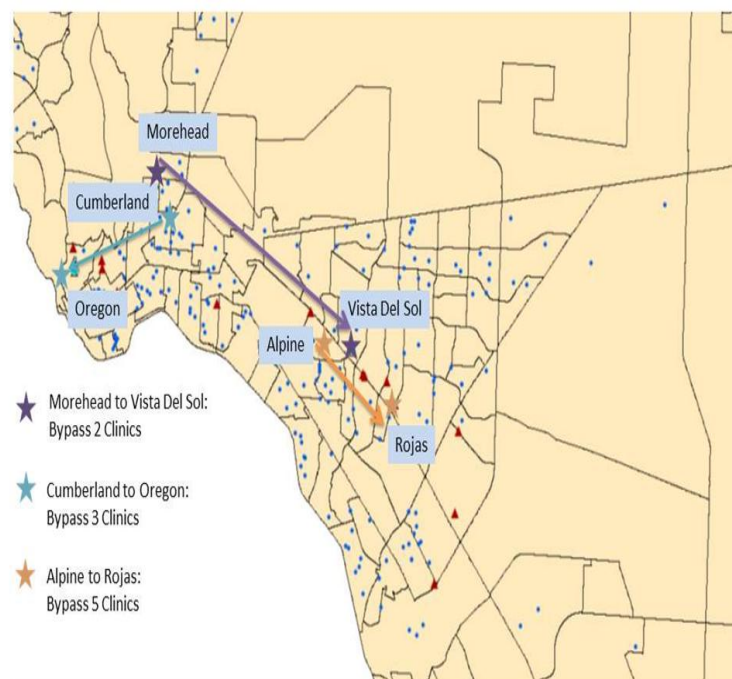


Figure 6. Example of Dialysis Trips bypassing 3-5 Clinics.

Figure 7 shows an example of dialysis transportation trips where patients are bypassing 8-12 clinics. The transportation routes bypass a number of clinics, even though there are other clinics much closer to the patients' addresses.



Figure 7. Three different patients bypassing 8-12 clinics.

Table 5 provides the number and percentage of clinics bypassed by each of the 287 patient trips mapped, showing that more than 50% of the patients bypassed two or more clinics.

Table 5. Number of Clinics Bypassed During a trip (n= 287 trips).

# Clinics Bypassed	n (%)
0	70 (24.5)
1	57 (20.0)
2	39 (13.6)
3	55 (19.2)
4	26 (9.1)
5	9 (3.2)
6	9 (3.2)
7	5 (1.7)
8	3 (1.0)
9	10 (3.5)
10	2 (0.70)
12	1 (0.35)

Besides decreasing patients' quality of life, and increasing the cost incurred by transportation providers and to Medicaid, in the very near future long trips will cause the system to become fiscally unsustainable.

In order to ensure the sustainability of the transportation services to the dialysis clinics, mileage and fuel costs are very important factors that must be taken into account when assigning patients to various clinics. Table 6 shows the mileage and fuel costs for the transportation of six dialysis patients, the distances and fuel costs were calculated using Mapquest (<http://mapquest.com>)

Table 6. Example of Selected Mileage and Estimated Fuel Costs.

Patient Address / Assigned clinic address	Mileage (Round trip)	Daily Fuel cost (15 miles/gallon @ \$3.45 gallon)	Yearly fuel cost (52 weeks/ 3 times/week)
3700 Cumberland / 2400 N. Oregon	9.94	\$1.70	\$356.65
7600 Alpine / 12245 Rojas	15.08	\$1.71	\$541.07
3100 Morehead / 10420 Vista Del Sol	18.4	\$2.48	\$660.19
14400 Misty Point / 600 Newman	33.66	\$4.51	\$1,207.72
600 Copperfield / 10737 Gateway West	40.10	\$4.83	\$1,438.79
6300 Salas Ln/ 1382 Lomaland	47.26	\$5.82	\$1,695.69

If the average round trip could be limited to 10 miles, which is achievable if the patients are assigned to nearby clinics, there would be a decrease in costs of transportation, less air pollution, and a large increase in the quality of life of patients

## Conclusions and Recommendations

The main complaint of almost all participants in the study was the waiting time during the transportation to and from dialysis clinics that patients have to endure.

Both dialysis patients and clinic personnel mentioned that some patients have to be transported a long distance to the dialysis clinics to which they were admitted. If they are picked up late at their homes they will start treatment late at the clinic and run the risk of having their dialysis treatment time shortened. This situation places unnecessary pressure on the patients and on the dialysis clinic personnel as treatment schedules have to be modified, inconveniencing other patients and pushing back scheduled pickups.

Nephrologists and social workers stated that decreasing dialysis treatment time is a serious issue that negatively impacts the patients' health and may lead to a shorter life span. If this situation is repeated often, toxins are not removed adequately from the

patients' system and will result in health complications that may lead to premature death. Some patients have complained that they sometimes miss complete dialysis treatments because they were not picked up at home at all, even if a pickup had been scheduled at least one day in advance.

Since the main concern voiced seems to be protracted waiting time, most of the recommendations by nephrologist, social workers, transportation staff and patients are centered on ways to shorten it, especially after the dialysis treatment is completed.

Since a dialysis patient's transportation is shared with others who are being taken to medical appointments, shopping malls, etc., it was suggested by some transportation providers staff, dialysis clinic personnel, and many patients that a certain number of vans be used exclusively to transport dialysis patients. This would ensure a timely pickup and reduced travel time to and from dialysis clinics and would eliminate the possibility of shortened dialysis treatment times for patients.

Participants in the study suggested that a committee be formed to achieve a better consensus on how to resolve various issues related to dialysis transportation and to improve services provided to the patients. This committee should include the El Paso County Transportation Program, as well as all the other transportation providers such as, Sun Metro, Viba, Project Amistad, Sun City Cab and BienVivir; and dialysis clinic personnel, nephrologists, and patients and their caretakers.

Some solutions suggested by van drivers and dialysis clinics' social workers were geared toward an improved scheduling system that would allow for constant communication between drivers and dispatchers to decrease the pickup times at the patient's homes and clinics.

Social workers and dialysis clinic administrators commented that the various transportation providers should take into account that the dialysis treatment may have started late because of equipment problems, another patient's delay in completing the dialysis, late arrivals, etc., and that patients are not necessarily ready to be transported to their home immediately after the treatment is completed. Moreover, there is always a short period of time when the clinics' nurses have to check the patients to ensure that they are ready to be transported home.

## **CIHRE Recommendations**

The most important recommendation, without which all the following suggestions will be moot, is that a Transportation Committee be created to discuss, modify, improve these ideas and have the motivation to implement and enforce them. This committee should be composed of El Paso City transportation and health authorities, transportation providers, dialysis clinic personnel, nephrologists, and patients and their caretakers. The Transportation Committee would be a forum to discuss possible solutions for the problems outlined in this report, and to arrive at a consensus on the actions to be taken.

The recommendations that follow are the result of observations, interview analysis, literature review, and internal discussions among CIHRE staff.

### ***Delays***

To deal with delays between scheduled and actual pickup time at the clinics, we suggest that an extra 15-20 minutes should be added to each pickup schedule, as a buffer for unexpected delays, such as bleeding from the cannula in their arms, or an abnormally high blood pressure.

This extra time, which may be needed for patient stabilization, is not currently being taken into account in the drivers' pickup schedule. Presently, drivers are allowed only a few minutes to wait for the patient before they have to leave to continue their routes to serve other riders. A change in this single procedure will increase the possibility that the patient will be picked up on time and will not have to wait for a long time at the clinic until another van is available. Furthermore, this change would eliminate the need for patients to shorten the treatment time and would improve their overall quality of life.

Since most of the dialysis patients are older adults who concurrently suffer from various comorbidities related to kidney dysfunction such as Type 2 Diabetes, they might suffer from hypoglycemia after waiting for many hours. We suggest that all dialysis clinics provide at least a small snack for their patients when they have to wait for more than half hour. How to finance this extra cost could be an item to be included in the proposed Transportain Committee agenda.

### ***Communication***

There should be improved and constant communication between all stakeholders: dialysis clinic personnel, dispatchers, drivers, and patients in order to adapt the pickup schedules to predictable or unforeseen circumstances, such as rush hour traffic, snow storms, heavy rain, street closures, accidents, etc. Global Positioning System (GPS) devices should be mandatory in each van, to allow the driver to easily change routes in an unfamiliar part of town, when a traffic emergency arises, or even to locate a new patient's address.

### ***Scheduling Software***

There are computer based systems currently being used around the world, such as RAPID™ (<http://www.sigtec.com>) to track transportation of patients, monitoring service adherence and allowing transportation managers/dispatchers the visibility and flexibility to better administer their fleet. It can predict the arrival time of a van at each designated stop taking into consideration a number of variables (weather, traffic, etc) and can be used to notify patients in their homes, or clinic personnel of delays.

This innovative program is used in Australia and New Zealand and is currently in development in various other countries. We are unaware if this system is currently being used for transportation to dialysis clinics in the United States.

This and other software programs can decrease the operational costs for the transportation providers including a decreased in fuel costs, better utilization of the vans' passenger load, and decrease the cost of vehicle maintenance.

### ***Increased Number of Transportation Providers***

We also recommend that more transportation companies be engaged to provide transportation of dialysis patients to minimize the waiting times for patients. This could include existing taxi companies, New Mexico transportation providers, and even a payment to caretakers who could drive their charges to and from a clinic.

### ***Clinic Assignment***

Some patients may prefer attending a clinic far away from their homes because they want to be treated by a familiar nephrologist. To accommodate both patients and their nephrologists, we suggest that the dialysis patients always be assigned to the nearest clinic regardless of the dialysis provider and that all nephrologists be allowed to visit their patients in any clinic. Patients who initially have been assigned to clinics that are distant from their residences because of lack of space in nearby clinics, should be assured that they will be placed a waiting list and be reassigned to a clinic near their home as soon as a vacancy occurs.

### ***Exclusive Zoning for Transportation Providers***

One of the recommendations made by patients was that transportation providers assign a number of vans exclusively to transport dialysis patients. While worthy of closer examination, the idea does not deal with the problem of transportation of a single patient to a distant clinic.

We recommend instead that transportation zones, designated by mutual agreement among transportation providers, be created within the City of El Paso to expedite travel time, minimize the cost of transportation, and decrease the duration of patient waiting time at the dialysis clinics.

The CIHRE's staff, in cooperation with Dr. Bradley Lane, professor with the Public Administration Department at UTEP, and using the travel data collected to examine the number of clinic bypassed, proposes a total of six tentative zones designed to serve as transportation boundaries within which a single transportation provider would operate. Each proposed zone would have one or more dialysis clinics and would allow patients to receive treatment by their own nephrologist at a clinic closer to their homes.

Within these zones, patients would be assigned to a single transportation provider serving the zone. This arrangement would allow for more cooperation among transportation providers and a better and more efficient use of vehicles and a decrease in the use of fuel and of transportation costs overall.

This approach requires that patients be assigned to clinics nearest their homes and that nephrologists be allowed to visit patients at those clinics. The illustration of the proposed zoning boundaries is provided in Figure 8.

### Recommended Transportation Zones by El Paso County Dialysis Clinics

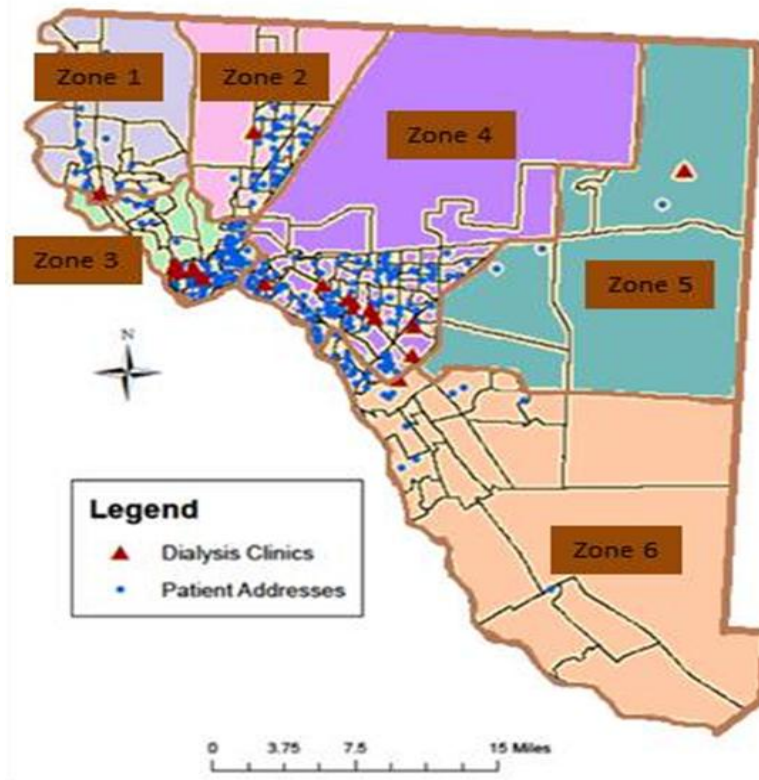


Figure 8. Proposed zones for transportation to dialysis clinics.

Table 7 shows the number of Dialysis Clinics in each of our proposed zones, along with the number of patients per zone.

Table 7. Number of Dialysis Clinics and Patients per Zone.

Zone	#Clinics per Zone	Patients per Zone
Zone 1	1	20
Zone 2	1	35
Zone 3	6	70
Zone 4	9	135
Zone 5	1	3
Zone 6	1	23
<b>Totals</b>	<b>19</b>	<b>286</b>

### In-home Hemodialysis for Rural Patients

More than 90% of patients undergoing dialysis in the United States are on a three times a week in-center therapy schedule. Many clinicians recognize the limitations of traditional three times per week in-center therapy, and accept that more frequent home

therapies offer many potential benefits for some clients, including the possibility of a more normal lifestyle.<sup>11</sup>

Although we agree that in urban areas most patients will probably need to continue to receive in-center hemodialysis, in-home dialysis is an alternative that should be available for some patients.

We suggest that for rural patients in-home dialysis should be examined as a practical alternative to in-center dialysis. In most cases dialysis patients living in rural areas have to be taken to a central dialysis clinic in a larger town which serves patients from smaller towns, sometimes located in different counties.

Trips to these central clinics may last from one to three or four hours each way. Adding an average of two and a half hours each way of transportation time to the four hours for a dialysis treatment means that a patient may spend nine hours a day, three times a week to have their dialysis treatment. A four-hour dialysis treatment is quite debilitating and the five-hour bus ride compounds the physical exhaustion that patients suffer.

Although the in-home dialysis requires some knowledge on how to manage a dialysis machine and requires five to six days a week of treatment, it keeps the amount of bodily toxins and water build-up to a minimum, which makes for a shorter duration treatment (2.5 to 3 hours) and may reduce or eliminate many side effects patients experience during in-center dialysis, and completely avoid the physical fatigue of being transported in a van for hours, three times a week.

In-home dialysis is not without risks. Complications range from unmonitored low and high blood pressure, fluid overload, heart-related issues, and vascular access complications may occur. Furthermore, machines used in hemodialysis therapies may add additional risks including air entering the bloodstream, and blood loss due to clotting or accidental disconnection of the blood tubing set.

In rural and urban areas, in-home hemodialysis could be a viable option for many patients who cannot afford to be transported to a dialysis clinic three times a week—for example those who are not Medicaid eligible and have to pay for their own transportation. This is especially important for patients living in remote rural areas and who may not have a reliable source of transportation to far away clinics.

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### Abstract

Kidney failure is when the kidneys stop working well enough for the patient to live without dialysis or a kidney transplant. Kidney failure can happen very suddenly (called acute renal failure) or slowly over time. In most cases, kidney failure is permanent. This is called end-stage renal disease or ESRD. Chronic Kidney Disease (CKD) means that the kidneys are damaged. With CKD, the kidneys may still be working, but they are not working as well as they should. Kidney failure is the most severe stage of CKD. Kidney failure is when the kidneys are no longer working well enough for the patient to live without dialysis or a kidney transplant.

2. Azar, A.T., Wahba, K., Mohamed, A.S., Massoud, W.A. (2007) *Association between dialysis dose improvement and nutritional status among hemodialysis patients. American Journal of Nephrology*, 27(2), 113-119.

### Abstract

Several studies suggest an association between improved survival and better nutritional status. It has been suggested that there is a correlation between dose of dialysis and nutritional status. However, in spite of the current practice, there are conflicting reports regarding the relationship between dose of dialysis or malnutrition, and biochemical outcome. In this article, we will discuss the impact of dose of dialysis on nutritional status and biochemical outcome in hemodialysis patients. We will also mention the interrelationships of dialysis dose, malnutrition, and biochemical outcome with respect to these patients.

The statistical analysis demonstrated that there was a significant improvement in mean URR and Kt/V from the baseline to the intervention group. The intervention group had a considerably higher rate than the baseline group for all nutritional and biochemical outcome parameters. All the available evidence in hemodialysis patients confirms the close association between dialysis dose and biochemical outcome. A body of evidence also highlights the existence of relationship between malnutrition and outcome among these patients. Dose of dialysis and nutrition are considered to be interrelated.

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### Abstract

The authors conducted focus groups with dialysis patients and dialysis professionals to determine whether this qualitative method would reveal differences between patients' and providers' views about several domains concerning their Quality of Life (QOL), as well as aspects of dialysis that affect QOL. Separate focus group discussions were held with: 8 adult hemodialysis patients (mean age 50 years; 3 women; mean duration of

dialysis 8.5 years), 5 adult peritoneal dialysis patients (mean age 54 years; 3 women; mean duration of dialysis 4.6 years), 8 nephrologists (mean of 12 years of dialysis practice), and 9 other health professionals involved in dialysis care (3 nurses, 2 dietitians, 2 social workers, and 2 technicians; mean of 10 years experience in dialysis care). Although health professionals have a good understanding of patient concerns about the effects of ESRD and dialysis, the focus group discussions revealed a breadth and depth of QOL concerns that they may not fully appreciate.

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#### Abstract

Along with basic survival and other clinical outcomes, patients' quality of life is an important indicator to reflect the needs of these patients. Human needs are classified in Maslow's hierarchy, where the most essential basic physiological need provides the base, and self-actualization is at the top of pyramid. The aim of this study is to identify the patients' needs who are on maintenance hemodialysis using concept of Maslow's hierarchy. The descriptive study was conducted in the dialysis unit of Suez Canal University Hospitals. The study included 50 patients attending the dialysis unit. The findings showed that the patients' highest need was for self-esteem (92.0%), whereas the lowest was for love and belonging. Based on the main study findings it is concluded that hemodialysis patients' highest need was for self-esteem, and the lowest was for love and belonging. These needs increased with longer duration of dialysis. Nurses need to be aware of these findings in order to be able to supply the necessary support to help the patient regain his/her self-concept.

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#### Abstract

Transportation is frequently cited as a barrier to health care, but rarely have researchers analyzed the problems in depth. The purpose of this study was to assess the role transportation plays in the utilization of preventive health care services among Medicaid recipients ages 0 – 20 in Texas. This preventive care is known as Early Periodic Screening and Diagnostic Testing (EPSDT), a comprehensive prevention and treatment program for Medicaid eligible children. Our computer assisted telephone interviewing based survey was administered to Medicaid recipients selected from a representative sample through a stratified sampling scheme. Binary logistic regression models were used to assess and predict factors associated with utilization of the Texas Medicaid Transportation Program (MTP) and utilization of EPSDT. We also used k-means cluster analysis to identify subgroups of Medicaid clients with particularly acute transportation barriers. Of the 1,214 Medicaid recipients interviewed, the overall odds of a Medicaid recipient being a MTP non-user was 0.94. For clients with automobile access, the probability increases to 0.98. Clients who experienced difficulties paying for gasoline

decreased the overall odds to 0.86. When examining utilization of EPSDT, the overall probability of being a low utilizer was 0.59. Two factors, Spanish-speaking patients (0.21) and clients with more than one child at home (0.54) decreased the overall odds of being a low utilizer, while those with difficulty paying for gasoline increased the odds of being a low utilizer to 0.63. Increasing EPSDT utilization among the millions of Texas Medicaid recipients is an important policy objective. Because the Texas Medicaid population is large and diverse, no single approach to increasing utilization is likely to address all needs. The group concept provides a means to understand which Medicaid recipients do not access MTP services and those with low utilization rates. These groupings can be useful in targeting Medicaid clients with specific transportation difficulties. Instead of broad informational campaigns, policy makers should devise targeted strategies to promote the most appropriate types of assistance. In addition to expanding transportation options, policy makers should also examine the locations in which care is delivered, considering telemedicine, mobile health and school-based health clinics as options.

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#### Abstract

Functional measures have a great appeal for prognostic instruments because they are associated with mortality, they represent the end-impact of disease on the patient, and information about them can be obtained directly from the patient. However, there are no prognostic indices that have been developed for community-dwelling elders based primarily on functional measures. Our objective in this study was to develop and validate a prognostic index for 2-year mortality in community-dwelling elders, based on self-reported functional status, age, and gender. This was a population-based cohort study from 1993 to 1995, among community-dwelling elders within the United States. Prediction of 2-year mortality using risk factors such as activities of daily living, instrumental activities of daily living, additional measures of physical function, age, and gender. This prognostic index, which relies solely on self-reported functional status, age, and gender, provides a simple and accurate method of stratifying community-dwelling elders into groups at varying risk of mortality.

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#### Abstract

Chronic kidney disease (CKD) is a serious public health problem associated with increasing prevalence rates, rising healthcare costs, and high rates of mortality from comorbid conditions. In the US, based on 2008 data, the United States Renal Data System (USRDS) reports: An estimated 33 million Americans, 16 percent of the population, have kidney disease; Approximately 550,000 patients are undergoing dialysis or have had a kidney transplant to sustain life; In 2008, 88,620 people died of kidney failure; and Medicare costs reached \$59.4 billion and almost \$26.8 billion

respectively for CKD and End-Stage Renal Disease (ESRD) in 2008. In Texas, based on 2008 data, the End-Stage Renal Disease Network reports: Almost 44,000 Texans are receiving dialysis or have had a kidney transplant; The ESRD incidence rate in Texas exceeds the national rate; ESRD prevalence rates tripled from 1990 to 2008; and in 2008, 6,058 dialysis patients died. The number of new cases of CKD and patients on dialysis continue to escalate, yet many Texans remain unaware that they are at risk. Early detection and management of CKD can delay disease progression and decrease complications and co-morbidities, but CKD remains under-diagnosed. Diabetes and hypertension are the leading causes of kidney disease, yet fewer than 20 percent of Medicare patients with diabetes are screened for CKD.

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#### Abstract

For more than fifty years, low protein diets have been proposed to patients with kidney failure. However, the effects of these diets in preventing severe kidney failure and the need for maintenance dialysis have not been resolved to determine the efficacy of low protein diets in delaying the need to start maintenance dialysis. Randomised studies comparing two different levels of protein intake in adult patients suffering from moderate to severe kidney failure, followed for at least one year. The authors independently selected studies and extracted data. A total of 2000 patients were analysed, 1002 had received reduced protein intake and 998 a higher protein intake. There were 281 renal deaths recorded. Reducing protein intake in patients with chronic kidney disease reduces the occurrence of renal death by 32% as compared with higher or unrestricted protein intake. The optimal level of protein intake cannot be confirmed from these studies.

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#### Abstract

The nationwide dialysis patient population is growing at a rate of 10 percent annually. To accommodate the increase, existing dialysis treatment centers are being expanded, and new facilities are being planned and constructed. In many cases, dialysis patients are reliant on public transit for transportation to and from treatment. The increasing demand for dialysis transportation has created, and will continue to create, operational challenges for public transit providers. In addition, the rising cost of supplying the requisite transportation services to dialysis patients imposes an increasing financial burden on providers.

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#### Abstract

There are few studies evaluating exercise in the nondialysis chronic kidney disease (CKD) population. This review covers the rationale for exercise in patients with CKD not requiring dialysis and the effects of exercise training on physical functioning, progression of kidney disease, and cardiovascular risk factors. In addition, we address the issue of the risk of exercise and make recommendations for implementation of exercise in this population. Evidence from uncontrolled studies and small randomized controlled trials shows that exercise training results in improved physical performance and functioning in patients with CKD. In addition, although there are no studies examining cardiovascular outcomes, several studies suggest that cardiovascular risk factors such as hypertension, inflammation, and oxidative stress may be improved with exercise training in this population. Although the current literature does not allow for definitive conclusions about whether exercise training slows the progression of kidney disease, no study has reported worsening of kidney function as a result of exercise training. In the absence of guidelines specific to the CKD population, recent guidelines developed for older individuals and patients with chronic disease should be applied to the CKD population. In sum, exercise appears to be safe in this patient population if begun at moderate intensity and increased gradually. The evidence suggests that the risk of remaining inactive is higher. Patients should be advised to increase their physical activity when possible and be referred to physical therapy or cardiac rehabilitation programs when appropriate.

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#### Abstract

Although timely referral to and collaboration with a nephrologist is vital in caring for patients with renal disease, it is important for the primary care physician to be familiar with measures aimed at preventing the progression and complications of renal failure. The number of patients with end-stage renal disease (ESRD) is rising rapidly in the United States. Early recognition of renal disease and appropriate interventions to delay its progression may decrease both human suffering and the financial costs associated with ESRD. Primary care physicians usually treat patients with diabetes and hypertension, the two leading causes of ESRD in this country. Since most patients with early renal failure are asymptomatic, awareness and vigilance on the part of the primary care physician are essential for the early diagnosis, appropriate referral, and collaborative management of these patients. The clinical management of the patient with progressive renal failure may be divided into several components: (1) early recognition of renal failure; (2) monitoring the progression of renal failure; (3) detection and correction of reversible causes of renal failure; (4) institution of interventions to delay progression of renal failure; (5) avoidance of additional renal injury; (6) treatment

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#### Abstract

It is unclear whether functional status before dialysis is maintained after the initiation of this therapy in elderly patients with end-stage renal disease (ESRD). Using a national registry of patients undergoing dialysis, which was linked to a national registry of nursing home residents, we identified all 3702 nursing home residents in the United States who were starting treatment with dialysis between June 1998 and October 2000 and for whom at least one measurement of functional status was available before the initiation of dialysis. Among nursing home residents with ESRD, the initiation of dialysis is associated with a substantial and sustained decline in functional status.

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#### Abstract

Hispanics are the most highly represented ethnic group in the Texas ESRD population, with approximately 42 percent comprising newly diagnosed (incident) patients in 2011 and 45 percent comprising all (prevalent) Texas ESRD patients (Chart 2), compared to 38.1 percent Hispanic in the total 2011 Texas estimated population. African-Americans make up 30 percent of the ESRD patients in Texas, nearly triple the 12.2 2011 Texas estimated population percentage. The incidence of ESRD in Texas is above the national average and trended upward annually for many years with the exception of 2007. The rate increased to 387 per million in 2010, but decreased to 376 per million in 2011. The prevalence of ESRD in Texas, however, continues to rise. In 1990, 524 out of each million Texans had a diagnosis of ESRD; in 2011 the unadjusted prevalence rate for the Texas population had climbed to 1,524 per million, up from 1,489 in 2010.

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#### Abstract

There are numerous barriers to delivering the prescribed quantity of dialysis. Noncompliance in terms of shortening and skipping treatments is common and negatively impacts on delivered dialysis. A significant number of shortened treatments are caused by reasons within the patient's control, whereas others, such as transportation, can be influenced by others. This article will review the prevalence of patient noncompliance with the dose of dialysis and the relationship to process and

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15. Murray, D. (2009). *Dialysis Treatment and the Impact on Transportation Services for Patients* [http://web1.ctaa.org/webmodules/webarticles/articlefiles/Dialysis\\_for\\_reprint.pdf](http://web1.ctaa.org/webmodules/webarticles/articlefiles/Dialysis_for_reprint.pdf)

*Abstract*

Chronic kidney disease affects more than 2,325 Kansans, and in 2006 approximately 89 percent (2,073) of them regularly received treatment at a dialysis center, up to three times a week (ESRD 12 2006 Annual Report, 5). Many dialysis patients are dependent on public transportation to get to treatment centers, and they have special scheduling needs due to the nature of those treatments. This article provides some information about kidney disease, the challenges facing dialysis patients in obtaining treatment due to access to transportation, and examples of how some Kansas rural transit systems are trying to meet the challenge.

16. Murtagh, F.E., Cohen, L.M., Germain, M.J., (2011). *The "no dialysis" option. Advanced Chronic Kidney Disease*, 18(6), 443-9.

*Abstract*

Increasing numbers of patients are starting dialysis who have limited prognoses for 6-month survival. The presence of multiple comorbidities, aging, and frailty contributes to this phenomenon. The rate of dialysis withdrawal has been accelerating over the past decade, and this calls into question the condition of patients who are initiating dialysis. One option is to consider and discuss the "no dialysis" option with patients and family. Patients need to be identified who may benefit from this option, and their medical management needs to be reviewed.

17. Pushkal, P., Garg, P.P., Frick, K.D., Diener-West, M., Powe, N.R. (1999). *Effect of the ownership of dialysis facilities on patients' survival and referral for transplantation. New England Journal of Medicine*. 25; 341(22):1653-1660.

*Abstract*

More than 200,000 patients with end-stage renal disease undergo dialysis in the United States each year, about two thirds in for-profit centers. Economic pressures, such as the decline in inflation-adjusted Medicare payments for dialysis, may compromise the quality of care. Facilities may also be reluctant to refer patients to be evaluated for transplantation because of the loss of revenues from dialysis after patients receive transplants. It is unknown whether for-profit facilities respond more aggressively than not-for-profit facilities to these financial pressures. Therefore, we examined the effect of for-profit ownership of dialysis facilities on patients' survival and referral for possible transplantation.

We used data from the U.S. Renal Data System to assemble a nationally representative cohort of patients with end-stage renal disease of recent onset. We followed patients for a minimum of three years and a maximum of six years, until death, placement on the waiting list for a renal transplant, or loss to follow-up, or until May 31, 1996. We used proportional-hazards models to assess the effect of the profit status of the dialysis facility on patients' outcomes and adjusted for differences in sociodemographic, clinical,

and facility-level characteristics. In the United States, for-profit ownership of dialysis facilities, as compared with not-for-profit ownership, is associated with increased mortality and decreased rates of placement on the waiting list for a renal transplant.

18. Rocco, M.J., Burkart, J.M. (1993). *Prevalence of missed treatments and early sign-offs in hemodialysis patients. Journal of the American Society of Nephrology*, 4, 1178-1183.

#### Abstract

Hemodialysis patients often do not complete their full amount of time on dialysis and at times miss their hemodialysis treatments completely. However, neither the magnitude nor the potential reasons for this problem are known. The prevalence of unauthorized absences from hemodialysis sessions (no shows) and both the prevalence and reasons for early terminations from hemodialysis sessions (early sign-offs) were prospectively studied at a large hemodialysis unit in the southeastern United States. This unit provided a total of 31,212 hemodialysis sessions in a 12-month period to an average of 231 patients. There was a total of 2,108 early sign-offs (6.8 +/- 0.9%/mo) and 387 "no-shows" (1.2 +/- 0.2%/mo) during this 12-month period. The most common reasons for early sign-off were cramping (17.9%), followed by "feels bad or sick" (14.2%), personal business or errands (12.1%), lack of transportation later in the day (7.7%), and refusal to comply with the prescribed treatment time (6.4%). In sum, approximately 55% of early sign-offs were due to medically related problems, whereas most of the remainder occurred because of either personal obligations or noncompliance with the dialysis prescription. This information should be of value when designing programs intended to reduce the number of early sign-offs in hemodialysis patients.

19. Sarrias, L. X., Bardón, O. E., Vila Paz, M.L. (2008). *Patients in pre-dialysis: decision taking and free choice of treatment*. [Article in Spanish]. *Nefrología*, 28(3), 119-22.

#### Abstract

Predialysis is a clinical situation in which the patient has significant impairment of kidney function that will ultimately lead to either death or inclusion in kidney replacement therapy (dialysis and/or transplantation). Since a practical and effective dialysis technique was introduced, the length and quality of survival of patients with end-stage renal failure has constantly increased. Contraindications for dialysis are almost never of a renal origin. The obstacles are the concomitant diseases of the patient. The age of the patient may be one of these obstacles. The average age at initiation of dialysis in our country is currently 67 years and over 50% of patients are 60 years old or older. Decision making: From an ethical viewpoint, there is a consensus in stating that anything that can technically be done should be done. The principle of no maleficence and respect for the autonomy of the patients are "prima facie" principles when the physician has doubts as to whether dialysis provides a benefit to the patient. The principle of autonomy, which makes the patient a competent subject of treatment, allows a framework of shared decisions to be created in which physicians use their knowledge and experiences in assessing the risk and benefits of dialysis including the alternative of no dialysis. Competent patients, duly informed, will choose the option that is best for them and make the decision. Principle of treatment proportionality: This principle states

that there is a moral obligation to implement all therapeutic measures that show a relationship of due proportion between the resources used and the expected result. Dialysis is in principle a proportional treatment for end-stage renal failure. However, it may become a disproportional treatment because of the physical and mental conditions of the elderly patient. The good that is sought with institution of treatment can cause a harm to the patient that justifies non-inclusion of the patient in dialysis treatment. Because of the impossibility of establishing universal rules of proportionality, it is necessary to make a personal judgment of conscience in each specific case. Recommendations for initiation or not of dialysis: Taking shared decisions between the patient (or relatives and/or advisors) and the physician. These shared decisions will be documented with signing of the proposed informed consent or rejection of the treatment. The medical team should always be sure that the patients have fully understood the consequences of the decision taken. Explanation of the modalities should include: - Types of dialysis treatment available. - Not to initiate dialysis and continue with conservative treatment until death. This situation may cause many problems if we do not have the help of the palliative care service. - Try dialysis for a limited time. - Stop dialysis and receive medical care until death. - Evaluate the prognosis of renal disease and concomitant diseases, life expectancy and family support.

1. Schmidt, R.J., (2012). *Informing our elders about dialysis: is an age-attuned approach warranted? Clinical Journal of the American Society of Nephrology*, 7(1), 185-91.

#### Abstract

As the fastest growing sector of the incident ESRD population, older patients constitute a group for which renal replacement therapy has special implications. Older CKD patients have unique needs by virtue of advanced age, high prevalence of comorbid conditions, slower progression of renal disease, and reduced survival. Burdens and risks attendant to dialysis may be amplified in the older patient and patients with impaired functional status or comorbid conditions, and therefore, dialysis may confer little to no survival benefit. Rates of dialysis withdrawal are highest among the oldest patients, raising the possibility that the standard content of informed consent for dialysis warrants an age-sensitive approach that is attuned to the very different balance of pros and cons of dialysis for older patients with multiple comorbidities and younger patients with limited comorbidity. Informed consent for older patients should include presentation of risks, benefits, and burdens associated with dialysis, age-specific estimates of prognosis with and without dialysis, and potential for loss of independence and decline in functional status with initiation of dialysis. In this article, medical evidence and clinical practice guidelines relevant to advance care planning for the older patient with CKD are reviewed, issues to consider in the dialogue with older patients contemplating dialysis are presented, and recommendations for an age-attuned approach to informed consent for older CKD patients are made.

21. Stump, C.S. (2011). *Physical Activity in the Prevention of Chronic Kidney Disease. Cardiorenal Medicine*, 1(3), 164-173.

#### Abstract

Chronic kidney disease (CKD) is an important risk factor for cardiovascular disease (CVD) and mortality. The increase in CKD in recent decades has paralleled increases in obesity, diabetes, and the metabolic syndrome. Physical inactivity is a modifiable risk factor that may affect the development and course of CKD. It is well established that exercise training improves a number of metabolic factors, including blood pressure and insulin resistance, which would be expected to preserve renal function as well as lower CVD risk. Epidemiological studies have suggested that partaking in vigorous physical activity may protect against kidney disease. However, to date few studies have rigorously measured physical activity levels. Instead, investigators have relied on subjective measures of physical activity and patient recall. This is particularly problematic when attempting to capture low- and very-low-intensity physical activity and in quantifying sedentary behavior. Improvements in vascular endothelial function, insulin sensitivity, adipocytokine profiles, and oxidative stress likely mediate the benefits of physical activity on the kidney. While formal exercise recommendations have been published for diabetes and hypertension, guidelines regarding the optimal type, frequency, intensity and duration of physical activity for preventing CKD have yet to be formalized.

22. Teixeira, N.F., de Campos, G, Xavier de Paula, S.M., Merhi, V.A., Portero-McLellan, K.C., da Motta, D.G., de Oliveira, M.R.(2008). *Dialysis adequacy and nutritional status of hemodialysis patients. Hemodialysis International*, 12(1), 45-51.

#### Abstract

To characterize the nutritional status of renal failure patients and its relationship with hemodialysis adequacy measured by Kt/V, a study was carried out with a population of 44 adult patients with renal failure and mean age 51+/-15 years. Anthropometric data, such as dry weight, height, arm circumference, triceps skinfold thickness, mid-arm muscle circumference, and body mass index were assessed, and biochemical tests were conducted for urea, potassium, creatinine, serum albumin, and phosphorus levels, in addition to hemogram and quarterly urea reduction rate average (Kt/V). In order to evaluate calorie intake, a dietary questionnaire on habitual daily food ingestion was administered, taking into consideration the hemodialysis date. The patients were divided into 2 separate groups for the statistical analysis, with 50% of the patients in each group: A (Kt/V<1.2) and B (Kt/V>1.2). The data were tabulated as mean and standard deviation, with differences tested by Student's t test. The correlations between variables were established by the coefficient p of Pearson. Most of the patients (43%) were considered eutrophic, based on the BMI, and presented inadequate calorie intake, corresponding to 88.5+/-24% (30.8 kcal/kg actual weight) of the total energy required and adequate protein intake, reaching 109.9+/-40% of the recommended daily allowance (1.24 g/kg of actual weight). There was a correlation of Kt/V with anthropometric parameters such as body mass index, arm circumference, and mid-arm muscle circumference. The biochemical parameters related to dialysis adequacy were albumin, ferritin, and urea (predialysis). Well-dialyzed patients presented better levels of serum albumin. There was an influence of gender and age on correlations of the analyzed variables. Female and younger patients presented better dialysis adequacy. The dialysis adequacy was related to the nutritional status and influenced by the protein intake and body composition. Gender and age had an important influence in the dialysis

adequacy, as men presented lower dialysis adequacy and younger adults presented better dialysis adequacy. Further research is necessary to understand better how to facilitate effective and efficient techniques for the nutritional status assessment of hemodialysis patients.

23. Texas Department of State Health Services Regulatory Licensing Unit Facility Licensing Group. (2010). *End Stage Renal dialysis facilities licensing rules*.  
<http://www.dshs.state.tx.us/>

#### Abstract

The purpose of this chapter is to implement Health and Safety Code, Chapter 251, which requires an end stage renal disease facility providing routine, repetitive, outpatient dialysis to be licensed by the Department of State Health Services. This chapter provides minimum standards for the equipment used by the facility; water treatment and reuse; sanitary and hygienic conditions; quality assessment and performance improvement; indicators of quality of care; provision and coordination of treatment and services; qualifications and supervision of the professional staff, including physicians and other personnel; clinical records; curricula and instructors used to train dialysis technicians; the competency evaluation of dialysis technicians; enforcement standards, fire prevention and safety requirements; and physical plant and construction requirements.

24. United States Renal Data System (USRDS). (1997). *Annual Data Report. National Institute of Diabetes and Digestive and Kidney Diseases*.  
<http://www.usrds.org/download/1997/ch01.pdf>

#### Abstract

The USRDS is funded and directed by the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) of the National Institutes of Health (NIH). The Health Care Financing Administration (HCFA) of the United States Department of Health and Human Services is a major contributor to the project, providing expertise and most of the primary data in the system. The HCFA also funds the cost-effectiveness and economic studies performed by the USRDS. Design and implement a consolidated renal disease data system that will provide the biostatistical, data management and analytical expertise necessary to characterize the total renal patient population, and to describe the distribution of patients by sociodemographic variables across treatment modalities. Report on the incidence, prevalence, mortality rates and trends over time of renal disease by primary diagnosis, treatment modality and other sociodemographic variables. Develop and analyze aggregate data on the effect of various modalities of treatment by disease and patient group categories. These data will be used to analyze the prevention and progression of renal disease with special emphasis on morbidity and mortality. Identify problems and opportunities for more focused special studies of renal research issues currently not addressed by the consolidated data system. Conduct cost effectiveness and other economic studies pertaining to biomedical and epidemiological aspects of ESRD .

## Appendices

## **Appendix 1**

### **Recruiting Pamphlet English and Spanish**

## ENGLISH

### **UTEP College of Health Sciences - Center for Interdisciplinary Health Research and Evaluation (CIHRE)**

#### **Improving Transportation Services for Dialysis Patients**

Since many people in our region need to have dialysis treatment, we want to know ways to improve the transportation services to and from the patients' home on the days they are required to visit the clinic for dialysis.

We would like to invite you to participate in a study to help improve the transportation services to and from the dialysis clinics in the County of El Paso. If you are 21 years of age or older, you are eligible to participate in the study.

You will be interviewed for about 1 hour in your home or a place of your choosing and be asked questions about your experience with the dialysis treatment transportation services. We will use a recorder to store the information, but we will not use your name or address in the study and all your answers will be kept confidential. The tapes will be erased after the study and no information related to you will be kept on file.

It is important to know that you are not required to join this study. It is your decision. Your participation is voluntary. Whether or not you participate in this study will have no effect on your relationship with the dialysis clinic, your transportation provider, or your physician.

If you decide to participate you would receive a \$25.00 (twenty-five dollar) gift card as token of appreciation for having helped us with the study.

If you have any questions or comments, please contact Dr. Joao Ferreira –Pinto at (915) 747 7295

**Thank you for your consideration of this request!**

**Please complete the back of this form if you decide to participate in the study and hand it back to the person that asked you if you were interested in being a study participant (*Back of form*)**

☐ I am interested in learning more about this study. Please contact me using the following information:

Name: \_\_\_\_\_

Telephone(s): \_\_\_\_\_

Best time and day to call: \_\_\_\_\_

Email: \_\_\_\_\_ @ \_\_\_\_\_

## SPANISH

### **UTEP College of Health Sciences - Center for Interdisciplinary Health Research and Evaluation (CIHRE)**

#### **Mejorando los Servicios de Transporte para los Pacientes de Diálisis**

Debido a que muchas personas en nuestra región necesitan el tratamiento con diálisis, queremos conocer las maneras de mejorar los servicios de transporte que llevan a los pacientes de su casa a la clínica y de regreso a su casa, en los días en los que se requiere el tratamiento con diálisis.

Deseamos invitarle a participar en este estudio para ayudarnos a mejorar los servicios de transporte a la clínica y de regreso a la casa de los pacientes, dentro del Condado de El Paso. Si tiene 21 años de edad o más, Ud. puede participar en este estudio.

En caso que Ud. desee participar y nos otorgue su permiso, le haremos una entrevista de aproximadamente 1 hora, ya sea en su casa o en el lugar que mejor le parezca. Le haremos preguntas sobre su experiencia con los servicios de transporte a las clínicas de diálisis.

Utilizaremos una grabadora para almacenar la información, pero no vamos a utilizar su nombre o domicilio en este estudio. Todas sus respuestas serán confidenciales y las grabaciones serán borradas después del estudio. No nos quedaremos con ninguna información personal de Ud. en nuestros archivos.

Es importante que sepa que Ud. no está obligado(a) a participar en este estudio. El participar o no es su decisión. Su participación es voluntaria. El que Ud. participe o no en este estudio no tendrá ningún efecto sobre su relación con la clínica de diálisis, su proveedor de transporte o su médico.

Si Ud. decide participar, recibirá una tarjeta de regalo para hacer compras en una tienda, con un valor de \$25.00 (veinticinco dólares) como agradecimiento por ayudarnos con este estudio.

Si Ud. tiene alguna pregunta o comentario, por favor llame al Dr. Joao Ferreira –Pinto al (915) 747 7295

**¡Muchas gracias por su consideración!**

**Por favor llene el costado de esta forma si Usted decide participar y entréguesela a la persona que le preguntó si Ud. quisiera participar en este estudio.**

☐ Estoy interesado(a) en saber más sobre este estudio. Por favor contáctenme usando la siguiente información:

Nombre: \_\_\_\_\_

Teléfono(s): \_\_\_\_\_

La mejor hora del día para llamarme es: \_\_\_\_\_

Correo electrónico (Email): \_\_\_\_\_@\_\_\_\_\_

## **Appendix 2**

### **Interview Guides**

Patients English/Spanish  
Transportation Providers English/Spanish  
Dialysis clinic personnel  
Nephrologists

## Patient Interview

1. When were you informed that you needed dialysis treatment? Who informed you?
2. Did the doctor /nurse/social work (please specify who) explain to you what was involved in dialysis treatment?
3. Were you told that you could choose your own dialysis clinic? If yes, who told you?
4. Who decided which dialysis clinic you should go to? Did the medical providers give you a choice of clinics to choose from?
5. How far away from your house was your first dialysis clinic visit?
6. Do you still go to the same dialysis clinic you started initially?
7. If you do not go to the same clinic, why did you change dialysis clinics? How many times have you changed dialysis clinics?
8. When did you start your dialysis treatment?
9. What are the main problems you encountered with the treatment at the beginning? How about now?
10. How did you get from your house to the dialysis clinic at the beginning of your treatment? Did you drive yourself or did someone else drive (who)?
11. How many times a week are you going to the dialysis clinic now? Has the number of days increased from last year?
12. Tell me what happens in a typical day when you are transported to the dialysis clinic? Describe what happens from the moment you are picked up at your home until you come back. [Probe: "Anything else" for each leg of the journey.]
13. How many stops do you make before you get to the clinic? Do they vary each day?
14. Is the driver of the van the same person every time? Both ways? Do you like it this way? Why?
15. Is the van late often picking you up? How many times in a month?
16. After you arrive, how long do you have to wait before your dialysis is started?
17. How long do you have to wait until the van picks you up after dialysis?
18. Have you ever missed a dialysis appointment because of lack of transportation?
19. Have you ever missed a doctor's appointment because of lack of transportation?
20. What do you think has to be changed regarding transportation in order to improve your experience?

## Patient Interview - Spanish

1. ¿Cuándo le informaron que Ud. necesitaba empezar su tratamiento con diálisis? ¿Quién le informó?
2. ¿Le explicó el médico/enfermera/trabajador social (favor de especificar quién) los factores involucrados en el tratamiento con diálisis?
3. ¿Le informaron que Ud. podía elegir la clínica para su tratamiento de diálisis? Si es así, quien le informó?
4. ¿Quién decidió a cual clínica debía ir Ud. para su tratamiento? Le dieron los médicos u otros proveedores de salud una lista de clínicas para que Ud. escogiera?
5. ¿Qué tan lejos de su casa fue la primera visita a la clínica de diálisis?
6. ¿Sigue Ud. yendo a la misma clínica de diálisis con la que empezó su tratamiento?
7. En caso de que Ud. ya no vaya a la misma clínica de diálisis, ¿por qué razón cambió de clínica? ¿Cuántas veces ha cambiado de clínicas de diálisis?
8. ¿Cuándo comenzó su tratamiento con diálisis?
9. ¿Cuáles fueron los principales problemas con los que Ud. se encontró al comenzar con su tratamiento? ¿Existen problemas actualmente?
10. ¿Cómo iba de su casa la clínica de diálisis al principio de su tratamiento? Manejaba Ud. mismo (a) o lo llevaba otra persona (¿Quién?)
11. ¿Actualmente, cuantas veces (días) por semana visita la clínica de diálisis? ¿Ha aumentado el número de días comparado con el año pasado?
12. Dígame que pasa en un día típico cuando Ud. es transportado (a) a una clínica de diálisis? Describa lo que ocurre desde el momento en que lo recogen en su domicilio hasta el momento en que Ud. es llevado de regreso a su casa [Probe: "Anything else" for each leg of the journey.]
13. ¿Cuántas paradas hace su transporte antes de llegar a la clínica de diálisis? ¿Varía el número de paradas en cada ocasión o es el mismo?
14. Maneja siempre el (la) mismo chofer del camión o de su casa a la clínica y de regreso de la clínica a su casa, o son personas distintas? ¿Lo prefiere Ud. así? ¿Porque?
15. ¿Llega tarde frecuentemente el camión para recogerla en su casa? ¿Cuántas veces por mes llega tarde el camión?
16. Al llegar a la clínica, ¿Cuánto tiempo tiene Ud. que esperar antes de empezar su tratamiento con diálisis?
17. ¿Cuánto tiempo tiene Ud. que esperar al camión para llevarlo de regreso a su casa después de terminar su tratamiento con diálisis?
18. ¿Alguna vez ha perdido un tratamiento de diálisis a causa de falta de transporte a la clínica?
19. ¿Alguna vez ha perdido una consulta con su médico a causa de falta de transporte?
20. En su opinión, ¿Qué cambios son necesarios en el sistema de transporte para las clínicas de diálisis para mejorar el servicio (mejorar su experiencia como paciente)?

## Transportation Providers Interview

1. Who make referrals of Medicare and Medicaid patients for dialysis do your transportation services?
2. Do you know the criteria used by the medical provider to recommend a particular clinic to Medicare or Medicaid patient?
3. Do you know if the patient given a list of clinics to choose from?
4. Who contacts you to initiate the dialysis clinic transportation service?
5. Do you have a waiting list for dialysis patients that you cannot start transporting immediately?
6. What is the main problem you encounter during the transportation of dialysis patients to and from a clinic?
7. Do you also take dialysis patients to follow-up visits to the doctors' offices? Is that on a regular basis?
8. Do you recall how many patients change clinics annually? Is that a frequent occurrence?
9. What is the longest distance hat you have to transport a patient to a clinic? What is the shortest? What is an average distance?
10. Where to do you have the wait the longest to retrieve a patient to take his or her home; at the patients' home or at the clinic? What are the reasons?
11. How many of the patients you transport are wheelchair bound?
12. What is the biggest complaint that you hear from patients in regarding to their transportation to and from a clinic?
13. What is the most frequent complaint about the dialysis clinic?
14. What suggestions do you have to improve the transportation system for dialysis patients?
15. Do you currently have any major issues with transporting patients to and from the dialysis clinics that have interrupted their dialysis sessions or interfered with their treatment? What kind of issues are they?
16. If you answered yes to the preceding question, are any actions being undertaken to resolve the issues? If so, which ones?
17. Does your transportation company provide emergency services for dialysis patients? If so, which ones?
18. Does your company provide transportation to a dialysis clinic for a patient who is currently not assigned to your company on an ongoing basis, but who only requests the service from time to time?

## Transportation providers- Spanish

1. ¿Quién refiere a los pacientes de diálisis a su servicio de transporte?
2. ¿Conoce usted el criterio utilizado por el médico para recomendar una clínica en particular para el paciente bajo Medicare o Medicaid?
3. ¿Sabe usted si al paciente se le da una lista de clínicas para que pueda escoger?
4. ¿Quién se comunica con usted para iniciar el servicio de transporte a las clínicas de diálisis?
5. ¿Tiene usted una lista de espera para los pacientes de diálisis que usted no pueda transportar en este momento?
6. ¿Cuál es el principal problema que se le presenta durante el transporte de los pacientes a las clínicas de diálisis y después de su tratamiento de regreso a su casa?
7. ¿También lleva usted a los pacientes a visitas médicas? ¿Lo hace usted regularmente?
8. ¿Recuerda usted cuantos pacientes cambian de clínica anualmente? ¿Ocurre esto frecuentemente?
9. ¿Cuál es la distancia más larga que usted tiene que transportar a un paciente a la clínica? ¿Cuál es la más corta? Y ¿cuál es la distancia promedio?
10. ¿En dónde tiene usted que esperar más tiempo a los pacientes, en su casa o en la clínica de diálisis? ¿Cuáles son las razones?
11. ¿Cuantos pacientes de los que usted transporta usan silla de ruedas?
12. ¿Cuál es la queja más importante que usted escucha de los pacientes relacionada a el transporte de su casa a la clínica de diálisis y viceversa?
13. ¿Cuál es la queja más frecuente que usted escucha sobre la clínica de diálisis?
14. ¿Qué sugerencias tiene usted para mejorar el sistema de transporte para los pacientes de diálisis?
15. ¿Actualmente tiene usted algún problema mayor relacionado a transportar a los pacientes de su casa a la clínica de diálisis y viceversa que haya resultado en la interrupción de su tratamiento de diálisis o que haya interferido con su tratamiento? ¿Qué tipo de problemas son?
16. ¿Si usted respondió sí a la pregunta anterior, que acciones se están llevando a cabo para resolver esos problemas? Si es así, ¿cuáles son?
17. ¿Provee su compañía de transporte algún servicio de emergencia para los pacientes de diálisis? Si es así, ¿cuáles son?
18. ¿Provee su compañía de transporte servicio para un paciente de diálisis que no esté actualmente asignado a su compañía en forma regular pero quien solo solicita el servicio de tiempo en tiempo?

### **Dialysis Clinic Personnel**

1. How many transportation providers do you interact with at your clinic? Which are they?
2. In your experience, what are the most important issues related to transportation to and from the dialysis facility regarding the patients and the services provided by your clinic?
3. Have any of these issues influenced the rate of patient attendance or compliance to the dialysis sessions?
4. Does the transportation provider also help with emergency services, such as ambulances, for example?
5. What is the typical procedure your clinic follows when the patient is released from treatment? Does this involve only an order by the physician or do you also require a release or consent from the patients' families?
6. If the patients' physician decides a patient should resume dialysis even if they had previously terminated their sessions with your clinic, can you readmit them with a medical referral or do you refer them to another clinic?

## **Nephrologists Interview**

1. When you refer Medicare and Medicaid patients for dialysis, do you or your nurse or PA make a recommendation to the patient to receive the treatment in a specific dialysis clinic?
2. What criteria do you use to recommend a specific dialysis clinic?
3. Do you take into account the location of the clinic in relation to its proximity to the patients' home addresses or is the referral made taking account only the availability of service in a particular clinic?
4. Do you refer your patients to colleagues or clinics you trust or is the decision made taking account only the availability of service in a particular clinic?
5. Is there any financial or other benefit for the physician and/or dialysis provider involved in the decision making process regarding the patients' referral to a particular clinic?
6. Is the patient given a list of dialysis clinics to choose from?
7. Does your nurse or PA call the dialysis clinic to set up an appointment for the patient?
8. Is it hard to place a new patient in a dialysis clinic? Is there usually a waiting list in some clinics?
9. If a patient lives in a remote rural area with no dialysis clinic in his/her town, how is the referral made and who are the most reliable transportation services employed?
10. Do you know to which dialysis clinics your patients still go to? Are they the same you recommended initially, or do you have a way of knowing if the dialysis clinics your patients are going to are the same ones you initially recommended?
11. Are you in frequent contact with the dialysis clinic medical personnel regarding the dialysis patients' health status?
12. Are patients informed about meal portion size as well as how to make food choices based on their most recent blood /lab values? If so, is special attention given to maintaining adequate potassium, phosphorus, sodium and protein levels?
13. Do any of the patients comment on the transportation provider? Are there any complaints? If so, which are you aware of?
14. Are you involved, in any way, in establishing transportation services for the Medicaid or Medicare patients for office follow-up visits (how)?
15. At which intervals do Medicaid and Medicare dialysis patients have follow-up office visits? How often do Medicaid and Medicare Dialysis patients receive follow up office visits? Or after the dialysis session, how long is it before patients receive a follow up office visit?
16. Do you have meetings with the dialysis clinic personnel in order to discuss how to improve transportation and other ancillary services to patients?
17. Do you have any suggestions on how to improve the free transportation system for Medicare and Medicaid patients?
18. Do you know if the drivers of transportation units certified in CPR and / or other emergency procedures in case something happens en route to the clinic or patients' homes?

## **Appendix 3**

### **Informed Consent English and Spanish**

## Informed Consent English

### **El Paso County Dialysis Transportation Research Project**

#### **INDIVIDUAL INTERVIEW**

**Research Sites:** El Paso, Hudspeth, Pecos, and Presidio Counties

**University of Texas at El Paso (UTEP) Institutional Review Board**

**Informed Consent Form for Research Involving Human Subjects**

**Protocol Title:** El Paso County Dialysis Transportation Research Project

**Principal Investigator:** João Ferreira-Pinto, Ph.D.

**UTEP: Center for Interdisciplinary Health Research and Evaluation, College of Health Sciences,**

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You are being requested to participate voluntarily in a research study conducted by the Center for Interdisciplinary Health Research and Evaluation (CIHRE) at the College of Health Sciences, UTEP on behalf of the Texas Department of Transportation El Paso County Regional Transportation Department. Please take your time making a decision and feel free to discuss it with your friends and family. Before agreeing to take part in this research study, it is important that you read this consent form that describes the study. Please ask the study researcher to explain any words or information that you do not clearly understand.

#### **Why is this study being done?**

This research study is being done in order to explore the process involved in the dialysis treatments of Medicaid and Medicare patients. You are being asked to participate because you are a dialysis patient in one of the dialysis clinics in El Paso, Hudspeth, Pecos, or Presidio Counties.

Your answers are important because the researcher wants to learn from your knowledge and opinions about the transportation provider from your home to and from the dialysis clinics that is providing you the transportation service. The researcher is also interested on how you have started dialysis, how you were referred to your dialysis clinic, and the transportation to the doctor's office visits. We will also ask you questions about the type of service you are receiving before, during, and after the dialysis treatment is completed. All this information will help provide information to health care and transportation providers that will be useful to improve your dialysis treatment.

#### **Taking part in this study involves:**

You will be taking part in an individual interview that can last for about 60 minutes. During the interview, you will be asked questions about the provider that is providing you transportation service from your home to and from the dialysis clinics. We will also be asking you questions on how you have started dialysis, how you were referred to your dialysis clinic, and about the transportation to the doctor's office visits. We will also ask you questions about the type of service you are receiving before, during, and after the dialysis treatment is completed.

You will not be asked any personal questions about the status of your personal health, medications you may be taking, or any other question that is not related to issues related to the transportation being provided to you. The interview will be recorded digitally. During the meeting, both you and the researcher will be careful not to mention any information that could identify you (or any other person). In addition, you

will be asked to fill a small survey that will gather information about your age, sex, education level, County of residency, name of the transportation provider, name of your physician, how long you have been receiving dialysis treatment, etc. This survey will not ask your name or any other confidential information that can connect your responses to you.

### **Risks and discomforts of the study**

This individual interview has no physical risks. The only anticipated discomfort to study participants created by the proposed study is the discomfort of sitting down for about 60 minutes and answering questions. The researcher will be asking about your opinion and knowledge of the dialysis transportation system. No invasive or personal questions will be asked. The researcher will not ask your name or address. Although the researcher will not write your name on anything and will not have information to tell anyone the names of persons who join the study, there is a minute chance that what you are stating in a public forum may be divulged. The researcher will take all precautions that this will not occur.

Although no invasive or personal questions will be asked, participants' opinions and knowledge of the dialysis transportation system may be embarrassing to some participants. If you feel upset or uncomfortable, you can stop the interview at any time. You will not lose any services that are being provided to you by refusing to continue, and will still be eligible to receive the proposed incentive.

### **What will happen if I am injured in this study?**

Taking part in this study does not involve any physical harm. The University of Texas at El Paso and its affiliates do not offer to pay for or cover the cost of medical treatment for research related illness or injury. No funds have been set aside to pay or reimburse you in the event of such injury or illness. You will not give up any of your legal rights by signing this consent form. You should report any such injury to Dr. João Ferreira-Pinto, the Principal Investigator of this study, at 915-747-7295 or joao@utep.edu and to Athena Fester Administrator of the Institutional Review Board (IRB) at UTEP at (915-747-8841) or afester@utep.edu.

### **Benefits to taking part in this study**

There are no direct benefits for you from taking part in this study. By answering the researcher questions, you will be contributing to increasing the knowledge of providers about how the transportation system to and from dialysis clinics are working and what steps should be taken to improve it. Taking part in this study is also an opportunity for you to let others know your opinions about this issue.

### **Participation in this study is voluntary**

You have the option not to take part in this study. If you choose to take part, you have the right to stop at any time. There will be no penalties involved if you choose not to take part in this study. However, if you decide not to take part in this study you are encouraged to talk to the interviewer so that he or she knows why you are leaving the study. The researcher may also decide to stop your participation without your permission, if she thinks that being in the study is making you psychologically stressed.

### **Who is paying for this study?**

Taking part in this study is free.

You may ask any questions you have now or at any time. If you have questions about this study later, you may contact Dr. João Ferreira-Pinto, at 915-747-7295 at the College of Health Sciences, UTEP, U.S.A. or on his personal cell phone at (915)-274-0802. He will be happy to tell you more about this research.

If you have questions or concerns about your participation as a research subject, please contact Athena Fester Administrator of the Institutional Review Board (IRB) at UTEP at (915-747-8841) or afester@utep.edu. .

### Your responses will be kept confidential

Your part in this study is confidential. The data collected will be kept confidential and your name will not be connected with the answers you give the researcher or used in any reports. The interviewer can write down notes during the interview but these notes will not contain your name or any other information that can connect you with your responses. Only the researcher will have access to the recordings. If an interview transcriber is employed to transcribe the interview notes, then this transcriber will have restricted access to the database. All data will be coded and your name cannot be connected with any answers you give during the interview.

A back-up database of the recordings will be created in order to protect against loss of electronic data due to technical difficulties and will be accessible only to the researcher. All interview notes will be kept in a locked cabinet and will be accessed only by Dr. Ferreira-Pinto. After the recordings from this study are analyzed, the digital recordings will be stored in a password locked electronic file for the purpose of future data analysis and reference. Your name or any personal information that may identify you with your interview answers will not be used when the findings from this study are reported. Only false name (pseudonyms) will be used if it becomes necessary to do so when the findings are reported. The recordings will not be directly presented to any individual, in an oral or written report or in any meeting.

### Authorization Statement

I have read each page of this paper about the study. I know that being in this study is voluntary and I choose to be in this study. I know I can stop being in this study without penalty. I will get a copy of this consent form now and can get information on results of the study later if I wish.

I have read all the items on the information sheet, and all questions about the study have been answered to my satisfaction.

I understand the following:

- My participation is voluntary;
- I can discontinue participation at any time without penalty.
- My name will not appear on interview or other data collection forms: only a code number will be used;
- All information will be kept in a locked electronic file (digital recordings) and a locked cabinet (written material).
- All written and published information will be reported with no reference to individuals

\_\_\_\_\_  
Participant Signature                      Date

\_\_\_\_\_  
Interviewer Signature                      Date

Consent form explained/witnessed by:

\_\_\_\_\_  
Signature

Code Number \_\_\_\_\_

## Spanish

### El Paso County Dialysis Transportation Research Project

#### ENTREVISTA INDIVIDUAL

**Sitios de investigación:** Condados de El Paso, Hudspeth, Pecos, y Presidio

**Universidad de Texas en El Paso (UTEP) Junta de Revisión Institucional**

**Formulario de Consentimiento Informado para la Investigación en Seres Humanos**

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**Título del Protocolo:** Proyecto de Investigación sobre Transporte para Diálisis en El Paso

**Investigador principal:** João Ferreira-Pinto, Ph.D.

**UTEP:** Centro Interdisciplinario de Investigación en Salud y Evaluación Facultad de Ciencias de la Salud

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Se le ha invitado a participar voluntariamente en un estudio de investigación que está siendo realizado por el Centro Interdisciplinario de Investigación en Salud y Evaluación (CIHRE) de la Facultad de Ciencias de la Salud, UTEP, en nombre del Departamento de Transporte de Texas para el Condado de El Paso - Departamento Regional de Transporte. Por favor, tómese su tiempo para tomar una decisión y no dude en consultar su decisión con sus amigos y familiares. Antes de aceptar participar en este estudio, es importante que usted lea este formulario de consentimiento que describe el estudio. Por favor, pregunte al investigador principal del estudio que le explique cualquier palabra o información que no se entienda claramente.

#### ¿Por qué se realiza este estudio?

Este estudio de investigación que se está haciendo con el fin de explorar los procesos involucrados en los tratamientos de diálisis de pacientes de Medicaid y Medicare. Usted está siendo invitado a participar, porque usted es un paciente de diálisis en una de las clínicas de diálisis en el condado de El Paso, Hudspeth, Pecos, o Presidio.

Sus respuestas son importantes debido a que el investigador quiere aprender de sus conocimientos y opiniones sobre el proveedor de servicio de transporte de su hogar a y de las clínicas de diálisis. El investigador también está interesado en la forma en que han comenzado la diálisis, como fue canalizado o referido a su clínica de diálisis, y el transporte para sus visitas al consultorio del médico. También le hará preguntas sobre el tipo de servicio que estaba recibiendo antes, durante y después que termina el tratamiento de diálisis. Toda esta información ayudará a proporcionar información a los servicios de salud y proveedores de transporte que serán de utilidad para mejorar su tratamiento de diálisis.

#### La participación en este estudio implica que:

Usted va a tomar parte en una entrevista que puede durar aproximadamente 60 minutos. Durante la entrevista, se le harán preguntas sobre el proveedor que les proporciona servicio de transporte de su casa a y de las clínicas de diálisis. También se les harán preguntas sobre cómo se han iniciado diálisis, sobre la canalización o referencia a la clínica de diálisis, y sobre el transporte para las visitas al consultorio del médico. También le hará preguntas sobre el tipo de servicio que está recibiendo antes, durante y después del tratamiento de diálisis.

No se le harán preguntas personales sobre su estado de su salud, ni los medicamentos que está tomando, o cualquier otra pregunta que no está relacionado con cuestiones del transporte que se le proporciona a usted. La entrevista será grabada digitalmente. Durante la reunión, usted y el investigador tendrá cuidado de no mencionar ninguna información que pueda identificarlo (o cualquier otra persona). Además, se le pedirá llenar una pequeña encuesta que recogerá información sobre su edad, sexo, nivel educativo, el condado de residencia, nombre del proveedor de transporte, el nombre de su médico,

cuánto tiempo ha estado recibiendo tratamiento de diálisis, etc. Para esta encuesta no se le preguntará su nombre o ni ninguna otra información confidencial que se pueda asociarse con usted.

### **Riesgos y molestias del estudio**

Esta entrevista de grupo no tiene riesgos físicos. La única incomodidad para los participantes del estudio es la molestia de sentarse durante unos 60 minutos y responder a las preguntas. El investigador va a preguntar sobre sus opiniones y conocimiento acerca del sistema de transporte de diálisis. No hay preguntas invasivas o personales. El investigador no le preguntará su nombre ni su dirección. Aunque el investigador no va a escribir su nombre en ninguna parte y no se tiene información acerca de nombres de las personas que se incorporan al estudio, existe una muy remota posibilidad que lo dicho en un foro público sea divulgado. El investigador va a tomar todas las precauciones que esto no ocurra.

Aunque no hay preguntas de índole personal, se le pedirá a usted y a los otros participantes que compartan sus opiniones y conocimiento del sistema de transporte de diálisis, es posible que algún comentario sea penoso para algún participante. Si usted se siente molesto o incómodo, puede detener la entrevista en cualquier momento. Usted no perderá ninguno de los servicios que se le prestan por negarse a continuar, y seguirá siendo elegible para recibir el incentivo propuesto.

### **¿Qué sucederá si me lesiono en este estudio?**

La participación en este estudio no implica ningún daño físico. La Universidad de Texas en El Paso y sus afiliados no ofrecen a pagar o cubrir el costo del tratamiento médico para la enfermedad o lesión relacionada con la investigación. Ninguno de los fondos se ha destinado a pagar en caso de lesión o enfermedad. Usted no va a renunciar a ninguno de sus derechos legales al firmar este formulario de consentimiento. Usted debe reportar cualquier lesión al Dr. João Ferreira-Pinto, el investigador principal de este estudio, al 915-747-7295 o joao@utep.edu y al administrador de Athena Fester de la Junta de Revisión Institucional (IRB) en UTEP (915-747-8841) o afester@utep.edu.

### **Beneficios por participar en este estudio**

No hay beneficios directos para usted participar en este estudio. Al contestar las preguntas investigador, usted estará contribuyendo a aumentar el conocimiento de los proveedores acerca de cómo el sistema de transporte hacia y desde las clínicas de diálisis están trabajando y qué medidas se deben tomar para mejorarlo. La participación en este estudio es también una oportunidad para informar a los demás sus opiniones acerca de este tema.

### **La participación en este estudio es voluntaria**

Usted tiene la opción de no participar en este estudio. Si usted decide participar, usted tiene el derecho de suspender su participación en cualquier momento. No habrá sanciones involucrados si decide no tomar parte en este estudio. Sin embargo, si usted decide no tomar parte en este estudio se le anima a hablar con el entrevistador para que él o ella sepan por qué va a salir del estudio. Asimismo, el investigador puede decidir terminar su participación sin su permiso, si ella/el piensa que en el estudio le está causando estrés.

### **¿Quién paga por este trabajo?**

La participación en este estudio es totalmente gratuita. Usted será compensado por su tiempo para tomar parte en este estudio \$ 25,00 dólares. Este incentivo es posible gracias al Departamento de Transporte de Texas, Departamento Regional de Transporte, Condado de El Paso. Usted recibirá el incentivo después de completar la entrevista.

Usted puede hacer cualquier pregunta ahora o en cualquier momento. Si usted tiene preguntas acerca de este estudio, puede comunicarse con el Dr. João Ferreira-Pinto, en el 915-747-7295 en la Facultad de Ciencias de la Salud, UTEP, EE.UU. o en el teléfono celular IES personal al (915) -274-0802. Estaremos encantados de darle más información sobre esta investigación.

Si usted tiene preguntas o inquietudes acerca de su participación como sujeto de investigación, por favor póngase en contacto con Athena Fester la Administradora de la Junta de Revisión Institucional (IRB) de UTEP al (915-747-8841) o afester@utep.edu. .

### **Sus respuestas serán confidenciales**

Su participación en este estudio es confidencial. Los datos recabados serán confidenciales y su nombre no estará asociado a las respuestas que dará el investigador en los informes. El entrevistador puede tomar notas durante la entrevista, pero estas notas no contienen su nombre o ni ninguna otra información que puede asociar su identidad con las respuestas. Sólo el investigador tendrá acceso a las grabaciones. Si se emplea un transcriptor para transcribir las notas de la entrevista, este transcriptor tendrá acceso restringido a la base de datos. Todos los datos serán codificados y su nombre no se podrá asociar con las respuestas de durante la entrevista.

Una base de datos de respaldo de las grabaciones se creará con el fin de proteger contra la pérdida de datos electrónicos, debido a dificultades técnicas pero esta sólo será accesible al investigador. Todas las notas de la entrevista se mantendrá en un armario cerrado con llave y sólo el Dr. Ferreira-Pinto tendrá acceso. Después de las grabaciones de este estudio se analizan, se almacenan en un archivo electrónico con una contraseña que bloquea el acceso, esta se hará solo con el propósito de análisis de datos y referencia. Su nombre o cualquier información personal que pueda identificarlo con las respuestas de la entrevista no se utilizarán cuando los resultados de este estudio se presenten. Sólo un nombre falso (seudónimos) se utiliza si es necesario hacerlo cuando los resultados son reportados. Las grabaciones nunca se presentan directamente a ninguna persona, en un informe oral o escrito ni tampoco en ninguna reunión.

### **Declaración de autorización**

He leído cada página de este documento sobre el estudio. Yo sé que en este estudio es voluntario y puedo optar participar o no en este estudio. Sé que puedo dejar de ser parte de este estudio sin que se me penalice. Voy a obtener una copia de este formulario de consentimiento ahora y más adelante puedo obtener información sobre los resultados del estudio si lo deseo.

He leído todos los artículos en la hoja de información, y todas las preguntas sobre el estudio han sido contestadas a mi satisfacción.

Yo entiendo lo siguiente:

- Mi participación es voluntaria;
- Puedo dejar de participar en cualquier momento sin que se me penalice por ello;
- Mi nombre no aparecerá en la entrevista ni en las otras formas de recolección de datos: sólo un número de código será utilizado;
- Toda la información se guardará en un archivo bajo llave electrónica (grabaciones digitales) y un armario con llave (material escrito).
- La información, los escritos y los informes serán publicados sin hacer mención de las personas

\_\_\_\_\_  
Firma del Participante

\_\_\_\_\_  
Fecha

\_\_\_\_\_  
Firma del Entrevistador

\_\_\_\_\_  
Fecha

Formulario de consentimiento fue explicada / presenciada por:

\_\_\_\_\_  
Firma

Número de Código \_\_\_\_

## **Appendix 4**

### **Final Coding Schema**

## Final Coding Schema

### Administrators

Transportation providers' ambulances  
Transportation providers' special assistance  
Transportation providers' interactions  
Transportation providers' companies  
Returning procedure  
Release procedure  
Patients on wheelchairs  
Issues related to transportation and waiting time  
Issues related to transportation and dialysis  
Issues related to transportation  
Irrelevant  
Dialysis patient diet  
Clinic location  
Choice of clinics  
Available Chairs  
Administrators

### Dispatchers

Available chairs  
Backup Drivers  
Choice of clinics  
Clinic complaints  
Clinic location  
Dispatcher  
Dispatcher interaction driver  
Dispatcher interaction manager  
Dispatcher interaction social worker  
Dispatcher recommendations  
Distance mileage  
Driver schedule pick-ups  
Irrelevant  
Issues related to transportation and dialysis  
Issues related to transportation and waiting time  
Patient change of clinics  
Patient interaction dispatcher  
Patient referral transportation  
Patients' complaints about transportation  
Patients on wheelchairs  
Transportation providers' interactions  
Transportation providers' special assistance  
Transportation medical appointments

### Drivers

Available chairs  
Backup driver  
Choice of clinic  
Clinic complaints  
Clinic location  
Dialysis patient diet  
Dispatcher interaction with driver  
Distance mileage  
Driver  
Driver recommendations  
Driver schedule pick-ups  
Irrelevant

Issues related to transportation and dialysis  
Issues related to waiting time  
Patient complaints  
Patient interaction with dispatcher  
Patients on wheelchairs  
Quality of life  
Shifts  
Technicians  
Transportation providers' companies  
Transportation providers interactions Medicare/Medicaid  
Transportation medical appointments  
Transportation providers' special assistance  
Vehicle repair and maintenance

## **Managers**

Available chairs  
Backup driver  
Choice of clinics  
Clinic complaints  
Clinic hygiene  
Clinic location  
Dispatcher interaction manager  
Distance mileage  
Driver interaction patient  
Irrelevant  
Issues related to transportation  
Issues related to transportation and waiting time  
Manager interaction social worker  
Manager recommendation  
Managers  
Patient change of clinics  
Patient interaction with dispatcher  
Patient interaction with managers  
Patients' complaints  
Patients on wheelchairs  
Quality of life  
Transportation providers' interactions  
Transportation providers' interactions' Medicare/Medicaid  
Transportation providers' special assistance  
Transportation medical appointments

## **Nephrologists**

Available chairs  
Choice of clinics  
Clinic location  
Clinic recommendation  
Dialysis patient diet  
Follow-up visits  
Irrelevant  
Issues related to transportation and dialysis  
Issues with transportation  
Nephrologist  
Nephrologist interaction dialysis clinic  
Nephrologist interaction with dialysis clinic  
Nephrologists' recommendations  
Parameters dialysis  
Patient change of clinic  
Patient change of clinics  
Patient referral to clinic  
Patients' complaints about transportation  
Patients on wheelchairsProblems with transportation

Retain nephrologist different clinic  
Transportation Providers special assistance  
Transportation providers' special assistance

## **Social Workers**

Available chairs  
Dialysis demand  
Dialysis patient diet  
Drivers negligence  
Interactions with patients  
Irrelevant  
Issues related to dialysis  
Issues related to transportation and dialysis  
Issues related to transportation and waiting time  
Outsourcing  
Patient referral to clinic  
Patients' complaints about transportation  
Patients on wheelchairs  
Quality of life  
Release procedure  
Returning procedure  
Shifts  
Social worker  
Social worker recommendations  
Transportation affordability

## **Patients**

Clinic continuity  
Clinic location  
Dialysis patient diet  
Distance mileage  
Doctor's choice of clinic  
Drivers negligence  
Initial explanation of dialysis  
Initial transportation  
Initial treatment  
Irrelevant  
Issues related to transportation  
Issues related to waiting time  
Medicaid/Medicare  
Patient's complaints  
Patient choice of clinic  
Patient knowledge of need of dialysis  
Patient payment of transportation  
Patient recommendation  
Patient referral to clinic  
Patient symptoms  
Patients  
Quality of life  
Transportation description  
Treatment

## **Appendix 5**

### **Transcription Examples**

## **Center for Interdisciplinary Health Research and Evaluation (CIHRE)**

### **DoT Project**

#### **Nephrologist**

**Q:** Thank you doctor for your time. Uhmm, basically when you refer a Medicare/Medicaid patient for dialysis, do you or your nurse make any recommendation to the patient that receives the treatment in a specific dialysis clinic?

**P:** Generally speaking I do so closest to their home. We try to get them scheduled for an outpatient clinic that's as close to their home as possible to try to reduce the difficulty they have with transportation to and from the dialysis center but that's not always possible.

**Q:** I see, ok. Uh would it be a matter of availability of chairs or that the patient wants to go to another clinic?

**P:** Uhmm most of the time it's an availability of chairs. They in general want to go to the dialysis clinic closest to their home.

**Q:** I see.

**P:** And those dialysis units sometimes fill up and they don't always have available chairs.

**Q:** I see. Is the patient given a list of dialysis clinics to choose from?

**P:** Uhmm, what we generally do is contact the Da Vita corporation central scheduling office and they go over what dialysis centers are available uh. If a lot of them are full and so it's not quite uhmm, convenient to give them a list of every dialysis center if some of them have no openings.

**Q:** I see, of course. Now does anybody from your office call the dialysis clinic to set up the appointment for the patient? Who does that?

**P:** Usually it's done from the social workers from the hospitals. Sometimes uh, one of our office staff will call the dialysis center if we know if there's an opening in the dialysis center and we can, and the, that they're closest to that dialysis center. Sometimes we'll do it that way, but most of the time it's from the, social worker at the hospital.

**Q:** I see, social worker at the hospital. Now if a patient would like to change to another clinic uh, does he or she notify you first? Or who notifies you of the change?

**P:** Uh, generally speaking the uh social worker at the dialysis center calls the other dialysis center calls if there's any chairs available and then, goes through that social worker.

**Q:** I see. Ok. Uhmm are you uhmm in contact with the medical personnel uh, or the biomedical personnel in the dialysis clinics where your patients are?

**P:** Of course, yes we are.

**Q:** Ok, how often are you contact with them?

**P:** We uh, speak to them several times a week and then we usually go that dialysis center at least once a week.

**Q:** Ok do you have like a meeting with them uh specifically?

**P:** Well we go to see the patients and if they have any questions or papers they need to sign they'll bring them to your attention at that time we round for that dialysis schedule.

**Q:** Now if there would be an issue with the transportation to the dialysis clinics to and from uh would that be addressed at those meetings as well?

**P:** Uhmm, I would say when they come, when it comes up yes. But, often it's just when we round at the dialysis center the nurse or the social worker comes and tells us if there's an issue with transportation.

**Q:** Ok, have any of the patients given you any complaint or comment about the transportation providers to and from their, the dialysis clinics?

**P:** Generally if I'm going to hear about the complaint I hear about them through the social workers. They tell us uhmm that sometimes they're people,.they're slow to get the patients picked up or that they rush them off their dialysis treatments to be taken by the bus or transportation back home.

**Q:** Ok so that would mean in the case of a patient uhh would it also,.would that translate into non-adherence to their treatment? In other words shortening the treatment?

**P:** Sometimes they do shorten their treatment due to the fact that the uh transportation is there to pick them up and they rushed them off the dialysis treatment so they don't lose their ride home.

**Q:** How does that,.If that were to continue week after week uhmm or treatment after treatment, how does that impact the quality of life of the patient?

**P:** I think it makes it more stressful for the patient and also it reduces how well the,.how much they get dialysis in the ,.and that,.therefore impacts how well they get their blood cleaned by the dialysis treatment.

**Q:** So could we say, at least theoretically that that could... that could be a factor in shortening the lifespan of the patient regarding their treatment?

**P:** Theoretically, when you shorts, when you decrease how well their blood gets cleaned or in uh technical terms how low the KT over V is driven by the reduced treatment time. Yes it could shorten their life.

**Q:** I see, and uhmm have there been any other comments or any other complaints about the transportation providers?

**P:** Uh, I think that I've heard from several social workers that the, the drivers of the transportation have at times been uh at least court or short with the patients to get on the bus or get off the bus a little more quickly.

**Q:** I see, I see. Has any patient told you directly? Not just the social worker from the clinic?

**P:** Yes. I have heard that from a couple of different patients uh a couple of different patients have actually had uh accidents where they were tipped off of their motorized wheel chair or just off their wheelchair because of uh the driver being in a hurry.

**Q:** I see well uh ...about how...what percentage of your patients who are under dialysis are wheelchair bound approximately?

**P:** Probably, at least uh...15-20%.

**Q:** I see, and uh do you know uhmm have you heard any suggestions or do you have any suggestions on how to improve the transportation system for the Medicare and Medicaid patients do the dialysis clinics?

**P:** They need to be a little more responsive to the patient's actual treatment times.

**Q:** Ok.

**P:** And not cut them short just to meet their own scheduling.

**Q:** Ok so what I understand is that most of these situations have been picking them up at the dialysis clinic more than picking them up at home. Am I correct?

**P:** Uh...occasionally we'll hear about how their late to pick them up at home or uh that they won't wait for them even a few minutes when they pick them up at home.

**Q:** I see I see and uhmm. Do you know if uh the drivers of these units are certified for any emergency procedures if something happens to the patient during the uh transit time?

**P:** I do not know if they're certified.

**Q:** Ok, would you suggest that they should be certified in CPR or something or not?

**P:** I think that would be a wise idea.

**Q:** Ok very good. Are there any other comments that you have regarding the transportation for the patients here in El Paso County?

**P:** Uh, I've heard...I just want to make the statement that I've heard from several social workers that they felt that the county transportation had not been very responsive to the patients and had uhmm treated the patients uh less than kindly when they pick them up or drop them off.

**Q:** I see and uhmm have you heard...this is basically the county transportation...have you heard anything from the other private providers of transportation?

**P:** Such as?

**Q:** Well there is also for example VIVA. There is also uhmm Sun City, there are also for example uhmm some senior centers like Bien Vivir also have transportation for dialysis.

**P:** I have not heard as many comments about those providers...uh as not as many as I've heard about the city and county providers.

**Q:** Ok, thank you very much doctor for your time. Thank you.

**P:** Thank you.

**Center for Interdisciplinary Health Research and Evaluation (CIHRE)**

**DoT Project**

**Clinic administrator**

**Q:** Ok, thank you for you for your time. And I'd like to know how many transportation providers do you interact with at your clinic? We're talking about Medicare/Medicaid patients only.

**P:** Right. Ah...4.

**Q:** 4! Which are they?

**P:** It would be Sun Metro, VIVA, ah there is this taxi transportation that New Mexico patients use...I really don't remember the name of it.

**Q:** Would it be Sun City Cab?

**P:** Yes.

**Q:** Ok.

**P:** And uhmm. LULAC.

**Q:** LULAC? Project Amistad.

**P:** Yes.

**Q:** Ok. What about dominion of the ambulance service? Do they ever bring patients from Medicare/Medicaid?

**P:** Yes, we have 2.

**Q:** Oh ok, you have 2. Ok, very good. That'd be 5.

**P:** Yes.

**Q:** 5, ok very good. Now, in your experience what are the most important issues related to transportation to and from your dialysis facility, regarding the patients?

**P:** Ah, the biggest ones we have is the time they take to be driving around time...

**Q:** Ok.

**P:** ...the timeline as far as the...they have a pick-up time or a you know, it's not prompt.

**Q:** Ok.

**P:** They will give them a time but then it's a later time.

**Q:** The pick-up time where? At the patients home or at the clinic?

**P:** At the Clinic.

**Q:** After the dialysis?

**P:** Yes sir.

**Q:** Ok, now have any of these issues influenced the rate of patient attendance? Or have they influenced the compliance of the dialysis in other words are they, do they complete their dialysis session as it should or do some of them cut them off early so that they can get their ride back home?

**P:** No, it does affect because they have to...uh they are very worried about their pick up times.

**Q:** The patients?

**P:** Patients are very worried about pick up time so sometimes they will even give them a time before they complete the treatment so they know they will waiting a long time so they too...ask to uhmm shorten the treatment or if they are not satisfied with the service sometimes they will not even come to treatment.

**Q:** What service are you talking about?

**P:** Transportation service.

**Q:** So you mean that that because they are dissatisfied, the patient's dissatisfied with the transportation he or she is receiving they just do not attend the clinic...

**P:** Correct.

**Q:** ...they miss the whole treatment.

**P:** Correct.

**Q:** How many times a week does this happen? Is this a common occurrence?

**P:** It's not common but it does happen.

**Q:** And...on average, if possible, uhmm how many minutes in general have you seen that that the patients sometimes have to uh reduce their treatment...their dialysis session in order to be ready for, for the van to pick them up?

**P:** 15, 15 and 30 minutes.

**Q:** 15 and 30 minutes? Out of how many? Out of...what is the complete session?

**P:** 4 hours.

**Q:** 4 hours so, they will be getting only...for an example 3:30...3 hours and 30 minutes?

**P:** Correct.

**Q:** Ok. Is this a common occurrence?

**P:** Lately yes, it's become more...more frequent.

**Q:** Lately?

**P:** About 3 weeks, 4 weeks.

**Q:** 4 weeks, what's been happening?

**P:** Ah they ah they cut their treatment time because they are even told that they are going to be here earlier and like I said before, they're not ready...they will leave them until the end of the of the pick-up schedule that they have so they don't want to be waiting.

**Q:** What transportation was this? Do you know?

**P:** LULAC.

**Q:** LULAC.

**P:** LULAC.

**Q:** So, LULAC informed the patients directly, or did they inform them through the clinic? How do how do the clinics...how do...I'm sorry...How do the patients know about this these changes?

**P:** No, they do them directly. We don't intervene in their transportation schedule.

**Q:** Ok, the transportation company then in this case LULAC would notify the patient themselves?

**P:** Correct.

**Q:** Ok, of this. Ok do they do they give a specific reason why this change of schedule or this change of itinerary?

**P:** Ah, what they've said was because of all the delays that they're having or the rescheduling is because they are technically running out of buses.

**Q:** I see.

**P:** Because of the number of patients that are being admitted now to the dialysis due to the growth of dialysis patients. So at this time it's making it more difficult, the waiting time is longer or the rescheduling is ...has to be less flexible for the patients.

**Q:** So it means now that that there are ...now so many dialysis patients that...that the number of patients needing dialysis is growing. Am i correct?

**P:** Correct.

**Q:** And so the demand is bigger and they don't...they are not being able to satisfy it because of lack of vans or lack of buses?

**P:** Correct.

**Q:** I see ok. Uhhh, what is the typical procedure that your clinic follows when a patient is released from treatment? Let's say the patient...let's say does not want to have treatment or simply changes, wants to change...move to another city or another clinic. What is the procedure? Who initiates this? The patient or...how does this start?

**P:** The patient would be the one either requesting the transfer to another facilities and the with the social workers, and the social workers will coordinate the placement of this patient to whatever they're transferring to or the clinic that they choose to. If they decide to discontinue the dialysis as a whole, that's something that has been discussed with a physician.

**Q:** I see. I see. And if a patient, let's say six months later wishes to move back to El Paso, wishes to come back to this one, again the patient contacts whom?

**P:** Ah, the Central \*\*\* Registration.

**Q:** Ok.

**P:** And they will be the one coordinating the patient according to the facility availability.

**Q:** Ok, Ok. Very good. Now does this involve uh for example does the patient need any consent from the family or the physician to change the clinic or can her or she just do it themselves. I mean do they need a special consent form or permission to do something to do that?

**P:** One it's the patient's choice.

**Q:** Ok, Ok.

**P:** So, Uh they are the ones to re...ah decide which clinic they'd like to continue their clinic service. And so our job is to facilitate that process.

**Q:** I see. Uhhh, now going back to the transportation. Does the transportation provider also help with emergency services such as ambulances you said that...dominion sometimes does this service right? Do you know if the other companies also provide emergency services for the patients?

**P:** Not that I am aware of.

**Q:** Ok. What suggestions would you have in order to improve the transportation services for the dialysis patients?

**P:** Uh to say that we need to add more transportation vehicles.

**Q:** More vehicles?

**P:** Yes. And of course staffing\* with it. I think they should...they should coordinate the transportation based on zip codes.

**Q:** On zip codes?

**P:** Yes, uh instead of driving all over town and driving these patients all over town.

**Q:** So it'd be better by zones? So you say? Ok.

**P:** Yes. Absolutely.

**Q:** Ok well, thank very much.

**P:** You're welcome.

## **Center for Interdisciplinary Health Research and Evaluation (CIHRE)**

### **DoT Project**

#### **Social Worker**

**Q:** I'll be very brief, we are just trying to know how to improve the transportation services for dialysis patients and, how many transportation providers do you interact with at this clinic?

**S:** Minimum of 3.

**Q:** Minimum of 3. Ok, which ones would be the major ones?

**S:** It'll be Sun Metro Lift, LULAC through Project Amistad, I mean Project Amistad through LULAC, and then Ambulance Services. The one primarily used at least for patients in our facility is Dominion.

**Q:** Dominion ok. What about Bien Vivir? Do you have...?

**S:** I don't have anybody right now from Bien Vivir to the best of my recollection.

**Q:** What about Viva? Viva transportation?

**S:** No, we do not have anybody from Viva. My understanding primarily because nobody... unless the patient themselves contracts them, no payer is in place for them. And most of our patients are either low income, in other words, because I call them once they wanted like a 24 hour notice and they wanted... what else? I think it was like 60 or 80 bucks for the trip. And none of my patients can afford that.

**Q:** Obviously. So, it would be like 80 dollars both ways like 40 dollars...

**S:** I can't remember if it was, it was a... for our patients it would be an exorbitant amount and it was just one trip.

**Q:** One trip only, not even round trip?

**S:** Not... I can't remember if it was round trip but it was a one, one day thing where our patients come here 13, 12, 14 times out of a month.

**Q:** So that would be 3 times a week right.

**S:** Three times a week throughout the month.

**Q:** So, that would be easily like a thousand dollars a month.

**S:** At least.

**Q:** Which is a... yeah, ok.

**S:** Which for most of my patients here, that's more than what they are getting in their SSDI (Social Security Disability Insurance).

**Q:** Pensions, alright, ok. What are the most important issues that you know of related to transportation to and from the dialysis clinic regarding the patients?

**S:** Pick up time. Either pick-up time at their home or pick up time here.

**Q:** Both, both?

**S:** Yes.

**Q:** What is the main issue at the pick-up time in their homes for example? At their homes?

**S:** That they arrive late, for the most part.

**Q:** So the drivers are the ones that arrive late? Or are they late to... for example to be ready for to be picked up?

**S:** Well, got to remember that this is the patient telling us the information. Every now and then we'll have a person that says "yeah I wasn't ready I wasn't expecting them," mostly because they weren't expecting them quite at the time that they got there, for the most part. Every now and then it's like one, "oh yeah I just wasn't ready" and they left. But for the most part from what I recall our patients saying is "the bus did not get there," either did not get there, did not get there on time, as far as arrived late. So for example, the one patient that I was trying to talk to when you arrived is there are times when they don't pick him up from the nursing home. The nursing home claims that they are calling for him to be picked up and then they don't show up.

**Q:** So you mean that, that the patient is just not brought here because they never, the... whatever service transportation did just not pick him up?

**S:** Exactly.

**Q:** And they didn't... they let them know or they just left them waiting...

**S:** They just didn't, yeah exactly.

**Q:** Does this happen very often?

**S:** For some people more than others yes. For him, it happens quite frequently.

**Q:** What is... what would be the provider for this patient?

**S:** For that one it's LULAC.

**Q:** LULAC.

**S:** My two problems, my two biggest problems patients here, their providers are LULAC and both of them either wait. Well one is pretty good about getting here, I don't know if there is any issues about getting picked up, I have not been informed of that, but once he is here, after treatment that man has been not, it amazes me that he still comes. He waits for a minimum of about an hour and a half, minimum, average it's more like 2 to 3 hours, and there's been times when he is here when all of our fourth shift is already on, which is somewhere between 3:30 and 4. So he's waited about 4 hours.

**Q:** So, the waiting time, the waiting time is basically more for them to get picked up from here to be taken back home? Am I correct?

**S:** Yes.

**Q:** So they are just waiting here at the dialysis clinic for hours. Is there a way that a patient could somehow request to be changed to another transportation system? Or is there any..?

**S:** Yes, they can, they can go to a different system but neither of them is that much better.

**Q:** So we are talking about basically Sun Metro and LULAC or...?

**S:** Sun Metro, and LULAC. There are certain criteria, my understanding is, I am not too familiar with this part of it, but there are certain criteria to be met before they are transported by ambulance, and have their insurance pay. The reason this patients are coming via LULAC is because quite frankly there is a convenience for whoever is setting it up.

**Q:** For example?

**S:** For example, for LULAC as long as they call, within... Sometimes after the 15th and before the end of the month on any given month, medical transportation program, their following month is all set up. It's one call. For those that are using Sun Metro lift, must call on a treatment basis for the following weeks to pick up because they run in a week in advance. So for example,

today's patients have be calling Sun Metro lift so that they could have a ride next Monday.

**Q:** So basically every week they would have to be calling?

**S:** Every treatment day, not every week. So it's user friendly in some aspects, one service above the other, but it's not user friendly in some aspects as opposed to the other. Because I've had patients waiting on Sun Metro lift, usually those patients are a little more... capable so that if the bus doesn't come here, where close to bus stops, they'll get to the bus stop and then just use the regular routes home.

**Q:** Right, but they still have to pay?

**S:** If they are on the regular bus routes and they have a Sun Metro lift, no they don't.

**Q:** Ok, but if they would be on LULAC for example?

**S:** Exactly, and most that are on LULAC, are on LULAC because they can't really manage the regular bus routes.

**Q:** Right ok so..

**S:** Then is the convenience of only calling once a month.

**Q:** A month, I see, ok. Alright, now how have these issues influence the rate of patient attendance to your clinic for the regular... sessions, and to compliance for dialysis?

**S:** Well compliance in as much as it relates to attendance. For the most part, as I've stated before, I'm amazed that other patients still keeps coming, and hasn't missed, so in his, in his regard, he just sits and doesn't complain a whole lot but when does he's just, we know he is like really tired.

**Q:** Obviously.

**S:** For this one patient, yes, it has affected compliance in as much as he's actually told the nursing home at, by this year has been the worst. This year he has actually said "I am not going to dialysis. I want to stop, if this it's how is going to be." He just gets frustrated very easily.

**Q:** Understandably.

**S:** And I was just going to say that, and I don't blame him because who wants to sit after 4 hours of sitting in a treatment chair, where after the second hour its torture, until the fourth hour to be sitting out on a waiting room in a wheel chair, for another 2 or 3 hours.

**Q:** Now, since most of these patients I assume are diabetics, or at least a good, a good...

**S:** A good chunk of them yes.

**Q:** A good chunk of them. I mean for anybody regardless of what disease they have aside from kidney failure but what happens when they are hungry, is there anything that... Do you have any facilities?

**S:** We do not provide food, we do not provide drinks, we don't, I mean I don't know if you noticed our waiting room but we don't even have coffee, aside from water, they have nothing. So if they don't bring something with them, they are not going to have anything.

**Q:** Wow, so what do you, in your experience, for example, a patient who is really fed up with the system and just says I am not going to treatment, period. What would be the life expectancy for that person, I mean...?

**S:** That is a medical question more for nurses and the doctors, only based on what I've seen and not necessarily what I've seen, but what I've heard is from the nephrologists themselves is there is no easy way of knowing this stuff, it can be, some people have been a few treatments and then they pass away. There's been, the longest standing in the city of El Paso that I've

heard of has been a year.

**Q:** After terminating treatment?

**S:** After stopping treatment, which have nothing to do with this. They have their own other issues going on, but that one person, to my knowledge, lasted either 12 months or a little over 12 months and then passed away.

**Q:** Without dialysis? Now, in the case of this gentleman that I've just met outside... Can he, if not change the transportation system, can he ask to be transferred to another clinic? Even though, maybe I don't know...

**S:** And actually those are the things that I offer our patients when they're having these issues. For good or for bad, when they start their medical care at any given place and this kind of medical care where it's continuous they get "tied", no that's not the right word. They... well that's the best word that I am going to come up with in this process. They get "tied" and they get set up with the people that they are interacting with, and they have confidence because that's also a big part of this treatment is they have to have confidence at the people that are sticking the needles in them, are going to do it, and do it correctly.

**Q:** Yes of course.

**S:** And, so getting them to go somewhere else is not always the easiest thing to do, and in his case, I had already offered, because we used to be like maybe well, the blocks are a little bit long but we used to be in our old location about two blocks from where he was at. Now we're half way across town. There is another facility where he would not have to change doctors, he has difficulty with speech, so he has difficulty communicating, and so the less change the better, I had offered that to him, he didn't want to move, when he started talking about not coming I said "well that is better than no treatment," so he started coming back (laughs).

**Q:** But he did miss some treatments?

**S:** But he missed, just off the top of my head (a "guesstimate"), but this is a guess, he missed about two treatments.

**Q:** Consecutive treatments, two?

**S:** Consecutive.

**Q:** Ok.

**S:** And for some patients that could land him in the hospital.

**Q:** Of course, we are talking about 3 treatments per week right, 3 sessions?

**S:** Exactly. So he missed over a half.

**Q:** So he missed 2 out of 3? I see, for that week.

**S:** Yes, for that, yes. Or it may have gotten into the next week, I don't remember but I do know that he missed about 2 treatments after one of the incidences where he was like "I don't want to go. I don't want to go because I don't want to be stocked there." And right now he was basically saying the same thing. "I don't want to come here anymore."

**Q:** And with that Dominion ambulance, would they be able to take care of him? Or not, is there another?

**S:** Yes, however that's who is transporting him today (laughs). It wasn't even LULAC; it was the ambulance because I guess LULAC didn't show up. I am not really sure.

**Q:** So what happened?

**S:** I just called (Dominion) and they said they had no ambulance available and they will send

one as soon as they can.

**Q:** So he is still waiting?

**S:** So he is still waiting. And I am sure that our technician called as he was getting off treatment, and he gets off treatment in about two-ish (2 p.m.)? So when I saw him out there at 4 (p.m.), I knew he was start having a connection? so I started trying to problem solve what's going on, but from 4:15 I needed to do 20 minutes and then try calling them again because if not, It'll go off the wayside.

**Q:** I would be very concerned, excuse me, I mean just from a medical point of view that a diabetic person going without food, I mean anybody, I mean no matter what their condition is but I mean a diabetic going you know, without maybe 6/7 hours without food, and it's a risk that this person probably is just going to faint, you know not this person in particular, somebody in this condition, but I mean, what would happen then? I mean you know I think it a... I think it's a health issue, that should be, that cannot be ignored. I am sorry; I did not mean to interrupt.

**S:** No and you have a very valid point things that the Drs. have been expressing at some point over the last 9 years that I've been doing this work. The nursing homes, well sometimes send them with a meal or with a snack but what they have for take-out so to speak is not what they want to be eating. And that's actually a concern that one of the patients has verbalized, the one that's coming tomorrow as a matter of fact.

**Q:** Yes.

**S:** That has this big issue he's like "and when I get back then there's no food, because they have already closed down the kitchen. And so, what am I supposed to eat?" And I was like "you are telling me that they don't set food aside for you?" He's like "well yeah the do, but..." once again, but it's not a meal that he would have gotten had he been at the cafeteria at the time that food was served.

**Q:** A normal meal. That is a really, an important issue definitely. Now, does any other transportation provider aside from Dominion, do they also help with emergency services like ambulances for example?

**S:** I am mentioned they do, that I wouldn't be able to answer. I know that when we have had to call 911 usually the ambulance responding it's being, I guess the city one, I am not too sure.

**Q:** The city one, but that's just on an emergency basis?

**S:** Yeah, and mostly because that's usually that's on an emergency. I don't think I ever seen Dominion responding to one of our emergencies because usually it's the fire department with their people.

**Q:** I see. I am sure you are aware that LULAC has changed; they are going to change their schedule as of...?

**S:** I got the memo from one of my colleagues in...

**Q:** ...as of august the 1st of this year? How is that going to impact your services here at the clinic if LULAC changes their schedule?

**S:** I feel kind of bad, initially when I was told by my colleague, because I had not seen the memo, when they told me the hours I was thinking that 7 o'clock they meant 7 o'clock am which would have been a big issue, and so I started researching that on that day last week, because I just got it like I think on Friday. Today I haven't really looked at the schedule to see how is that going to impact. What patients are do we have on third shift, but we have a whole lot more patients, probably using that service on third shifts than what we do on first shift.

**Q:** I see.

**S:** So, truthfully I can't answer that question, but there will be an impact.

**Q:** There would be an impact, ok, I see. Ok, so a patient, like this gentleman, I just saw outside wishes to terminate treatment he doesn't need consent from the physician, he can just say he is not coming back anymore and he...?

**S:** Oh no, well actually no, treatment is voluntary, in other words they choose to be here, nobody is forcing them to have their dialysis. We do want the opportunity to talk to them, had it been a different circumstance the opportunity to say "ok, do you realize all these consequences of the decision that you are making?" In his case, I know he is upset right now, and I don't want to overset my bounds in speaking with a... that he is going to change his mind, but today he was finally open to saying "ok, I'll go to a different center if it could alleviate..." And I did make it clear "you may continue to have the same problems, but at least you'll be closer to your, to the nursing home, to your home," to for maybe they could send their divers in between they're picking somebody up or taking somebody somewhere he would be like right there.

**Q:** So you mean the city center or I am sorry the nursing home has its own drivers as well?

**S:** Yes.

**Q:** So, they could, theoretically at least, sometimes cover and pick him up if he called?

**S:** Yes.

**Q:** I see, ok. That would be...

**S:** Now getting them to come all the way over here has also been an issue because like I said, now we are not down the street so to speak, now we're half the city...

**Q:** Away?

**S:** Away.

**Q:** Ok, so now I guess that the change of clinic logistically will be less of a risk, not exactly assuredly he would be receiving timely transportation, but at least he'll be closer to his, to his nursing home.

**S:** Mhm (yes).

**Q:** I see, very good, ok. If the patient would, let's say change to another clinic and then later on wish to come back, can he do so?

**S:** Yes, patients can choose to go and come but once they leave if they want to come back then they get on a waiting list, if that facility has a waiting list. In our case, we have a waiting list that is over a year old.

**Q:** About how many people are in the waiting list right now?

**S:** (Sighs) I stopped trying to put people on it, because it was just was getting so long. There are about 20 people.

**Q:** Twenty people on a waiting list?

**S:** To come here.

**Q:** To come here specifically?

**S:** Yes.

**Q:** And to the one this gentleman wants to go to, do you know if by any chance if they do have availability?

**S:** I don't believe they do, but I would need to double check with him and then what makes it kind of complicated with nursing home patients, is they prefer a Monday through Friday kind of

schedule, so they prefer Monday, Wednesday, Friday, as opposed to have Tuesday, Thursday, Saturday, and whenever you are going in to another facility that's u... if they have anything available that's usually what they have, it's a Saturday schedule.

**Q:** Tuesday, Thursdays and Saturdays?

**S:** Yeah, Saturday schedule.

**Q:** I see, I see, very good. That's basically all. Thank you very much for your help.

**S:** Ok.

## **Center for Interdisciplinary Health Research and Evaluation (CIHRE)**

### **DoT Project**

#### **Transcription Transportation -Manager**

**Q:** Thank you for your participation. Who makes the referrals of Medicare or Medicaid patients for dialysis to your transportation services?

**M:** It can be anybody from the patients themselves.

**Q:** The patients themselves can call?

**M:** The patients, oh yes, the patients they do call, we give them the information and they are the ones that provide the referrals from the doctors.

**Q:** So the physician would be a... Would you need a referral from the physician?

**M:** We also... actually is not a referral from a physician, it's an application that he fills out. The client fills out an application and there's a, I believe it's a two page portion in there that the client take to their physician and the physician fills it out, and once we receive the whole application we enter them into the system.

**Q:** Ok, do you know what criteria are used by the medical provider, the clinic itself, or the nephrologist to recommend a particular clinic to a Medicare or Medicaid patient?

**M:** No, because we just provide the transportation to anybody that has a disability.

**Q:** Ok, but in the case, do you have more Medicaid or more Medicare patients? We are talking about dialysis specifically.

**M:** We have a lot of dialysis patients. I am not too sure if they are Medicare or Medicaid. We don't ask about...

**Q:** About what affiliation they have?

**M:** Right.

**Q:** Ok, good. Now who contacts you? Again, kind of redundant perhaps, to initiate the dialysis clinic transportation service? Now once you are going to actually go and get a patient?

**M:** The client, they set up their schedules.

**Q:** They set up their schedules?

**M:** Yes.

**Q:** They call somebody here?

**M:** They call the schedulers yes.

**Q:** The schedulers?

**M:** yes.

**Q:** Ok, would that be the same as the dispatchers or not?

**M:**No,that'sdifferent.

**Q:** That's different.

**M:** Dispatch actually looks at the screens and they are monitoring the drivers, to where they are at. And sometimes clients will call the dispatchers to find out where their ride is.

**Q:** Ok, but that's it, but the person who actually...

**M:** Schedules.

**Q:** Schedules, is...?

**M:** The scheduler.

**Q:** Ok, I would like to speak to one of those if possible. Because I haven't ran across a scheduler before.

**M:** Ok.

**Q:** Ok, thank you. Do you have any waiting list for dialysis patients that you cannot start transporting immediately? The people that...

**M:** No.

**Q:** No waiting list?

**M:** No waiting list.

**Q:** Ok, what it's the main problem that you've encountered during transportation of dialysis patients to and or from a dialysis clinic?

**M:** They may not be picked up on time because it is shared transportation, so sometimes when they are picking up another client, maybe that client, maybe they went to the restroom maybe they are having problems getting in the wheel chair. There are a number of reasons why that could happen... traffic.

**Q:** Ok, now that's for example from the patient's home to the clinic?

**M:** Right.

**Q:** In other words, sometimes some patients may not be ready to be picked up, is that correct?

**M:** Right, or if another patient needs to be picked up on the way, exactly they are not ready. That, I think that would be the biggest problem.

**Q:** Now, what about picking them up at the clinic to bring them back home?

**M:** That happens also, that does happen also, but not very often.

**Q:** Not very often? Ok, so again you said that there is no problem picking them up from the clinic to their homes?

**M:** Sometimes if they run a little late also for the same reasons, there it is their transportation, they may be picking up another client that is not ready, so that will delay them.

**Q:** Delay the drivers getting to the clinic?

**M:** Getting to the clinic.

**Q:** Now, how long would the wait for a patient, let's say who is running a little bit late. How long can they wait for them?

**M:** It depends how much they have on their manifest, I mean but a good time is that if they say 10 minutes, they'll wait up to 10 minutes, but I mean if they know the client, a lot of times they'll call dispatch, and dispatch will contact the client, and they'll give them a couple of extra minutes, you know. They are pretty good about waiting.

**Q:** They are pretty good about waiting ok. And you also take dialysis patients to follow up visits to the physicians' offices not just the clinics?

**M:** Anywhere, we provide transportation anywhere they want to go.

**Q:** So it's done on a regular basis?

**M:** Stores, Walt-Mart, anywhere.

**Q:** Yeah, I am interested basically in the follow ups for their physicians especially for dialysis patients, ok. Do you know how many patients change clinics annually, in other words that they would be changing their route? In other words, asking for...?

**M:** No.

**Q:** No, you have no, ok. Where do you have to wait the longest to pick up a patient, at the clinic or at their homes?

**M:** I would say, Jesus it's so hard when I think... I think the dispatcher will probably answer that better.

**Q:** The dispatcher ok.

**M:** \_\_\_\_\_ Mike, you are going to be seeing Mikael, so.

**Q:** Ok, what portion of the patients that you transport is wheel chair bound, approximately, what percentage? For dialysis specifically.

**M:** Oh god, you know what, I really can't say, I don't know what the percentage is I am sorry.

**Q:** Ok, who would, does anybody keep record of that?

**M:** Well we do have in the computer. In fact I was just looking at stuff like that yesterday. Let's see, it won't tell you which ones are going to dialysis, it will just give you the wrong/raw figure of which ones are wheel chair.

**Q:** Ok, but not necessarily for dialysis?

**M:** Right.

**Q:** Ok, what is the biggest complaint that you hear from the patients regarding the transportation service?

**M:** Arriving there late for their pick-up.

**Q:** Getting late for their pick-up, in other words picking them up at home or at the clinic?

**M:** At home, at home.

**Q:** At home, ok. Have you heard any complaint about the dialysis clinic itself?

**M:** No, I have not. I believe that would probably go to the dialysis clinic.

**Q:** Ok, now what suggestions would you have to improve the transportation system for the dialysis patients? What would need to be done to improve that... less waiting time and so forth?

**M:** If it wasn't chair transportation. That's only guaranteed \_\_\_\_\_ because other than that I mean things arise, you know, people are late, sometimes they have another pick-up to do. So that's my personal opinion, you know if somebody has dialysis I think a family member would be best to transport them. That way they would guarantee not losing any time. Because I feel so bad for the patients when they are late and then they have to cut 15 minutes of the dialysis. I mean that's their life. I mean that's what I think, I really haven't thought much into that.

**Q:** Yeah, but what happens to people who have no \_\_\_\_\_?

**M:** Right, right.

**Q:** They are basically...

**M:** They depend on \_\_\_\_\_.

**Q:** They depend on the service. Ok, thank you very much for your time. Thank you.

## **Center for Interdisciplinary Health Research and Evaluation (CIHRE)**

### **DoT Project**

#### **Dispatcher**

**Q:** Who makes the referrals off...first of all what type of patients do you give service to? Medicare or just Medicaid or both?

**P:** Both.

**Q:** Both Medicare and Medicaid. Ok and who makes the referrals of these patients for dialysis to your transportation services.

**P:** Social worker.

**Q:** From where?

**P:** From our organization.

**Q:** From your organization?

**P:** Yes.

**Q:** Ok, very good. Now, do you know if the patient is given a list of clinics to choose from?

**P:** I'm not aware.

**Q:** Ok and the person then who initiates...who contacts you to imitate the dialysis clinic transportation service would be the social worker within your organization?

**P:** Yes.

**Q:** Ok and what is the main problem that you are aware that most drivers encounter during the transportation of dialysis patients to and from a dialysis clinic?

**P:** To dialysis none. When they're being picked up from dialysis, just that their dialysis time might go over depending on the time they were you know, taken in?

**Q:** All right.

**P:** And if they've stopped the bleeding so it ...that just becomes a problem for transportation cause we're on a set schedule.

**Q:** And how many minutes can a driver usually wait for a patient to be ready?

**P:** They wait about 15 minutes and they go ahead and ask if the patient is almost ready for pick up or not and then from there on they go ahead and contact the dispatcher and depending on if they're going to be ready within the next 10-15 or maybe even more, the dispatcher will let the driver know go ahead and wait or you know what have dialysis go ahead and call us back when they are ready for pick up and then we go ahead...

**Q:** So basically that would be your job as a dispatcher or not?

**P:** The dispatcher yes.

**Q:** In other words the drivers would report to you that there is a patient that's taking longer and then you would check the schedule and tell them, yes you can and no you can't.

**P:** Correct.

**Q:** Let's imagine that the patient is a diabetic who needs to be stabilized; blood sugar stabilized, and is going to take him half an hour. What happens then to that patient?

**P:** The driver goes ahead and like I said, report it to the dispatcher; the dispatcher will either make the decision of having the driver wait or we ask for the driver to inform the staff at the dialysis that he's about to leave and provides them a card with a call back number for when he is ready for pick up they're to ask to call us so we can go ahead and send a driver.

**Q:** All right, very good. Thank you. Do you have a waiting list for dialysis patients that you cannot start transporting immediately? Are there any that for example you have not been able to give a service because they...there need to be...i don't know, you don't have the capacity yet?

**P:** No.

**Q:** No, ok. Do you also uh...do this transportation service take dialysis patients for follow up visits to the physicians' offices, not just to the clinics?

**P:** Yes

**Q:** Is this a common occurrence?

**P:** Well can you specify more...

**Q:** Yea for example if the physician at the clinic tells the patient i need to see you next week in my office. Will this company also send... take them to the office?

**P:** Yes.

**Q:** Or just the dialysis clinic? To the office for a visit?

**P:** Ok.

**Q:** Very good, ok. Do you know? Do you have any way of knowing if patients uh, in your service change clinics every year or if there's any changes?

**P:** They do change clinic; because from what the social worker tells us is that a certain location is already full with the shift that the patient would like. So as soon as that shift is available they go ahead and transfer the patient to that, that other clinic with that shift that the patient wanted.

**Q:** Ok so the person who actually has the record of that would be the social worker in your company?

**P:** Yes.

**Q:** Not at the dialysis clinic, in your company? Because social worker, let me put it this way. The way we understand it in this project, social worker is a person who works for the clinic not for the transportation services.

**P:** Well we have social workers on for our organization and I understand there are social workers for the clinic. But the ones that coordinate the transportation would be our social worker.

**Q:** Ok, in the transportation.

**P:** Yes and I believe it's from information that they're given from social workers at the clinic.

**Q:** at the clinic? All right very good yes, that sounded logical ok. Do you know the longest distance that your transportation service has to take a patient to a clinic? Approximately? Doesn't have to be...

**P:** I don't know the distance as far as miles. I know that there's a patient on Remcon.

**Q:** On the Westside?

**P:** On the Westside...no...Yea...on the Westside.

**Q:** Ok, do you know the shortest distance that the driver has to take a patient?

**P:** There's one here on gateway, so maybe travel time, 10-15 minutes.

**Q:** 10-15 minutes, ok. Where does the driver from your organization have to wait the longest to pick up a patient at the patients home, or at the clinic?

**P:** Most of the time it's the clinic.

**Q:** It's at the clinic? Most of the time?

**P:** It is the clinic just again if they have to stabilize the patient.

**Q:** So because the patient may not be ready yet to be picked up?

**P:** Right.

**Q:** Ok, may not be stabilized. Now what portion of the patients that you transport for dialysis is on wheelchairs, do you know?

**P:** Let's see...I would say about half.

**Q:** About half the patients.

**P:** Right.

**Q:** Ok, you are transporting, half to be on a wheelchair. Ok, 50%. Now what is the biggest complaint that you hear from patients regarding the transportation, to and from the clinic?

**P:** Biggest complaint? Would be, that we're not there on time when they get out.

**Q:** Of the clinic?

**P:** Right.

**Q:** Ok. Are there any issues with picking them up at their homes? Like they're not ready or that sometimes...

**P:** There has been minimal though.

**Q:** Minimal.

**P:** Right, because they know it's a set schedule. When to be ready and what time they're going to be picked up.

**Q:** Have there been cases in your company that the driver just doesn't go by and pick them up at all that day? Because maybe there was a schedule mix up or something. Has that happened? In other words...

**P:** Yea.

**Q:** No?

**P:** No, I'm trying to think. It's pretty much like I'm telling you. It is a set schedule so everyone knows when these people are supposed to get picked up.

**Q:** Very good. Now have you ever heard any complaints regarding the dialysis clinic that these patients go to?

**P:** NO, I haven't.

**Q:** Ok, what suggestions would you have, in your experience, to improve the transportation system for these dialysis patients? What could be done as a suggestion?

**P:** As far as transportation?

**Q:** Yes, how would you improve for example the...lessen the time, to give you just one example, lessen the time that they have to be waiting for transportation after they're finished.

**P:** Well the way we have it set up it really depends on the person that's scheduled prior to them, that's why I say it depends on what time dialysis lets the patient go so that's what affects the whole picking up process, if one person is late 10-15 minutes it's going to affect the next person cause he's going to get picked up 10-15 minutes later.

**Q:** Ok, thank you very much for your participation.

## **Center for Interdisciplinary Health Research and Evaluation (CIHRE)**

### **DoT Project**

#### **Driver**

**Q:** Who makes the referrals of the Medicare Medicaid patients for dialysis to your transportation services? Do you know?

**P:** Well, it would depend on their either insurance companies or uhmm any other type of uhmm of uhmm say like a, if it's gonna be area agency ANIGING\*. They would refer.

**Q:** Because we're talking about Medicare/Medicaid specifically.

**P:** Medicare and Medicaid ok.

**Q:** Ok. Right, uhmm who contacts you as a driver to initiate the clinic transportation service? To the service to the clinics?

**P:** Contacts the driver himself?

**Q:** Yea, you.

**P:** That would be our dispatcher.

**Q:** Your dispatcher, ok very good ok. Do you know if there's a waiting list for the dialysis patients that you cannot start transporting immediately?

**P:** A waiting list say to start uhmm the same day or...

**Q:** No simply just to transport them. That there are people who've actually called you and said I need transportation for next week and you say well you know we just cannot give you that service now.

**P:** As far as I know that hasn't happened.

**Q:** That has not happened, ok. Do you know what is the main problem if any that you encounter during the transportation of the dialysis patients either from their homes to the clinic or from their clinics back to their home?

**P:** The biggest problem?

**Q:** Yea.

**P:** Hmm probably... not that I would consider a problem...it's more of an observation, that you need to be taking a little extra care. When they're when they get out of their treatment, they tend to be dizzy.

**Q:** When they come out of their treatment. Yea, could you speak a little bit louder also.

**P:** Yea they tend to be dizzy and a little tired.

**Q:** Tired of course after their dialysis treatment.

**P:** After dialysis yea. Not all of them...most...just some of them.

**Q:** Ok, so that would be basically it. Has anyone ever gotten sick on your route? For example, that they were very sick that you had to go back to the clinic or something like that?

**P:** Getting sick, no. The only problem I had one time was I had a patient, client start bleeding from his arm.

**Q:** Right from the catheter.

**P:** Yea, exactly. But that was taken care of really quick.

**Q:** How was that?

**P:** Uh, the nurse from the clinic they just came out, they took her down, they're applied the pressure and then she came on and cleaned the bus with chemicals.

**Q:** Ok so that happened before you start...or did you have to go back to the clinic a few minutes.

**P:** Actually she was she was boarding the bus.

**Q:** She was boarding the bus. Oh ok good.

**P:** And she was being assisted by 2 people that who worked in the clinic.

**Q:** Oh ok, to get on the bus itself.

**P:** to get on the bus yes.

**Q:** Ok all right ok. Actually, how many...now that you mention a very important topic. How many patients that are on your route, dialysis patients need help getting on the bus? In other words how many are there...what proportion is on wheelchairs?

**P:** I would say, 30%.

**Q:** 30% only.

**P:** 30% of the people that we transport that require dialysis treatment, I'd say about 30%. Maybe we could say 1 out of 5 people.

**Q:** Needs a wheelchair. The rest can walk?

**P:** The rest can walk yes, slowly but you know just with assistance they can walk.

**Q:** Ok, all right. You also take patients, dialysis patients that means. That is you also aside from the clinics you also take them to a doctor's office appointment. Do you not?

**P:** Yes.

**Q:** Is this very often?

**P:** Yea, it happens quite often, it does quite often.

**Q:** OK, uhmm what is the longest distance that you have to transport a patient to a dialysis clinic? Medicare/Medicaid patient.

**P:** Ah, longest distance would be from Tornillo, Texas to her dialysis which is on Yarbrough and I-10. So I that's, it's a pretty long way out there.

**Q:** It's a long...but what is the average distance that you would cover in a day? Just normal...normally.

**P:** You mean the... my route?

**Q:** Yea your route...average distance a day. How many miles would that be more or less?

**P:** I would say...depends on the route we get, anywhere from ...depends what time of day we come in and our route so it would be anywhere from 60 to 170 miles.

**Q:** 60 to 170 miles. Now you mentioned the shifts, how many shifts are there really, to take dialysis patients to the clinic?

**P:** Ok we usually tend to run 2 shifts. It's AM which we come in at maybe 5 or 6am.

**Q:** 5 or 6AM.

**P:** And then we have second shift which we come in around 1-2pm.

**Q:** 1-2. Ok very good.

**P:** And in between we also have a driver who will assist you know who will help out anybody who gets behind or, you know.

**Q:** Ok so if understand correctly let's say a person from the dialysis clinic got there late or for whatever reason did not start his or her treatment and then of course will have to wait until another chair is available but will not be at the same at the pickup route at the time that he or she was expecting to be. Now, am I correct? Now would...another driver picks them up eh another time or what do you mean that there's another driver that would help out?

**P:** If for example say that there's an accident on I-10 or the freeway and he closer to the house then our dispatcher would send him.

**Q:** Ok.

**P:** because he would get there sooner.

**Q:** All right.

**P:** It very rarely will we arrive late.

**Q:** Ok very good. Where do you have to wait the longest to pick up a dialysis patient at his home or at the clinic?

**P:** I would say at the clinic.

**Q:** At the clinic, you wait more time?

**P:** Yea.

**Q:** Do you know...any reasons specifically why?

**P:** They check their blood pressure and they have to be at a certain range and if not they I don't know exactly what they do but they'll I think they give them sugar water or something like that.

**Q:** Ok.

**P:** Just to bring their blood pressure down to a safe level and also it depends on their bleeding from the catheter like you said.

**Q:** Ok, all right ok.

**P:** Some of them clog\* quicker than others.

**Q:** Right ok. Now what is the biggest complaint or any complaint that you've heard regarding the transportation services?

**P:** The biggest complaint, you know to be honest with you, in my experience its more compliments like they say, if it wasn't for you guys I don't know how I'd get to my treatments. And they're very grateful, very grateful for it.

**Q:** Ok, ok now have you heard any complaints about the dialysis clinics themselves from the patients?

**P:** Yes.

**Q:** Ok, what are they more or less?

**P:** Waiting times, they they'll their start time 9am, they won't sit them down till 1030-1100.

**Q:** So they have to wait an hour and a half?

**P:** Sometimes yea, and some of them that's been my experience.

**Q:** But what happens then let's say, they were supposed to be at 9, right? And they're about 3 hours right minimum? So you would be there at approximately between 12 and 1230, am I correct?

**P:** No If we...if their appointment is at 9 for the treatment we'll go for them an hour early and we'll either drop them off a half hour to 15 minutes before their treatment. But they have to actually wait there sitting down because there's either...they're cleaning the machines or the person before them got there late so you know...

**Q:** They have to finish.

**P:** Exactly.

**Q:** Ok, uhmm lastly what suggestions do you have to improve the transportation system for the dialysis patients? What, how could something be improved the transportation.

**P:** Well, asking the driver that's good. Let's see, to improve transportation to dialysis patients, uhmm. As far as our company, I've noticed we're very professional on providing their service and uhmm I know you're interviewing other companies as well.

**Q:** Right that's true.

**P:** I've heard from other from other dialysis patients that maybe if uhmm, a little more courteous maybe.

**Q:** The drivers being more courteous with the personnel?

**P:** A little more understanding you know, of the situation

**Q:** I see. Right.

**P:** That's basically...as far as...I'm very satisfied working with this company and I've noticed that our drivers, they're real courteous they're real professional about it. They are...they understand.

**Q:** More humane?

**P:** Exactly... if you sit there for 4 hours, I can imagine you know?

**Q:** How you would feel.

**P:** How you would feel, exactly.

**Q:** OF course sir, well thank you very much for your help sir.

**Center for Interdisciplinary Health Research and Evaluation (CIHRE)**

**DoT Project**

**Patient (English)**

**Q:** Ok, so thank you for taking the time and during this interview with us, first of all, when were you informed that you need a dialysis treatment?

**P:** About 3 months ago, yeah 3 months ago.

**Q:** Ok, who informed you?

**P:** My doctor.

**Q:** Your doctor? Ok, and did the doctor explained to you what was involved in dialysis treatment?

**P:** Yes he did.

**Q:** Ok, and who decided which dialysis clinic you should go to?

**P:** My doctor.

**Q:** Ok. Did the medical providers give you a choice of clinics to go to, to choose from?

**P:** You know, I told him that I wanted a clinic close to the...

**Q:** To your house?

**P:** To my house.

**Q:** Ok, and how far away from your house was your first dialysis clinic visit?

**P:** What do you mean, how far?

**Q:** How far was it from your house?

**P:** About 9 minutes, 10 minutes.

**Q:** Ok, and do you, and you still go to the same clinic?

**P:** Yes ma'am.

**Q:** Ok, so when did you start your dialysis treatment, that was 3 months ago right?

**P:** Three months ago.

**Q:** Ok, what are the main problems you encountered with the treatment at the beginning?

**P:** Just tired, weak, and that's all... cramps in my legs.

**Q:** Cramping in your legs, ok. And are you experiencing any problems now?

**P:** No ma'am.

**Q:** No? How did you get from your house to the dialysis clinic at the beginning of your treatment?

**P:** My son would have to get out of work and take me.

**Q:** Take you, ok.

**P:** Make arrangements like that with the family.

**Q:** Ok so are they still driving you now?

**P:** No.

**Q:** You are taking the lift? (SunMetro Lift)

**P:** Yes ma'am.

**Q:** Ok, how many times a week are you going to the dialysis clinic?

**P:** Three times.

**Q:** Ok, has it increased?

**P:** No, I was like that all the time.

**Q:** Ok, so tell me what happens in a typical day when you are transported to the dialysis clinic? Like describe what happens from the moment you are being picked up from your home until you come back.

**P:** Ok, I make my schedule for Tuesday, Thursdays and Saturdays and they tell me that they are going to, my pick-up time is from 8:10 to 8:40 and I sit out there, and I wait for them and I waited like yesterday I waited and they were late half an hour.

**Q:** Wow.

**P:** So I got a half an hour late to my dialysis.

**Q:** To your treatment.

**P:** Yeah but most of the time they are always on time or before my, but yesterday, yesterday was just, I guess a bad day.

**Q:** Ok, all right, and how many stops do you make before you get to the dialysis clinic?

**P:** Would it be like?

**Q:** Like say yesterday you went to your treatment, how many stops does the...?

**P:** It's about...

**Q:** Do they make before you get to the dialysis clinic?

**P:** I think there are about 3 lights, stop lights before we get there.

**Q:** Do they pick-up any other people before you?

**P:** No, no, no.

**Q:** Or did they just go straight?

**P:** No, sometimes they do it and sometimes they just go straight.

**Q:** Ok.

**P:** Yeah, most of the time they, I, they just go straight and take me.

**Q:** Ok, and when they have to make other stops how many stops do they make.

**P:** They make about 1 or 2.

**Q:** Ok.

**P:** That's not bad.

**Q:** (yes), and is the driver of the Van the same person every time both ways?

**P:** No ma'am they are different drivers.

**Q:** Different drivers?

**P:** Yes.

**Q:** And do you like it this way?

**P:** Yeah... well you get to know most of them, so you know their characters, and they are really nice people, I can't say anything bad about them.

**Q:** Ok, and is the Van often picking you up late?

**P:** No, just that...

**Q:** Just that time?

**P:** Yeah. Well it, the one I was having a little bit of trouble with was LULAC before, when my insurance was covering that I didn't have to pay, now that I get Sun Metro and pay they are more or less all the time, on time.

**Q:** Ok, and after you arrive, how long do you have to wait before you get your... before your dialysis started?

**P:** No, when I arrive at dialysis in the morning?

**Q:** Yeah, yeah.

**P:** Sometimes I arrive 30 minutes before or 20 minutes, you know it depends if he picks me up at 8:10, I'll be there early, if he picks me up at 8:40 then I'll be there just exactly on time.

**Q:** Ok and when do you get there do you wait, do you wait...

**P:** I don't wait that long.

**Q:** No?

**P:** No they...

**Q:** How long do you wait maybe?

**P:** I wait about 5/10 minutes and then they put me in there.

**Q:** Ok and how long do you have to wait until the Van picks you up from, after dialysis?

**P:** Oh, they give me a schedule, if I get out its 9:00, 10:00, 11:00, 12:30, they pick me up about 1:30 or 1:10 around there, and it depends because I get out at 12:30 or at 1:00. So it depends.

**Q:** It depends ok. How long have you had to wait till they pick you up when you finished your treatment? Have you ever have to wait like maybe 45 minutes or an hour?

**P:** I see, that was, that was with LULAC but Sun Metro no, unless "hablo luego luego" (Spanish – I call them immediately-) "I call them" and they tell me "ok you are scheduled for this" and they send somebody, but the one that is picking me up is Amistad, Amistad (Project Amistad) yeah.

**Q:** Ok, ok and have you every missed any appointments, any dialysis appointments or any doctors' appointments because of the lack of transportation?

**P:** No ma'am.

**Q:** No?

**P:** No.

**Q:** Ok, and what do you think has to be changed regarding transportation in order to improve your experience?

**P:** I think they should give the drivers a better schedule or something because if they go to pick-up somebody else ok, let's say if I have to be there at 9:00 and then this other patient has to be at their doctors' at 10:00 you know they have to give them a schedule so that they can pick us up at more or less earlier or something so they won't be late 'cause it's a kind of bad. You know if you are late to your doctors' appointment or to your dialysis 'cause if you are late to dialysis you lose your chair, you got to wait a couple of more hours. And I mean, the drivers are good and everything but I mean I don't like being with them just taking one patient. I mean they are spending more gas and just they come and get me and take me and then they go and pick another person and take him, so you know I think with a better schedule we are done and all that would comply with everybody.

**Q:** Getting coordinated?

**P:** Yeah, yeah.

**Q:** Ok, the drivers are very friendly? Are they?

**P:** They are very friendly, very nice people. They are very helpful.

**Q:** And how about when you call and make your schedule, are the dispatchers friendly with you? Do they...?

**P:** Yes they are, but sometimes they are really busy and you got to stay in the line for about 10/15 minutes, that's about it, but I mean I don't know how many people they have working for them or what, and but that's the problem, but most of the time they pick up right away.

**Q:** Ok.

**P:** And most, sometimes they make you wait until they can contact the drivers see where he is. Like yesterday when I called "where's my driver? You know I am going to be late" and it was this and that, and I said "ok" so, that was it.

**Q:** So if you arrive late at your treatment, do they take time off? No le quitan tiempo? (Spanish – they don't take time off?-)

**P:** No, no, if I get there late. Let's say like, well yesterday I was I was half an hour late, so that patient that was in there in my chair had just gotten out. So that was more or less I was just getting there, but if I am an hour late or something I have to wait until there's an open chair. I may have to wait an hour, 2 hours, or half an hour before I go in, you know, that's what it is.

**Q:** Ok, and let's first say that they come and pick you up at a certain time and you are not done with the treatment. Do they wait for you?

**P:** I don't... If it's 5 minutes they'll wait for you. If it's longer I don't think so, they'll come back.

**Q:** They'll come back?

**P:** Yeah.

**Q:** Ok, and how long...?

**P:** It never happened to me before.

**Q:** No?

**P:** No.

**Q:** Ok, all right.

**P:** So I wouldn't exactly know how to...

**Q:** Ok.

**P:** So, no se (Spanish -I don't know-).

**Q:** Ok, all right, well thank you very much for taking the time and...

**P:** There's no problem mi hija (Spanish -my daughter-). I am here to help you and anybody else.

**Q:** All right.

**P:** But I am very happy with the, with the services, except for yesterday, you know but I am happy.

**Q:** Ok, thank you.

**P:** Thank you mi hija.

**Center for Interdisciplinary Health Research and Evaluation (CIHRE)**  
**DoT Project**  
**Patient (Spanish)**

**Q:** Ok, Muchas gracias por tomarse del tiempo para este hacer esta...

**P:** Entrevista...

**Q:** Entrevista.

**P:** Correcto.

**Q:** Primero, quiero uh. ¿Cuando le informaron a usted que necesitaba empezar su tratamiento con diálisis?

**P:** Hace 4 anos ya. ¿En junio...lo tengo muy presente...en junio de hace 4 anos que seria? el 2007? 2008.

**Q:** ¿Ok, quien le informo?

**P:** Ah, el doctor González.

**Q:** El Doctor. Ok y el doctor le explico los factores involucrados en el tratamiento con diálisis?

**P:** Si...me dio una, me dijo que tenía que tomar ese tratamiento porque ya no estaban trabajando muy bien mis riñones.

**Q:** Ok, muy bien. ¿Y también le informaron que usted podría elegir la clínica para su tratamiento de diálisis?

**P:** No, en eso no me dijeron.

**Q:** ¿Ok, este entonces quien decidió a cual clínica debería de ir usted para su tratamiento?

**P:** El doctor.

**Q:** ¿El doctor?

**P:** El doctor.

**Q:** Ok. ¿Y le dieron también este como médicos este los proveedores de salud una lista de clínicas para que usted escogiera entonces?

**P:** Eh, pues...

**Q:** ¿O directamente lo mando?

**P:** No me mandaron directamente con doctor con Da Vita ahí este inmediatamente me pidieron las recetas, que llevara las recetas y ahí ellos me mandan la medicina.

**Q:** Ok. Y que tan lejos fue, de su casa, la primera visita a la clínica de diálisis.

**P:** Pues es la misma de ahorita es, pos digamos unas dos millas mas o menos de aquí a ahí.

**Q:** ¿Ok, y sigue yendo a la misma clínica?

**P:** A la misma clínica todavía.

**Q:** ¿No a no ha cambiado de clínica anteriormente?

**P:** Nada nada nada.

**Q:** Ok

**P:** Desde siempre e estado en la misma clínica.

**Q:** Ok. ¿Y, cuales fueron los principales problemas con...con los que usted se encontró al comenzar su tratamiento?

**P:** Pues la el tiempo a veces este se me hacía muy largo ahí y todo eso de ir para la mañana tempranito, todo eso sí.

**Q:** Ok. ¿Y existen problemas actualmente?

**P:** Pues nomas un poquito con la transportación por de...me cambiaron del camioncito a un taxi y la señora esta estaba viniendo muy tarde. Tuve que estar pidiendo que me cortaran porque como si llegaba tarde te tenía que salir tarde y ya para ese tiempo ya mi transporte ya se había ido y ya me dejaron varias veces ahí pero me fueron a levantar después pero este, si esa era una...una situación medio molesta ahí de que de que llegaba muy tarde la muchacha esta la señora y luego llego y tenía que pedir que me cortara porque si no... Por decirlo mi entrada debería ser 15 pa la 5. ¿Verdad? Entonces salir a las 915 mas o menos porque es media hora pa que lo desconecten a uno y que sale uno ya entonces este salía muy bien a muy a muy buen tiempo para esperar mi bus que llegaba de 9 y media a 10. Y este y no últimamente estuvo como llego...salía tarde y me tenían que cortar nada más un cierto tiempo de hasta las nueve. Le decía no pos córtame los de la media hora o los 45 minutos que llegue tarde y para salir a las nueve pero de todos modos salía como a las nueve y media. A las nueve y venia apenas saliendo a veces ya estaba el señor ahí de la de del transporte que me trae para la casa. Eso era fue...es la única situación molesta mas o menos que hemos tenido últimamente.

**Q:** Ok

**P:** No más que lo bueno que ya este para el para el miércoles...

**Q:** Si.

**P:** Este miércoles ya se eh llego bien temprano. El taxi llego muy bien. Ya salimos bien todo. Entonces este pos ya esperando que se corrigiera ya yo creo la esta señora ya quería se dio cuenta que tamos haciendo mal.

**Q:** Si.

**P:** Porque yo le dije al él el...técnico que me, que me hace la diálisis me dijo no pos sabes que si no está bien dice...pierdes media hora pero dice pero estas perdiendo media hora día por día y luego y por mes vas a perder como 4 o 5 horas es como un tratamiento.

**Q:** Si.

**P:** Dije, ah no si no había caído en eso le dije...no pos yo pensaba que nomas media hora que pasa que no te agarraba uno no la aceptaba uno tanto pero si viendo viéndolo a larga si...

**Q:** Si.

**P:**...si es dificultoso eso. Y si ojala y ya con eso ojala que la señora esta ya llegue más temprano. Por mi me entiende...por eso es toda la...es lo único por decirlo.

**Q:** Si.

**P:** Lo único que podría digamos de quejas. Ahí ya ahí en la en la clínica pos no hay mayor problema.

**Q:** Ok. ¿Y como iba de su casa a la clínica de diálisis al principio de su tratamiento?

**P:** O me de me mi muchachita mi hija me llevaba todos los días. Todos los días que me tocaba pues. Los lunes miércoles y viernes así. Y ella me estuvo llevando como por un ano oiga. Hasta que arreglo...me arreglo la esta Ivonne la trabajadora social de ahí.

**Q:** Si.

**P:** Me arreglo con Sun Metro que porque no de, originalmente no me quieran llevar. Yo ya había hablado y había pedido el transporte, había pedido el servicio y me dijeron que no podían que porque era muy temprano. Que en la tarde si me podía...eh o como se a...de traerme si me podía traer. Pero de llevarme era muy temprano.

**Q:** Si.

**P:** Entonces no se como arreglaron, de repente ya me dijo Ivonne. No si ya van a ir por usted y todo y ya me dio hasta el número, mi número de cliente, y todo eso y se...me arreglo ella. Me arreglo muy bien ella. Y ya tengo como tres anos, ya voy pa tres anos. Si tengo cuatro. Como

por ano y pasadito me estuvo llevando mi hija todos los días. Mi hija o mi nuero. Mi yerno mas bien.

**Q:** Si.

**P:** Me...él llegaba por mi en la mañana y me llevaban, y me recogían.

**Q:** Ok, y actualmente cuantas veces por semana visita la clínica de diálisis.

**P:** Tres.

**Q:** ¿Tres días? ¿Y a aumentado el numero de días a comparado con el ano pasado?

**P:** No, siempre ha sido el lunes, miércoles, y viernes. Esos han sido mis días siempre.

**Q:** Ok.

**P:** Desde que empezó.

**Q:** Ok, y ahora si me podría describir un día típico cuando usted es transportado a la clínica de diálisis, si me podría describir que ocurre cuando lo recogen y cuando...

**P:** Llego...

**Q:** ...aquí en su casa y cuando llega a su casa.

**P:** Bueno en las mañanas yo me levanto a las 3 y media...me preparo y como le digo a veces llega, como como a este miércoles si llego a las 425. O sea supuestamente mi horario que me dan ellos es que vienen de las 350 y 420. O sea que es media hora. Así también me la dan en la traída de 9 y media a 10. Entonces este, yo estoy listo poquito antes de las 4:20 por decirlo es que es la hora en el tiempo máximo que me dan para que me levanten. Ya a las 420 yo ya estoy esperando la señora aquí afuera pero muchas veces no llega hasta las 5, 5 y cacho y luego todavía aquí a que lleguemos. Llegamos 520 y ya como te le digo ya de en ese momento y a le tengo que, cuando me meten pa dentro decirle sabes que pos córtale del dile que me pusiste de las cinco pa salir a las nueve. A las nueve me empiezan a quitar y a las 915, 920 ya voy saliendo que ya más o menos esta mi transporte ahí. Entonces esa es la única, embarazoso pues que es. Que tengo que decirle que me corten, y tengo que firmar un papel. Ahí, que me dicen sabes que bueno pos tu pediste que que...que te cortáramos el tratamiento, tu firmale ahí. Y si, firmo un papel que me dicen que, que es autorizando yo que me hagan la diálisis mas corta.

**Q:** Si, ok. Y cuanto tiempo tiene que esperar usted ah para que lo recojan ya que usted termina su tratamiento y todo.

**P:** Ah, pues lo regular es...pos...es que yo siempre me, como, antes...precisamente por eso de batallar con el transporte

**Q:** Si.

**P:** Y cuando salía. ¿Me entiende, y luego ya sale uno con un hambre de la fregada, me entiende?

**Q:** Si.

**P:** En la mañana, pos ya tiene toda la mañana yo no mas tomo café en la mañana y ya es todo.

**Q:** Si.

**P:** Entonces, casi por lo regular salgo con mucha hambre. Entonces, como nos quitaron un microondas que nos tenían ahí, y llevaba ahí un burrito y calentaba ahí uno muy suave. Y no ya lo quitaron entonces, ya se me ocurrió decirle a mi vieja que me hiciera un sándwich frio, de salchichón y todo eso.

**Q:** Si.

**P:** Que ese se puede comer frio muy bien. Y este y, y me llevo un sándwich todos los días en la mañana. Si mira hasta por cierto ahí...siempre tiene que haber pan.

**Q:** Si.

**P:** Por que es pa mi sándwich, es ah ya mi vieja ya me lo tiene ahí este...preparado. Y en y en la mañana nomas este...o en la noche me lo hace tostado el pan y me lo hace, y me lo deja ahí listo pa en la mañana. Yo en la mañana nomas agarro mi juguito mi de esto y ya preparo mi café y todo. Y ya me estoy listo para que venga el señor...la señora por mí. Y este, y esa es la grande rasgos todo lo que, de lo que pasa en las mañanas. Preparo todo mi, mis cosas me tengo listo mi chamarra mi mis mi cobija que me llevo. Y ya nomas me estoy listo esperando que lleguen por mí.

**Q:** ¿Ok, cuantas paradas hace su transporte antes de llegar a la clínica de diálisis?

**P:** Ah a veces dos. A veces dos. Como esta vez que...este miércoles fue la primera vez que llegue perfectamente. Porque llego como a las 4:25, fue la última vez que mire el reloj. Apenas iba prender la televisión porque ya no me... ¿no me quiero estar desesperando ahí porque se me a figura que ahí viene me entiende? Y es lo que le estaba comentando ahí a uno de los de la diálisis. Que ese...que llegue con la presión muy alta.

**Q:** Ok.

**P:** Me dijo. ¿Pos porque traes la presión muy alta? Y no me la podían bajar y que todo. Y luego ya pensando...no pues el mendigo coraje que estaba haciendo que no llegaban por mí ya de y...y ya tiene tiempo que está llegando constantemente por mí tarde. Y ya \*hasta vi\*, y esta señora no entiende le dijo que llegamos bien tarde y le da uno una indicación. Sabe que pos ya vengo bien tarde, ya venimos bien tarde, y no pos llega de todos modos bien tarde. Entonces ya en el miércoles llego temprano. Y ahora no traía un señor porque siempre vamos tres.

**Q:** Si.

**P:** Y llega un señor que va a una clínica ahí por la Brown y otro señor que la lo lleva después que a mi. Yo nunca cepo donde lo lleva por qué dice que va a como pa la Mesa palla pa arriba. Y este, y así estuvo por esto todo estos estos días estos, este mes pasado, todo este mes. De que así, de la misma rutina.

**Q:** Si.

**P:** Llegaba el señor este un peloncito, y este señor, y luego llega y lo deja al señor este a la Brown. Y luego ya me lleva a mi a la a la Mesa. Y luego ya se va con el señor este. Así a sido...había sido toda la rutina pasada. Y este miércoles cambio, llego con otra señora con el señor ese peloncillo y yo. Y ella la llevo a dejar aquí por la...por la Newman, o algo así. Hay otra clínica por aquí del de de...pegado al freeway...

**Q:** Ok.

**P:** De la, de la Cotton. Poquito más para allá.

**Q:** Si.

**P:** Y llego y la dejo a ella. Y luego sube y deja al señor este de la Brown, allá riba casi por la Schuster. Y luego ya de ahí se va para la...para mi clínica...para la...y llegamos muy bien. Llegamos a las que? a las 4:40...4:40 o sea que llegue todavía 5 minutos antes de que, de que es mi hora supuestamente que debo entrar yo, a las 4:45. Y luego entere muy bien. Entre muy bien, a la...diez minutos pa las pa las 5:00 ya estaba conectado ya me habían conectado. Como, no como a las, si como a los diez minutos para las cinco, ya me estaban preparando. Y casi...Si! Me conectaron como hasta las cinco. O sea que ya a las cinco ya empiezo mi tratamiento normal como debe de ser.

**Q:** Si.

**P:** Que es cuando ente...que entro a las 4:45 lo que se tarda en que lo pesen a uno a los todo eso todo el trámite del empezó...Y luego ya que le empiecen a uno. Si se hacen como las 5:00. Entonces es a la hora exactamente que debo yo empezar mi tratamiento.

**Q:** Muy bien. Y varía el número de paradas en cada ocasión o es el mismo.

**P:** Si varia. Como le digo, a veces de como de antes me tocaba...cuando venía el camioncito por mí, todavía teníamos que ir a levantar a...

**Q:** Si.

**P:** Casi siempre a dos personas mas. Llegaban por mí y ya traían como una persona...y luego me levantaban a mí y luego íbamos a levantar a otro señor y luego otra...casi era la misma ruta. Y este. Y si pero este le el bus siempre llegaba muy tempranito. El bus de Sun Metro ese siempre...hasta la mañana tenia que andar casi corriendo para prepararme el café y todo por que ya a veces ya cuando menos esperaba ya estaba allá fuera. ¿Entiende? Entonces con el bus nunca hubo problemas. Muy...es más no...Nomás una vez. Que si me dejaron, pero eso es muy común según taba oyendo. Porque yo nunca había sabido, porque como a mi nunca me habían dejado...esa ves que me dejaron...pos ya empezó a oír que a varia gente también a cada rato la dejaban. Que, "no ahora no fueron por mi, no fueron por mi, a canijo pos que paso?". No, no llego nunca llego el camioncito. Y ya después me empecé a dar cuenta que si fallaban a veces estos del Sun metro.

**Q:** Si.

**P:** A veces dejaban a las personas como a mí, que me dejaron una vez que...a carbón...pos no pasó. Y no mi muchachita me fue y me llevo. Yo ya ni quería ir porque ya ve como se le pasa uno y luego la vi...y ya en la mañana, no ya no voy, ya no. Y no, llegaba mí... mi hija y no vámonos ándele papi, ya te arregles que te van a hacer el tratamiento ahorita a las 9:00. Ándale ya te están esperando a las 9:00. Y esas veces, gracias a mi...mi hija fue que pude ir...pero me habían dejado.

**Q:** Si.

**P:** Totalmente.

**Q:** Y cuando maneja...Maneja siempre el mismo chofer del camión?

**P:** No, son diferentes. Es lo que lo...precisamente ayer venia comentando en eso porque me venia diciendo el señor este. Venia un señor \*trinando\* a un chofer. Y veníamos este comentando eso que...que le digo pos nomás que no hagan la misma política pos porque van a empezar con puros choferes nuevos. Todos los demás se van a mover. Los choferes viejos...

**Q:** Si.

**P:** Y le digo no mas pos ojala que no le vayan a hacer así nomás como le están haciendo con ustedes. Porque ah por decirle bien un chofer fue por mi una vez. Y ese chofer ya no vuelve venir por mí como por dos meses. O a veces hasta tres meses...o mas. ¿Me entiende? Y es lo que digo, siempre viene uno diferente. Siempre viene uno diferente. Le dijo pos debían de, si van a meter gente una...que siempre agarren la misma ruta. Pa que no...Porque si los mandan a...por decirlo a levantarme a mi ahí alguien mas y algo así ya conoce las direcciones. Y luego al otro día le dan otra ruta otras direcciones otra gente, pos siempre van a estar confundidos. ¿Me entiende?

**Q:** Si.

**P:** Entonces hasta que ya no se aprendan totalmente una ruta ya como los choferes viejos estos que ya son con un colmillo retorcido. Y saben como hacerle me entiende? Entonces este, es lo que estaba viendo dije. Ojala que no se les vaya ocurrir hacer lo que hacen ahorita. Dijo si se va a mejorar eso pos...un solo chofer que venga constantemente por una misma ruta. En las mañanas, "toma tu ruta ya sabes como hacerle".

**Q:** Si.

**P:** Para llevar a ello a los pacientes a tiempo. ¿Me entiende? Porque al momento que cambian, por decirlo, un día le toco a usted una ruta y luego otro día le dan otra. Y en la torre de aquí a

que...como le hacemos ahora para planear haber voy hoy por aquí luego tengo que volver por acá. Porque es lo que dice. Esa se quejan constantemente los choferes de que no están bien dirigidos. Algo pasa ahí no sé que...que este pasando pero eso comentan. De que este, siempre...les dan las rutas todas...muy muy mal echas por decirlo me dice mas...mira pos me dan a levantar a las 4:45 en el en el East Side, y luego me dan a las 4:50 acá en el West. ¿Le digo, como le voy a hacer? ¿Y hasta me acuerdo que le dije, no pos ni con helicóptero la hacías verdad? Dice no pos no. ¿Pos como? Si le dan...eh dijo es que no las hacen bien. O no se quien las prepara o no conoce la ciudad. ¿Me entiende? Porque como le van a dar a usted una un...a levantar una persona aquí en el East Side...en el allá que por la Hawkins que la Lee Trevino por allá. Y luego a las 4:50 tiene que levantar a alguien en la Doniphan...Dice como? pos como? Por eso...ósea esa es la razón, la justificación que dan, de que llegan tarde mucha gente se queja porque dicen, es que no esta en mi. Le digo, yo tengo que levantar este vato allá a las 4:45 y a las 4:50 acá en la Doniphan. ¿Como voy a llegar de aquí acá? Le digo, y el que hace la ruta... ¿lo le los schedule que no sabe? Pues me imagino que no. Porque como le va a decir usted, levanta a esta señora aquí en la en en...por decir en la Hawkins.

**Q:** Si.

**P:** Y luego levantas a este a las 4:50 en la Doniphan...es totalmente casi imposible hacerlo.

**Q:** Si.

**P:** ¿Me entiende? No se puede hacer, no se puede hacer. Y el vato que trae la ruta dice pos yo le ago. Lo mejor que puedo.

**Q:** Si.

**P:** Digo, trae...llego por ella y hay vengo a madre por esta, y hay va para llevarlo y constantemente están atrasados.

**Q:** Si.

**P:** ¿Me entiende? Y eso es lo que lo que dijo eso es el comentario que hacen ellos. Dicen pos no puedo. Porque yo ha a veces también llegan bien tarde por mí y luego fíjese...a a veces llegaba. Cuando llegaba bien temprano por mí ya sabía que íbamos a ir por una persona que íbamos hasta por allá. Más allá de Ascarate. No se si conozca aquí.

**Q:** A ha. Si.

**P:** De Ascarate allá pa Lakeside. Todavía como unas cuatro cuadras más para allá. Y luego pa dentro de acá de la de las de las callesitas por ahí.

**Q:** Si.

**P:** Fúguese, llegaba por mí aquí a las 3:50, a veces llegaba. No le digo que a veces por eso me impuse con ellos a andar corriendo en la mañana. Me levantaba y a lavarme y a...a empezar y todo. Y luego del café a veces...dos tres veces me tuve que ir sin café. Porque apenas estaba poniendo el café en el microondas. Cuando ya estaba el camioncito ahí. Pues ya ay voy ya. Ya iba sin café, ya porque no...Pues no ya alcanzaba. Y ya no quería esperar...y este. Y esa fue una...pos digamos esas nomas son...nomas anécdotas por decirlos. Porque pos todas salía bien afortunadamente. Pero de eso de ir hasta por allá hasta la punta de la fregada. Figúrese llegar por mí, venían ya por un señor allá arriba. Que era a veces venia...ahí una señora también. Que me tocaba muy seguido con ellos. Y llegaba aquí como a las 3:50...antes de las 4:00, y ya a las 4:00 ya íbamos a traer al señor a aquel que íbamos hasta por allá. Y luego todavía venia a levantar a alguien más acá por la Paisano.

**Q:** Si.

**P:** Por la Paisano acá por el lado acá de la Stanton por acá de este lado. Y luego ya veníamos y luego todo a veces los llevaba primero a sus clínicas a ellos. Y luego ya me...cuando llegaba yo, ya eran las 5:10, 5:15.

**Q:** Si.

**P:** ¿Me entiende? Y de desde las 3:50 que andaba yo allá en el camioncito Ese era uno de los problemas también.

**Q:** Si.

**P:** Pero no como le digo, no era por ellos. Si no porque el... ese es el schedule que les dieron.

**Q:** Si.

**P:** Y pos, tenían que hacerlo. Y si eso si me molestaba a veces también poquito. Porque no pos como. Lo levantan a uno a las 3:50 a antes de las 4:00 y llego a mi clínica a las 5:10. Pues como que no esta bien.

**Q:** Si. ¿Y cuantas veces por mes llega tarde el camión?

**P:** En ese tiempo no. El camioncito casi muchas...muy rara ves como le digo la...nomas la ves que me dejaron y una ves que también vinieron bien tarde. Que por cierto ya me había llevado mi hija.

**Q:** Si.

**P:** Y llegaron por mi. Me dijo mi hija cuando llego ya de allá para acá, que fue y me dejo. Dijo ya había llegado el bus ahí. ¿Y le dijo pos si pero ya pa que? Pues ya estaba allá de todos modos hasta en la clínica.

**Q:** Y cuanto tiempo tiene que esperar usted antes ah...de empezar su tratamiento con diálisis.

**P:** Nah, pos diez o quince minutos.

**Q:** ¿Quince minutos?

**P:** Eso si no es...pos nomas como a veces. Que les tiene problemas ahí...que las machinas que quien sabe que...le echan la culpa al agua...

**Q:** Si.

**P:** Que el agua que esta quien sabe que y que tiene que venir alguien y también esas veces nos a cortado el tratamiento. Porque, de aquí que viene el señor y que este. Y que todo el agua. Y si ya entramos tarde.

**Q:** Ok. ¿Y cuanto tiempo tiene que esperar al camión para llevarlo de regreso a su casa después de terminar su tratamiento?

**P:** También ese es muy raro que llegue tarde.

**Q:** Ok.

**P:** Y ya eso es casi siempre por lo regular llega entre el rango de las 9:30 y las 10:00.

**Q:** Si.

**P:** A veces se pasa 5 minutillos, 10 minutos, 9, a las 10:10 llega por mí. O más o menos. O sea nomas es muy raro que se tarde más de 15 o 20. Y a cuando se tarda mas de 15, 20 minutos, hablo y no pos que hay va ya que tuvo problemas en el en el Freeway. Ya ve que no falta.

**Q:** Si, si.

**P:** En el trafico. Y si que hay va ya en 10 minutos esta ahí. Ok bueno pos ya, pero ya almorcé como le digo ya no tengo que estar...por...eso él fue el pre... el problema principal de eso de que por eso acostumbre llevar mi lonche. Porque, salía...por decir a las 9:30.

**Q:** Si.

**P:** Y luego si no llegaba el camioncito por mi hasta las 10:00, 10:30. Póngale 10:15, 10:20 que a veces llegaba tarde. Y luego todavía venia a levantar alguien mas...o a veces iba a levantar alguien mas entonces ya venia llegando aquí casi a las 11 y pasadas 11:30.

**Q:** Ay no.

**P:** Y ya con una hambre de la fregada...

**Q:** Si.

**P:** ... ¿me entiende? Ya, entonces ya si ahora ya en realidad ya no le tomo a mal eso de que lleguen tarde por mi. ¿Me entiende? Yo ya no mas este...en la en la...cuando salgo inmediatamente me preparo mi lonchesito todo me lo como.

**Q:** Si.

**P:** Y ya, me estoy esperando a que lleguen por mi. Pero ya almorzadito. Y ya si llega tardecito o que todavía va a levantar a alguien mas o algo. ¿Pos ya vengo yo bien, hasta bien contento en el bus porque ya vengo almorzado me entiende?

**Q:** Si. Ok. ¿Y Alguna ves ha perdido un tratamiento de diálisis a causa de la falta de transporte?

**P:** No como le digo lo hubiera perdido. Pero me llevo mi muchacha que afortunadamente tenia ese momento en la troquita que usan.

**Q:** Si.

**P:** No se la llevo mi yerno al trabajo y me pudo venir a llevar. O sea que no hubo problema ahí.

**Q:** Ok. ¿Y también alguna ves a perdido una consulta con su medico, a falta de transporte?

**P:** ¿De transporte? No afortunadamente no, gracias a dios no.

**Q:** Ok. Muy bien. ¿Y en su opinión que cambios son necesarios en el sistema de transporte para las clínicas de diálisis para mejorar el servicio? ¿Mejorar su experiencia como paciente?

**P:** Pues eso, nomas que llegara mas temprano. Si tiene que hacer por decirlo, como le digo. Si llegara por mi, ya se fuera derecho conmigo...a si como a veces me tocaba. Pues no hay problema por que si llega tardecito por mi ya no se entretiene y se va derecho ya no...Ya nomas a agarrar el Freeway y para arriba y al la clínica y llegaba muy bien. ¿Me entiende? Y eso es lo que lo que pienso yo que... si llega poquito mas temprano aun que tenga que ser otra paradas, de todos modos me lleva a mi a tiempo. ¿Me entiende? Eso es... es todo lo mas, que llegue mas temprano.

**Q:** Mas temprano.

**P:** Es todo lo que es, nomas.

**Q:** ok. Bueno pues muchas gracias por este, esta entrevista y por este ah darnos esta información.

**P:** ok gracias...

**Q:** Gracias.

**P:** Ok, gracias a usted también.

## **Appendix 6**

### Project Timeline

Activities	January				February				March				April				May				June				July				August				September				October				November				December.			
Goal 1: Document process of diagnosis of End Stage Renal Disease (ESRD) and referral to dialysis treatment and how patient needs are considered in the decision																																																
Objective 1.1: Document how patients are informed about the need for dialysis treatment and the choices they have in the process																																																
Weeks	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48
Activity 1.1.2: Prepare script for interviews with private clinicians (Physicians, Nephrologists, Nurses) and patients about how patients are informed and offered choices of providers																																																
Activity 1.1.3: Interview private clinicians and patients about how patients are informed and offered choices of providers																																																
Activity 1.1.5: Discuss with Dialysis Workgroup and key stakeholders Done																																																
Activities	January				February				March				April				May				June				July				August				September				October				November				December.			
Objective 1.2: Document the medically indicated needs of the dialysis patient prior to and after dialysis treatment are taken into consideration during the dialysis referral process																																																
Weeks	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48
Activity 1.2.1: Conduct a literature review of the needs of patients (fasting, hydration, rest, movement, cognitive/decision making, etc.) before and after dialysis.																																																
Activity 1.2.2: Prepare script for interviews with physicians, nephrologists, Nurses, dialysis clinic staff about medical needs of patients																																																
Activity 1.2.3: Conduct Interview with private clinicians (Physicians, Nephrologists, PA's) to confirm literature review findings																																																
Activity 1.2.4: Comparative analysis of findings from literature search interviews with physicians and patients																																																
Activity 1.2.5: Discuss with Dialysis Workgroup and key stakeholders																																																

Activities	January				February				March				April				May				June				July				August				September				October				November				December			
Goal 2: Determine the dialysis clinic selection process and the factors and responsible parties influencing selection																																																
Objective 2.1: Document the factors that determine dialysis clinic selection																																																
Weeks	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48
Activity 2.1.1: Conduct a literature review of the factors that determine dialysis clinic selection, including Medicare and Medicaid requirements																																																
Activity 2.1.2: Prepare script for interviews with physicians, nephrologists, PA’s, nurses and patients about dialysis clinic selection																																																
Activity 2.1.3: Interview private physicians, nephrologists, PA’s, nurses and patients about dialysis clinic selection																																																
Activity 2.1.4: Comparative analysis of findings from interviews with physicians and patients																																																
Activity 2.1.5: Discuss with Dialysis Workgroup and key stakeholders																																																
Activities	January				February				March				April				May				June				July				August				September				October				November				December			
Objective 2.1: Document the factors that determine dialysis clinic selection																																																
Weeks	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48
Activity 2.2.1: Conduct a literature review medical, legal, ethical, practical, language, cost, insurance or other issues impacting physician and patient selection of dialysis clinic																																																
Activity 2.2.2: Prepare script for interviews with physicians, nephrologists, PA’s, nurses, dialysis providers about medical, legal, ethical, practical, language, cost, insurance or other issues impacting physician and patient selection of dialysis clinic																																																

Activities	January				February				March				April				May				June				July				August				September				October				November				December			
Objective 2.1: Document the factors that determine dialysis clinic selection																																																
Weeks	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48
Activity 2.2.3: Conduct interviews with private physicians, nephrologists, PA's, nurses and dialysis providers about dialysis clinic selection																																																
Activity 2.2.4: Comparative analysis of findings from interviews with clinicians and dialysis clinic providers																																																
Activity 2.2.5: Discuss with Dialysis Workgroup and key stakeholders																																																
Activities	January				February				March				April				May				June				July				August				September				October				November				December			
Objective 2.3: Determine the current actual role of the patient in dialysis clinic selection																																																
Weeks	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48
Activity 2.3.1: Prepare script for interviews with patients about medical, legal, ethical, practical, language, cost, insurance or other issues impacting physician and patient selection of dialysis clinic																																																
Activity 2.3.2: Conduct interviews with patients																																																
Activity 2.3.3: Comparative analysis of findings from interviews with patients clinicians and dialysis clinic providers																																																
Activity 2.3.4: Discuss with Dialysis Workgroup and key stakeholders																																																

Activities	January				February				March				April				May				June				July				August				September				October				November				December				
Objective 2.4: Determine the extent to which physical access (transportation) to dialysis clinics is factored into treatment location referrals																																																	
Weeks	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48	
Activity 2.4.1: Prepare script for interviews with physicians, nephrologists, PA's, nurses, dialysis providers about how transportation needs to dialysis clinics is factored into treatment location referrals																																																	
Activity 2.4.2: Conduct Interview private physicians, nephrologists, PA's, nurses and dialysis providers about how transportation needs to dialysis clinics is factored into treatment location referrals																																																	
Activities	January				February				March				April				May				June				July				August				September				October				November				December				
Goal 2: Determine the dialysis clinic selection process and the factors and responsible parties influencing selection (cont.)																																																	
Objective 2.4: Document the factors that determine dialysis clinic selection (cont.)																																																	
Weeks	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48	
Activity 2.4.3: Prepare script for interviews with patients how transportation needs to dialysis clinics is factored into treatment location referrals																																																	
Activity 2.4.4: Conduct interviews with patients																																																	
Activity 2.4.5: Comparative analysis of findings from interviews with clinicians and dialysis clinic providers and patients																																																	
Activity 2.4.6: Discuss with Dialysis Workgroup and key stakeholders																																																	

Activities	January			February			March			April			May			June			July			August			September			October			November			December																
Goal 3: Document the existing transportation services for dialysis patients in the six counties—including to and from dialysis centers in counties other than Brewster, Culberson, El Paso, Hudspeth, Jeff Davis, Presidio																																																		
Objective 3.1: Profile the typical/range of an actual door-to-door dialysis treatment experience with particular attention to condition of patient after treatment (i.e., what happens, how long it takes, what a patient is responsible for doing, what the clinic does, what the transportation provider does, what an attendant does																																																		
Weeks	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48		
Activity 3.1.1: Prepare script for interviews with dialysis clinic personnel about transportation issues to and from treatment including emergency services upon end of treatment and release responsibilities, etc.																																																		
Activity 3.1.2: Prepare script for interviews with the transportation provider personnel about transportation issues to and from dialysis clinics, including emergency services after patient is transferred to and from clinic																																																		
Activity 3.1.3: Conduct Interviews with dialysis clinic personnel, (supervisors, coordinators, dispatchers and drivers) and dialysis patients about all transportation related issues to trips to and from dialysis clinic.																																																		
Activity 3.1.4: Prepare script for interviews with patients about all transportation related issues to trips to and from dialysis clinic																																																		
Activity 3.1.5: Conduct interviews with patients																																																		
Activity 3.1.6: Comparative analysis of findings from interviews with dialysis clinic personnel and (supervisors, coordinators, dispatchers and drivers) and interviews with patients.																																																		
Activity 3.1.7: Discuss with Dialysis Workgroup and key stakeholders																																																		

Activities	January				February				March				April				May				June				July				August				September				October				November				December			
<b>Objective 3.2: Calculate the typical time span of the complete-to-door dialysis treatment experience, including time of the day scheduled for dialysis, transportation time, wait times at clinic before treatment is initiated, and after treatment is completed.</b>																																																
Weeks	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48
Activity 3.2.1: Prepare script for interviews with patients about typical time span of the complete-to-door dialysis treatment experience (delays, inconvenient times, etc.)																																																
Activity 3.2.2: Conduct interviews with patients about typical time span of the complete-to-door dialysis treatment experience																																																
Activity 3.2.3: Prepare script for in-depth interviews with selected patients to better clarify issues with issues raised during interviews (delays, inconvenient times, etc.)																																																
Activity 3.2.4: Conduct Interviews with patients about typical time span of the complete-to-door dialysis treatment experience																																																
Activity 3.2.5: Discuss with Dialysis Workgroup and key stakeholders																																																
Activities	January				February				March				April				May				June				July				August				September				October				November				December			
<b>Goal 4: Examine how patient transportation issues affect the prevention of End Stage Renal Disease (ESRD) and after ESRD diagnosis how it affects the speed of disease progression</b>																																																
<b>Objective 4.1: Determine the extent to which transportation or mobility barriers impact access to medical care that could have prevented or forestalled need for dialysis (i.e., estimated % of patients that could have prevented need for dialysis through better access to medical services)</b>																																																
Weeks	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48
Activity 4.1.1: Conduct a literature review of the preventive actions related to transportation that patients and physicians could take to prevent the onset of end stage renal disease (ESRD) and need for dialysis																																																
Activity 4.1.2: Prepare script for interviews with physicians, nephrologists, PA’s about how to prevent the onset of end stage renal disease (ESRD) and need for dialysis																																																

Activities	January				February				March				April				May				June				July				August				September				October				November				December			
Goal 4; Examine how patient transportation issues affect the prevention of End Stage Renal Disease (ESRD) and after ESRD diagnosis how it affects the speed of disease progression																																																
Objective 4.1: Determine the extent to which transportation or mobility barriers impact access to medical care that could have prevented or forestalled need for dialysis (i.e., estimated % of patients that could have prevented need for dialysis through better access to medical services)																																																
Weeks	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48
Activity 4.1.3: Interview private clinicians (Physicians, Nephrologists, PA's) to confirm literature review findings																																																
Activity 4.1.4: Access clinical documentation and possible-Medicaid and Medicare records about transportation related barriers to access to medical visits and regular test for Diabetes, Cholesterol, High blood pressure and Albumin in urine																																																
Activity 4.1.5: Comparative analysis of findings from literature review, interviews with physicians, nephrologists, PA's and medical records																																																
Activities	January				February				March				April				May				June				July				August				September				October				November				December			
Objective 4.2: Determine the extent to which transportation or mobility barriers impact access to dialysis treatment that could have prevented or forestalled need for more intensive dialysis, hospital admissions or other medical services (i.e., % of dialysis patients that do not attend prescribed dialysis seating's whose condition worsens for transportation reasons)																																																
Weeks	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48
Activity 4.2.1: Conduct a literature review of the preventive actions related to transportation that that could have prevented or forestalled need for more intensive dialysis, hospital admissions or other medical services																																																
Activity 4.2.2: Prepare script for interviews with physicians, nephrologists, PA's about how to take preventive actions related to transportation that that could have prevented or forestalled need for more intensive dialysis, hospital admissions or other medical services																																																

Activities	January				February				March				April				May				June				July				August				September				October				November				December					
<b>Objective 4.2: Determine the extent to which transportation or mobility barriers impact access to dialysis treatment that could have prevented or forestalled need for more intensive dialysis, hospital admissions or other medical services (i.e., % of dialysis patients that do not attend prescribed dialysis seating's whose condition worsens for transportation reasons)</b>																																																		
Weeks	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48		
Activity 4.2.3: Conduct interview private clinicians (Physicians, Nephrologists, PA's) to confirm literature review findings																																																		
Activity 4.2.4 Access Clinical Documentation and possible-Medicaid and Medicare records about transportation related barriers to access to dialysis visits and adherence to dialysis regimen and medications																																																		
Activity 4.2.5: Comparative analysis of findings from literature review interviews with physicians, nephrologists, PA's and medical records																																																		
Activity 4.2.6: Discuss with Dialysis Workgroup and key stakeholders																																																		
Activities	January				February				March				April				May				June				July				August				September				October				November				December					
<b>Goal 5: Recommend streamlined procedures to make transportation services to dialysis centers more efficient and cost effective</b>																																																		
<b>Objective 5.1: Profile each of the dialysis clinics in the region by location, services provided, days/hours of operation, appointment procedure, basic services protocols, insurance accepted, and ownership. —including dialysis clinics in other counties serving Brewster, Culberson, Hudspeth, Jeff Davis, and Presidio.</b>																																																		
Weeks	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48		
Activity 5.1.1: Develop a comprehensive list of all dialysis clinics serving dialysis patients from the counties of Brewster, Culberson, El Paso, Hudspeth, Jeff Davis, and Presidio.																																																		

Activities	January				February				March				April				May				June				July				August				September				October				November				December					
Goal 5: Recommend streamlined procedures to make transportation services to dialysis centers more efficient and cost effective																																																		
Objective 5.1: Profile each of the dialysis clinics in the region by location, services provided, days/hours of operation, appointment procedure, basic services protocols, insurance accepted, and ownership. —including dialysis clinics in other counties serving Brewster, Culberson, Hudspeth, Jeff Davis, and Presidio.																																																		
Weeks	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48		
Activity 5.1.2: Visit all dialysis clinics serving dialysis patients from the counties of Brewster, Culberson, El Paso, Hudspeth, Jeff Davis, and Presidio. Collect data about the clinic capacity, hours of operation, address and zip code of patients, duration of dialysis, and any information pertinent to transportation of patients to and from dialysis. Investigate Internet web page description, pamphlets, advertisements, etc..																																																		
Activity 5.1.3: Discuss with Dialysis Workgroup and key stakeholders																																																		
Activities	January				February				March				April				May				June				July				August				September				October				November				December					
Objective 5.2: Estimate the current and projected number of dialysis patients and dialysis clinic capacity in the region																																																		
Weeks	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48		
Activity 5.2.1: From Clinic records, and all official information about each clinic from Texas DSHS and The ESRD network of Texas collect data on the number of new dialysis cases, the rate of growth in cases in the last 10 years.																																																		
Activity 5.2.2: From official records Texas DSHS records collect data on the growth rate of Diabetes and HBP in the six counties number of new dialysis cases, the rate of growth in cases in the last 10 years.																																																		
Activity 5.2.3: Plot the growth rate in the last 10 years of new dialysis cases to depict trends that will inform projections for transportation needs in the near future																																																		

Activities	January				February				March				April				May				June				July				August				September				October				November				December						
Objective 5.2: Estimate the current and projected number of dialysis patients and dialysis clinic capacity in the region																																																			
Weeks	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48			
Activity 5.2.4: Compare the rate of growth of ESRD and the growth rate of Diabetes and HBP to see the predictive value of the interaction, and if there is a lag time between onset of Diabetes and HBP and the onset of ESRD, to help project transportation needs in the near future																																																			
Activity 5.2.5: Discuss with Dialysis Workgroup and key stakeholders																																																			
Activities	January				February				March				April				May				June				July				August				September				October				November				December						
Goal 6: Prepare documentation showing how the research was conducted and evaluated and provide recommendations on how to improve the efficiency, cost-effectiveness and additional revenue sources of dialysis transportation services																																																			
Objective 6.1: Prepare and deliver periodic presentations to the Far West Texas/El Paso Regional Transportation Coordination Steering Committee																																																			
Weeks	1	2	3	4	5	6	7	8					1	1	1	1	1	1	1	2	2	2	2	2	2	2	2	2	2	2	3	3	3	3	3	3	3	3	3	3	4	4	4	4	4	4	4	4	4	4	4
Activity 6.1.1: Continuously compile data collected during activities necessary to complete the five preceding project goals																																																			
Activity 6.1.2: Prepare monthly internal reports for CIHRE informed by a database of activities																																																			
Activity 6.1.3: Prepare written brief reports and a presentations to the Far West Texas/El Paso Regional Transportation Coordination Steering Committee																																																			
Activity 6.1.4: Discuss with Dialysis Workgroup and key stakeholders																																																			

Activities	January				February				March				April				May				June				July				August				September				October				November				December				
Objective 6.2:Identify sources of new revenues to help contribute to the reduction in dialysis costs to the State of Texas Department of Transportation																																																	
Weeks	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48	
Activity 6.2.1: Using the various databases developed to collect data and the extensive directory of contacts with financing agencies the local, state and federal level develop a strategic plan for the West Texas/El Paso Regional Transportation Coordination Steering Committee																																																	
Activity 6.2.2: Conduct internet searches to identify resources that can be accessed to finance dialysis transportation																																																	
Activity 6.2.3:Prepare a manual listing al the sources that can be tapped for venues West Texas/El Paso Regional Transportation Coordination Steering Committee																																																	
Activity 6.2.4: Discuss with Dialysis Workgroup and key stakeholders																																																	
Activities	January				February				March				April				May				June				July				August				September				October				November				December				
Objective 6.3: Prepare final report describing the research process and recommendations to improve efficiency and cost effectiveness of the transportation of dialysis patients and the possible sources of new revenues																																																	
Weeks	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48	
Activity 6.3.1:Using all data collected, prepare a final report describing the project, its results and recommendations to improve efficiency and cost effectiveness of the transportation of dialysis patients																																																	
Activity 6.6. 3: Prepare a final financial report																																																	
Activity 6.6.4: Discuss with Dialysis Workgroup and key stakeholders																																																	

## **Appendix 7**

### Dialysis Workgroup Meetings Agendas

### **El Paso Dialysis Transportation Coordination Workgroup**

Thursday, October 27<sup>th</sup> from 2 to 4 PM MDT

Volar – Center for Independent Living, 1220 Golden Key Circle in El Paso  
1220GoldenKeyCircle  
El Paso, Texas 79925

#### **AGENDA**

- I ☐ ☐ Recap last meeting
  - II. Update on dialysis study supplemental funding application and Letters of Support
  - III. Clinic inquiries soliciting meetings for emergency preparedness
  - IV. Impact of 24/7 dialysis services
  - V. Dialysis transportation workplan
  - VI. Role of passengers not currently eligible for transportation assistance in project
  - VII ☐ Confirm general project goals and strategies
  - VIII. Discuss next steps and timing
- 

### **El Paso Dialysis Transportation Coordination Workgroup**

Wednesday, November 14, 2012 - 3:15 to 4:30 PM MST

Volar – Center for Independent Living  
1220GoldenKeyCircle  
El Paso, Texas 79925

#### **AGENDA**

- ☐
- ☐ ☐ Welcome and Introductions
- ☐ ☐ ☐ Revised Dialysis Transportation Workplan
- ☐ ☐ ☐ Review Draft Patient Education Brochure
- IV. ☐ Assignment of Subcommittees for
  - Trip Assignment
  - Patient Education
  - Physician Referral Reform
  - Revenue Enhancement
- V ☐ Subcommittee Expectations, Next steps and Calendar ☐

**El Paso Dialysis Transportation Coordination Workgroup**  
Thursday, February 2, 2:00 to 4:00 PM MDT  
Volar – Center for Independent Living, 1220 Golden Key Circle in El Paso  
1220GoldenKeyCircle  
El Paso, Texas 79925

**AGENDA**

- ☐
  - ☐ ☐ Dialysis Transportation Study; Revised Research Objectives, Elements and Approach
  - ☐ ☐ ☐ Revised Dialysis Transportation Workplan
  - ☐ ☐ ☐ ☐ Assignment of Subcommittees for
    - Trip Assignment,
    - Patient Education
    - Physician Referral Reform
    - Revenue Enhancement
    - Rural Scheduling
  - ☐ ☐ Subcommittee Expectations, Next steps and Calendar ☐
- 

**Far West Texas / El Paso Regional Transportation Coordination Committee (WTEP)  
Stakeholder Committee Meeting**

Thursday, January 19, 2012  
10:00 AM Mountain Standard Time

El Paso MPO – 10767 Gateway Blvd. West, Suite 605, El Paso, Texas 79935  
Conference Call Number: 866-528-2256 or 216-706-7052 Access Code: 6673165  
(Please note the new numbers)

**AGENDA**

- I. Call to Order
- II. Welcome and Introductions
- III. Business Items
  - A. Approval of December 9, 2011 Far West Texas/ El Paso Regional Transportation Coordination Stakeholder Committee Minutes – Ivan Garza
  - B. Nominations Committee Report and Election of 2012 WTEP Officers and Steering Committee – Bob Geyer
  - C. Update on Veterans Transportation and Community Living Initiative – Julio Perez
  - D. Update on Dialysis Transportation Project and Supplemental-Funding Dialysis Study – Bob Geyer
- IV. Other Business
  - A. TxDOT Update - Armida Sagaribay
  - B. MPO Update – Efrén Meza
  - C. Other
  - V. Announcements
    - A. Next Regular Stakeholder Meeting – March 15, 2012
    - B. Other
  - VI. Adjourn

## **Far West Texas / El Paso Regional Transportation Coordination Stakeholder Committee**

January 19, 2012 at 10:00 AM (MDT)

El Paso MPO Boardroom, 10767 Gateway Blvd. West, Suite 605, El Paso, Texas

### **MINUTES**

#### **Member Attendees:**

Xavier Bañales, Project Amistad

M. Ivan Garza, Sun City Cab

Jane Jones, Volar CIL

Yvette Lugo, Area Agency on Aging

Efrén Meza, El Paso MPO

Benji Natividad, All Aboard America

Julio Perez, Sun Metro

Robin Roberts, Frontera Women's Foundation

Emma Vasquez, Big Bend Community Action Committee

Roberto Wallace, Viba Transportation

#### **Staff and Guests:**

Armida Sagaribay, TxDOT

Bob Schwab, El Paso County

### **I. Call to order: 10:10 AM MST**

### **II. Introduction of Attendees**

Jane Jones, Bob Schwab and Emma Vasquez attended by phone.

### **III. Business Items**

#### **A. Approval of Stakeholder Committee Meeting Minutes of December 9, 2011.**

Ivan Garza distributed minutes of the November 17, 2011 Stakeholder Committee meeting. Yvette Lugo made a motion to adopt the minutes as corrected and Xavier Bañales seconded. The motion passed.

#### **B. Nominations Committee Report and Election of Officers and Steering Committee for 2012**

Efrén Meza presented the Nomination Committee report noting that the committee was chaired by Bob Geyer and included Julio Perez, Xavier Bañales and himself. The committee was appointed by Chair Rene Pokrzywinski and met in November. The committee offered the following slate of officers and Steering Committee members, all of whom were contacted and agreed to serve:

##### **Officers:**

Chair Ivan Garza, Sun City Cab

Vice-Chair Roberto Wallace, Viba Transportation

Secretary Jane Jones, Volar

##### **Steering Committee:**

Xavier Bañales, Project Amistad

Bob Geyer, El Paso County Transportation

Julio Perez, Sun Metro

Robin Roberts, Frontera Womens' Foundation

Emma Vasquez, Big Bend Community Action Committee

Xavier Bañales made a motion to adopt the committee report. Yvette Lugo Seconded and the motion passed. The Stakeholders congratulated the newly elected officers and Steering Committee members.

#### **C. Veterans Transportation and Community Living Initiative Update**

Julio Perez reported that Sun Metro staff participated in a recent VTCLI webinar presented by the Federal Transit Administration (FTA) to discuss the rollout of the program with recently announced grantees and the next steps for getting local projects underway. FTA will be hiring a national program manager and is encouraging grantees to adopt an inclusive approach to involving transportation services and veterans organizations in their projects. Mr. Perez reported that Sun Metro submitted its revised Scope of Work and Preliminary Budget by the January 15, 2012 deadline and that a final application document is due on March 30, 2012. The FTA will obligate funds on June 30, 2012 which will constitute the official start of the 18 month project and when project expenditures can begin. Mr. Perez reminded the Stakeholders that the VTCLI grant does not cover the cost of transportation or operations and that the focus of the project is to increase veterans' and the public's access to transportation through call-center, interactive voice response (IVR) and web based technology. Sun Metro will be enlarging/adapting its existing call center as necessary to perform that function which will likely involve the design and installation of a phone, software, website, IVR systems.

Mr. Perez stated that the goal of the Transportation One-Call/One-Click would be to address callers transportation needs "right then and there" while the caller was on the phone and be able to help them qualify for special transit programs, schedule a trip or learn what bus to take to get them to their destination. Xavier Bañales noted that the Aging and Disability Resource Center (ADRC) would be able to receive calls transferred from the Transportation One-Call to address social services needs. Robin Roberts suggested that information about the project be placed on gobusgo.org. Bob Schwab noted that the announcement of the Sun Metro VTCLI grant award and link to the FTA press release was currently on the website under the News tab and that additional information could be added under the Coordination Activities tab.

**C. Dialysis Transportation and Study Projects Update** – Bob Schwab reported that the Supplemental Transportation Coordination grant agreement between El Paso County and TxDOT to conduct a study of End Stage Renal Disease and dialysis related transportation issues was executed and that the Interlocal Agreement between El Paso County and the University of Texas, College of Health Sciences – Center of Interdisciplinary Health Research and Evaluation to conduct the study was going before the Commissioners' Court on Monday, January 23<sup>rd</sup>. Mr. Schwab reported that the project proposal received high marks in the TxDOT review and that most of the research activities/areas of inquiry previously presented to and discussed by the Dialysis Workgroup will be part of the funded study, but will not include a look at how ESRD is diagnosed since TxDOT felt this was beyond the scope of a transportation focused study.

Mr. Schwab briefly discussed the relationship between the broader dialysis transportation project and the dialysis study and announced that the Dialysis Transportation Workgroup would meet the week of January 30 to revisit and refine the dialysis transportation workplan. Mr. Schwab stated that the meeting may include a discussion with João Batista Ferreira-Pinto, PhD, if he is available.

#### **IV. Other Business**

A. Armida Sagaribay announced that the TxDOT Simi-Annual Operators meeting has been scheduled for January 25, 2012 in Austin.

#### **V. Announcements**

The next Regional Transportation Coordination Stakeholders' meeting is scheduled for March 15, 2012 at 10:00 AM MST at the El Paso MPO

#### **VI. Adjournment**

Robin Roberts made a motion to adjourn the meeting. Roberto Wallace seconded and the meeting adjourned at 11:03 AM

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**Far West Texas / El Paso  
Regional Transportation Coordination Committee  
(WTEP)**

**Stakeholder Committee Meeting**

Thursday, March 15, 2012  
10:00 AM Mountain Daylight Savings Time

El Paso MPO – 10767 Gateway Blvd. West, Suite 605, El Paso, Texas 79935  
Conference Call Number: 866-528-2256 or 216-706-7052 Access Code: 6673165  
(Please note the new numbers)

#### **AGENDA**

- I. Call to Order
- II. Welcome and Introductions
- III. Business Items
  - A. Approval of the January 19, 2012 Far West Texas/ El Paso Regional Transportation Coordination Stakeholder Committee Minutes – Jane Jones
  - B. Discussion and Action on the FY2013 Regional Transportation Coordination Application – Bob Schwab
    - C. Public Comment Resolution Encouraging Full Consideration of the Need and Allocation of More Resources to Support Growing Demand For Public Transportation for the Texas Rural Transportation Plan 2035 – Bob Schwab
- IV. Other Business
  - A. Veterans Transportation and Community Living Initiative Status Report – Julio Perez
  - B. Dialysis Transportation Coordination Project and Study Update – Bob Geyer
  - C. TxDOT Regional Coordinated Transportation Best Practices Conference, Austin, April 17-18, 2012 – Bob Schwab
- V. Announcements
  - A. Accessible Taxi Technical Assistance Workgroup Meeting – March 15, 2012, 12:00 Noon, El Paso MPO – 10767 Gateway Blvd. West, Suite 605, El Paso, Texas 79935
  - B. Next Regular Stakeholder Meeting – May 17, 2012, 10:00 AM, El Paso MPO
- VI. Adjourn

**FAR WEST TEXAS / EL PASO REGIONAL TRANSPORTATION COORDINATION  
STAKEHOLDER COMMITTEE**

March 15, 2012 at 10:00 AM (MDT)

El Paso MPO Boardroom, 10767 Gateway Blvd. West, Suite 605, El Paso, Texas

**MINUTES**

**Member Attendees:**

Fred Armendariz, Health and Human Services Commission  
Xavier Bañales, Project Amistad  
William Bennett, City of El Paso  
Mike Drinkard, Family Crisis Center of the Big Bend  
M. Ivan Garza, Sun City Cab  
Bob Geyer, El Paso County  
Jane Jones, Volar CIL  
Frank Lozano, Desert Adapt  
Yvette Lugo, Area Agency on Aging  
Julio Perez, Sun Metro  
Christine Ponce-Diaz, El Paso MPO  
Rosario Reynoso, Project Amistad  
Robin Roberts, Frontera Women's Foundation  
Emma Vasquez, Big Bend Community Action Committee

**Staff and Guests:**

Armida Sagaribay, TxDOT  
Bob Schwab, El Paso County

**I. Call to order:** 10:12 AM MST

**II. Introduction of Attendees**

Mike Drinkard and Emma Vasquez attended by phone.

**III. Business Items**

**A. Approval of Stakeholder Committee Meeting Minutes of January 19, 2012.**

Jane Jones distributed minutes of the January 19, 2012 Stakeholder Committee meeting. Robin Roberts made a motion to adopt the minutes as presented and Armida Sagaribay seconded. The motion passed.

**B. Discussion and Action on the FY 2013 Regional Transportation Coordination Application**

Bob Schwab briefly described the history and evolution of regional transportation coordination funding and application process and the uniqueness of the FY 2013 application. Mr. Schwab then presented a list of ten proposed regional transportation coordination tasks to be included in the FY 2013 application to TxDOT noting that each was included in the Regional Transportation Coordination Plan as an implementing objective of the region's transportation goals. The ten proposed tasks are:

1. Prepare detailed workplan to obtain consensus, guide annual regional transportation coordination efforts and maximize effectiveness of stakeholder efforts
2. Facilitate planning and joint application among veteran's organizations for transportation funding
3. Establish workgroup, document existing processes and prepare plan to address duplicate use/scheduling of MTP, Lift, New Freedom and other shared-ride, demand-response services by users

4. Document First Aid/Blood Borne Pathogen/Defensive Driving skills requirements, determine training and certification standards, and prepare funding application for rural provider to acquire the capacity to provide all related driver training in-house to reduce costs and speed the process for drivers to be placed in service
5. Organize, host and facilitate annual transit funding forum to inform eligible organizations about transportation funding opportunities and encourage collaborative applications that are consistent with the Regional Transportation Coordination Plan
6. Survey community support to determine potential demand and fare-box revenue, research additional potential revenue sources including ICB, propose service mode and schedule and prepare recommendations and report related to mid-day demand-response and scheduled, deviated commuter service between selected cities in the rural counties
7. Research issues and legal process, establish workgroup to include the El Paso MPO, Camino RMA and transportation providers to study and plan the creation of an El Paso County-wide transit system
8. Research issues and process, develop background materials, document justification including potential ridership and prepare report with recommendations to encourage the addition of an Amtrak stop in Marfa and a Greyhound stop in Sierra Blanca
9. Document existing infrastructure, research potential additional use and prepare a report with recommendations encouraging the development of additional facilities and services at public airports in the five rural counties
10. Conduct community survey, organize community planning group and assist community in planning a car-sharing or other alternative transportation service for remote rural community

In response to a question, Mr. Schwab listed each of the current year regional coordination tasks and their status. After considerable discussion, Xavier Bañales made a motion that the item be placed on the agenda of a special meeting of the Steering Committee for further discussion and that the item then be brought to a special meeting of the Stakeholder's in April for final adoption. Bob Geyer offered a friendly amendment to the motion that the April Stakeholder vote to adopt the tasks be conducted by email. Mr. Banales accepted the amendment and Robin Roberts seconded. The motion passed and the Steering Committee meeting to further consider the tasks was set for 2:00 PM, Thursday March 22<sup>nd</sup>.

**C. Public Comment Resolution Encouraging Full Consideration of the Need and Allocation of More Resources to Support Growing Demand for Public Transportation for the Texas Rural Transportation Plan**

Bob Schwab distributed materials and provided a background on the Texas Rural Transportation Plan 2035 noting it was a component of the Statewide Long-Range Transportation Plan 2035 and included multiple non-highway elements. Mr. Schwab also noted that the TxDOT planning process referenced Regional Planning Organizations and their 2006 and 2012 Regional Human Services – Public Transportation Coordination Plans as a means to identify gaps in rural transit service. To highlight the rural elements of the Far West Texas/El Paso Regional Transportation Plan, Bob Schwab presented the following resolution for adoption:

**Far West Texas/El Paso  
Regional Transportation Coordination Committee  
Resolution Related to the Texas Rural Transportation Plan 2035  
March 15, 2012**

**Whereas**, the Texas Department of Transportation is developing a Rural Transportation Plan (TRTP) as a component of the Statewide Long-Range Transportation Plan 2035 (SLRTP), and is to include the identification of rural transportation needs for non-automobile/non-highway modes, and

**Whereas**, the goal of TRTP for non-highway modes is to investigate and plan for non-highway mode opportunities in rural Texas including public transportation, and

**Whereas**, coordinated regional planning is key to identifying needs, filling service gaps and enhancing efficiency and The Far West Texas/El Paso Regional Transportation Coordination Committee submitted Transportation Coordination Plans to TxDOT in 2006 and 2012 that include these components, and

**Whereas**, the rate of growth of the population of persons with disabilities, the elderly and persons living in households with incomes below poverty in Far West Texas is, and historically has been, much greater than other rural areas and the Texas average, and

**Whereas**, persons with disabilities, the elderly and the poor are much more dependent on public transportation, and

**Whereas**, the rural area of Far West Texas is characterized by small, extremely remote communities located at great distance from one another and larger urban areas that are the nearest site of many basic health and other amenities, and

**Whereas**, the size and remoteness of these communities inhibits their growth preventing them from sustaining these basic health services and therefore will require area residents to continue to have to travel long distances to access these important, sometimes life-sustaining services, and

**Whereas**, the likely continued increase in the cost of motor fuels creates economic hardship for rural residents and communities,

**Therefore be it Resolved**, that the Texas Department of Transportation carefully review and fully incorporates relevant rural Implementing Objectives of the *Far West Texas/El Paso Regional Transportation Coordination Plan – September 2011-August 2016* into the TRTP, and

**Be it Further Resolved**, that the Texas Department of Transportation recognize the rapid growth of transit dependent populations in Far West Texas that exceed the growth in other rural areas and the state as a whole and therefore include this growth as an additional need for public transportation that may not be factored into transit funding formulas, and

**Be it Further Resolved**, that the Texas Department of Transportation demonstrate leadership in recognizing the limits of the sustainability of automobile based transportation into the distant future and work to ensure mobility for all Texans by shifting a greater percentage of state and federal Surface Transportation Funds to building a more robust public transportation system for rural Texas.

Bob Geyer made a motion to adopt the resolution and for the Chair to submit it as public comment to TxDOT. Xavier Banales seconded. The motion passed.

#### **IV. Other Business**

A. Julio Perez provided an update of the Veterans Transportation and Community Living Initiative and announced that an initial implementation meeting is scheduled for March 29, 2012

B. Bob Geyer provided an update on the Dialysis Transportation Study and reported that several research permission letters had been received from transportation providers and that approval was pending from the various dialysis clinics upon their receiving approval from their corporate offices.

C. Bob Schwab reported that Ivan Garza, Roberto Wallace, Jane Jones and Bob Schwab will attend the SOLVE – TxDOT Regional Transportation Coordination Conference in Austin, April 17-18 and the several attendees from the region were asked to be presenters in panel discussions.

## **V. Announcements**

An Accessible Taxi Technical Assistance Project Workgroup meeting will be held immediately upon the conclusion of this meeting at the MPO.

The Special Far West Texas/El Paso Regional Transportation Coordination Steering Committee to consider FY 2013 regional transportation coordination tasks will be held on Thursday, March 22<sup>nd</sup> at 2:00 PM MDT, location to be determined.

The next Regional Transportation Coordination Stakeholders' meeting is scheduled for May 17, 2012 at 10:00 AM MDT at the El Paso MPO.

## **VI. Adjournment**

Robin Roberts made a motion to adjourn the meeting. Jane Jones seconded and the meeting adjourned at 11:43 AM.

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### **Far West Texas / El Paso**

#### **Regional Transportation Coordination Committee**

(WTEP)

#### **Stakeholder Committee Meeting**

Thursday, July 19, 2012 - 10:00 AM Mountain Daylight Time  
El Paso MPO – 10767 Gateway Blvd. West, Suite 605, El Paso Texas 79935

### **AGENDA**

- V. Call to Order
- VI. Welcome and Introductions
- VII. Business Items
  - A. Adoption of May 17, 2012 Far West Texas/El Paso Regional Transportation Coordination Stakeholder Committee Meeting Minutes – Jane Jones
  - B. Discussion on the FY2013 Regional Transportation Coordination Application – Bob Schwab
  - C. Update on El Paso Dialysis Transportation Study – Dr. Armando Gonzales, UTEP - Center for Interdisciplinary Health Research and Evaluation
  - D. Project Amistad Change in Service Hours – Xavier Bañales
    - E. Discuss Outcomes from FY 2012 Workplan – Bob Schwab
      - 1. Workforce transportation for mining and solar projects in rural counties
      - 2. Dialysis transportation and scheduling in rural counties
      - 3. Accessible taxi information meeting
  - F. El Paso MPO Urbanized Job Access Reverse Commute & New Freedom RFP – Efrén Meza
  - G. TxDOT §5310 Elderly & Disabled Funding Opportunity Public Meeting – 10:00 AM MDT

August 8, 2012, TxDOT District Office, 13301 Gateway Blvd. West, El Paso, Texas 79928

For more information call Armida Sagaribay at 915-790-4234

#### VIII. Other Business

- D. Lower Rio Grande Valley Development Council Transit – Peer-to-peer visit El Paso/WTEP August 15-16, 2012
- E. Kevin Bergin – Regional Coordinator-Veterans Transportation Service, U.S. Dept. Of Veterans Affairs – WTEP Stakeholder Meeting (AM) & Veterans Transportation Forum (PM), August 16
- F. Let's Talk – Finding Community Solutions to Meeting Client Transportation Needs TxDOT Training – August 27-28 Corpus Christi; August 29-30 Fort Worth – Roberto Wallace
- G. Discussion of Stakeholder Committee Oversight Responsibilities & FY 2012 Approved and FY 2013 Proposed Budget

#### V. Announcements

A. TxDOT Coordinated Call – Armida Sagaribay or Bob Schwab

B. Next Stakeholder Meeting:

– August 16, 2012, 10:00 AM MDT, El Paso MPO

VI. Adjourn

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### **FAR WEST TEXAS / EL PASO REGIONAL TRANSPORTATION COORDINATION STAKEHOLDER COMMITTEE**

July 19, 2012 at 10:00 AM (MDT)

El Paso MPO Boardroom, 10767 Gateway Blvd. West, Suite 605, El Paso, Texas

#### MINUTES

##### Member Attendees:

Xavier Bañales, Project Amistad

Linda DeBeer, Sun Metro

Mike Drinkard, Family Crisis Center of the Big Bend

M. Ivan Garza, Sun City Cab

Yvette Lugo, Area Agency on Aging

##### Staff and Guests:

Armando Gonzalez, PhD., UTEP-Center for Interdisciplinary Health Research & Evaluation

Bob Schwab, El Paso County

Steve Wright, TxDOT

#### **I. Call to order: 10:06 AM MST**

#### **II. Introduction of Attendees**

Mike Drinkard and Steve Wright attended by phone.

#### **III. Business Items**

##### **A. Approval of Stakeholder Committee Meeting Minutes of May 17, 2012**

The minutes of the May 17, 2012 Far West Texas/El Paso Regional Transportation Coordination Stakeholder Committee were distributed and reviewed. Robin Roberts made a motion to adopt the minutes as presented and Xavier Bañales seconded. The motion passed.

##### **B. Discussion on the FY 2013 Regional Transportation Coordination Application**

[moved to follow item III. D. on the agenda]

##### **C. Presentation by Dr. Armando Gonzalez on the Dialysis Transportation Study**

Dr. Gonzales delivered a PowerPoint presentation on the purpose, progress made to date and current findings of the on-going dialysis transportation study. Dr. Gonzalez discussed a range of issues associated with end stage renal disease and reported that so far the study has involved a review of prior research, interviews with 10 nephrologists; interviews with managers, dispatchers and drivers at 4 of the 6 main transportation providers with the remaining two scheduled for the next week; interviews with the managers and social workers at 4 DaVita clinics and completion of most of the interview transcripts.

Dr. Gonzalez discussed the demographic issues associated with dialysis and noted that the El Paso region is likely to see a very large increase in the number of persons requiring dialysis in the coming years. He noted that hemodialysis patients must rely on others to transport them to and from the treatment and that transportation issues are a main cause of treatment non-compliance or shortened treatment times. Dr. Gonzalez stated that in the El Paso study, the main complaints from nephrologists, clinic social workers and drivers were the long time patients have to wait for rides after treatment (30 minutes to over 2 hours), home pickups not on time (resulting in shorter than optimal treatment) or not being picked up at all. Dr. Gonzalez outlined the on-going and future elements of the study and answered numerous questions about the study and his presentation.

Bob Schwab stated that El Paso County has requested a four month extension to the contract due to the delays in obtaining interview permissions from the dialysis corporations and that the dialysis project involves nephrologist and patient education elements, a trip assignment element and a resource identification element which will benefit from the study results.

#### **D. Project Amistad Change in Service Hours**

Xavier Banales announced that Project Amistad was changing the service hours effective August 1, 2012 for all its programs, with service beginning at 5:30 AM and ending at 7:00 PM as a cost saving measure. Mr. Banales announced three public forums to answer questions and concerns about the change and acknowledged that this change would affect service for some current dialysis and other passengers. Ivan Garza stated that he was aware of the situation and that Sun City Cab would do what it could to fill the service gap. Bob Schwab stated that he had heard from a community member that the time and location of the forums will make it difficult for some people to attend and asked if the change affected the Project Amistad agreement with El Paso cab companies to provide 24/7 backup for accessible vehicles. Mr. Banales responded that it would and that there would be no backup with Project Amistad vehicles outside of the new service hours. Bob Schwab stated that since there was no alternative in the rural counties, Big Bend Community Action Committee had no alternative to limit its services to save money and that as the regional Medical Transportation Program prime contractor, Project Amistad should consider that fact in any future funding decisions related to BBCAC.

#### **B. Discussion on FY 2013 Regional Transportation Coordination Application to TxDOT [moved from above]**

Bob Schwab summarized the FY 2013 regional coordination application process noting the two Steering Committee and two Stakeholder meetings involved in the development and adoption of the application. He reported that eight of the ten projects submitted to TxDOT for the FY 2013 program year were approved: the Annual Workplan; Joint Veterans Transportation Funding Application; Transit Funding Forum; Rural Provider Driver Skills Training Plan; Rural Commuter Service Study; Inter-City Bus Service to Sierra Blanca Study; Remote Community Car Sharing/Van Pool Facilitation; and Seamless Transfer Between El Paso County Rural Transit and Sun Metro Study. The projects not approved were the Rural Airport Infrastructure Report and the El Paso County-Wide Transit System Study. Mr. Schwab reported that the original request of \$93,437 was reduced to \$88,921 as a result of the elimination of the two projects but

that the \$88,921 amount was proposed but not yet approved. Steve Wright stated that the \$88,921 was the amount appearing on the Texas Transportation Commission minute order, but confirmed that the final contract amount was subject to TxDOT negotiations.

Mr. Schwab also distributed the current year, FY 2012 Lead Agency budget which totals \$103,150 along with a statement of expenses, revenues, and billings into the month of June.

He noted that the expenses at year end would be less than the total budgeted amount due to no office space being rented; the late hiring of the administrative assistant; supplies and other ancillary items costing slightly less than budgeted and a trip for four persons to Twestown that was required by TxDOT to be budgeted but never materialized. Upon suggestions by committee members that the projected unused funds could be used for various purposes, Mr. Schwab stated that any changes to the budget required either a budget revision or amendment approved by TxDOT and that he felt it was important that TxDOT view our region maintain its reputation for submitting reasonable and responsible budgets that supply our needs but are not padded and reminded the committee that the FY 2012 Far West Texas/El Paso regional coordination grant was the largest in the State based on that reputation, our solid record of accomplishment and our substantial slate of projects.

Robin Roberts stated that she felt there needed to be more transparency in the process. Mr. Schwab responded that the FY 2013 application was derived exclusively from projects identified in the Regional Plan; that the projects were presented twice to the Steering Committee and twice to the Stakeholder committee and that historically, committee agendas are dominated by discussion of projects adopted by the Stakeholder in the annual workplan. Mr. Schwab added that the budget consists largely of his salary, benefits, travel, and minimal supportive expensed like supplies and phone.

Robin Roberts made a motion to establish an oversight committee. Xavier Banales seconded and the motion passed.

#### **E. Outcomes from FY 2012 Regional Transportation Coordination Workplan**

Bob Schwab reported on three recently completed regional transportation coordination tasks: Workforce transportation projects for solar and mining developments in Presidio County; Dialysis transportation and scheduling in the rural counties, and the Accessible Taxi informational meeting in El Paso.

##### Workforce Transportation

Mr. Schwab reported that the proposed solar plant in southern Presidio County had been delayed pending approval of a tax abatement which was recently awarded, but that construction and therefore any significant workforce transportation needs would not occur in the current program year. However; the Rio Grande Mine has gone into production and will soon reach full staffing levels. Mr. Schwab reported that initially the mine was enthusiastic about a workforce transportation program, but with a change in management the interest seemed to wane. Nevertheless, numerous overtures were made to assist with transportation issues considering the remote location and lack of a local workforce. A more recent change in management and high employee turnover attributable to the long commute caused the firm to reconsider some sort of workforce transportation program and welcomed assistance in finding a solution. An initial analysis of employee home locations revealed greater dispersion than assumed. Coupled with the complex work and 7 day schedules it was determined that a vanpool program most likely offered the appropriate service. The vanpool firm with a regional presence (VRide) was engaged and a series of meeting were facilitated with the mine to begin discussing the project. Rio Grande Mine agreed that vanpools were appropriate for their needs and VRide prepared a proposal for the employer's consideration. Rio Grande Mine is now working with VRide to identify employee groups and schedules to structure the various vanpools serving the

communities of Alpine and Marfa. It is anticipated that vanpools could begin in October or November.

In addition to Rio Grande Mine, Lead Agency staff also approached the Big Bend Sector Border Patrol Chief about a similar service. The Border Patrol is the largest employer in Marfa and it is well known that most of its agents reside in Alpine, 26 mile to the east, and commute each day. The Border Patrol was provided detailed information about how vanpooling works, employee transportation tax benefits and contact information for other Border Patrol sectors successfully using vanpools. Lead Agency staff will continue to work with the Big Bend Sector to assist with workforce transportation planning.

#### Rural Dialysis Transportation

Mr. Schwab noted that there are no dialysis clinics in Brewster, Culberson, Hudspeth, Jeff Davis or Presidio Counties and that residents requiring dialysis must travel to El Paso, Ft. Stockton or Pecos for that treatment. For a variety of reasons, it seems that those individuals were assigned early morning treatment sessions often starting at 5:00 or 5:30 AM. Since these individuals must commute between 80 and 180 miles each way to access this service, their trip can begin as early as 2:00 AM presenting a hardship for both the passenger and the transportation provider which must recruit and keep drivers willing to work such early hours. A FY 2012 transportation coordination was adopted to address this issue and, working with the transportation provider, began with an anonymous analysis of each passenger's starting location, destination, frequency of travel and other issues. Lead Agency staff communicated with the dialysis clinic staff to obtain information about its operation, scheduling decisions and process for re-scheduling dialysis sessions. After discussing with the transportation provider passenger willingness to change schedules, a meeting was held with the clinic's regional manager to discuss the issue. The meeting obtained an acknowledgement of the hardship on the part of the passenger as well as the importance of maintaining a public transportation option for the patients and a commitment to prioritize distant public transportation using patients for more favorable dialysis appointments. This outcome was reported back to the transportation provider which followed up with a meeting to discuss the logistics of a schedule change. As a result, most long distance dialysis patients now have appointment starting at 11:00 AM as opposed to 5:00 AM with their trips beginning at 8:00 AM instead of 2:00 AM, greatly improving work schedules for the drivers as well.

#### Accessible Taxi Project

Mr. Schwab reported on the process and culmination of the Accessible Taxi project to inform all of El Paso's taxi, shuttle and limousine companies of federal and local requirements to provide accessible transportation or equivalent service, information about firms and organizations that have accessible vehicles in their fleets licensed to provide equivalent service, information about funding programs that can assist with the retrofitting or purchase of accessible vehicle information about available free disability sensitivity training for drivers. Mr. Schwab reported that the training meeting held in early July was attended by over 25 individuals representing 18 different transportation firms and adopted the theme "No Ride Denied" which was also used on the laminated information sheet that was distributed at the meeting. Steering Committee members suggested that the sheet be posted on the gobusgo.org website.

#### **F. El Paso MPO Urbanized Job Access Reverse Commute & New Freedom RFP**

Efrén Meza reported that FY 2103 JARC and NF funds were \$1,456,674 and \$442,745 respectively noting that about 1% would be retained by the MPO for administration. Mr. Meza stated that the projected RFP release date was August 20<sup>th</sup> with proposal likely due September 20<sup>th</sup> or at least 30 days after the RFP is released. Mr. Meza also distributed an excerpt from the JARC/NF federal circular related to the renewal of existing projects.

#### **G. TxDOT \$5310 Funding Opportunity**

Bob Schwab reported that TxDOT has scheduled a public meeting regarding the current funding opportunity to support transportation services for the elderly and persons with disabilities for August 8, 2012 at 10:00 AM MDT in the TxDOT El Paso District Office at 13301 Gateway Blvd. West in El Paso. More information can be obtained from Armida Sagaribay at 915-790-4234.

#### **IV. Other Business**

##### **A. Lower Rio Grande Valley Development Council – Peer to peer site visit**

Bob Schwab announced that the Lower Rio Grande Development Council was the winner of a peer-to-peer visit contest held at the recent TxDOT Solve conference in Austin and has selected the Far West Texas/El Paso region as the location of their visit citing our regional plan, common demographics, Sun Metro service design, service to colonias, and veterans transportation initiatives as reasons we were selected. Mr. Schwab distributed a copy of draft itinerary for the site-visit beginning August 15<sup>th</sup>. Discussion ensued with Robin Roberts suggesting a reception sponsored by a private firm and Xavier Banales requesting that his presentation be lengthened.

##### **B. U.S. Department of Veterans Affairs, Regional Coordinator – Veterans Transportation Service, invitation and roundtable**

Bob Schwab reported that he contacted and invited Kevin Bergan to attend the August 16<sup>th</sup> Stakeholder meeting to present on the VA's Veterans Transportation Service. Noting that the LRGVDC group would be in attendance as well and had identified veterans transportation as an issue to explore, Mr. Schwab recommended that a Veterans Transportation Forum be held for the afternoon of August 16<sup>th</sup> to discuss the VA's program and how it can best be coordinated with existing transportation programs and Sun Metro's Veterans Transportation and Community Living Initiative One-Call/One-Click project.

##### **C. Let's Talk – Finding Community Solutions to Meeting Client Transportation Needs TxDOT Training**

Ivan Garza reviewed the training opportunities scheduled for August 27-28 in Corpus Christi and August 29-30 in Fort Worth. Mr. Garza stated that Roberto Wallace had contacted Karen Dunlap at TxDOT about the training and noted that teams are encouraged to apply and that TxDOT scholarship money was available to cover travel expenses. Steve Wright added that if a team worked on a project identified in the current workplan, funds in the local Lead Agency budget could be used for travel expenses.

##### **D. Discussion of Stakeholder Committee Oversight Responsibilities & FY 2012 Approved and FY 2013 Proposed Budgets**

[This item was incorporated into item III. B. above]

#### **V. Announcements**

A. Bob Schwab announced that the annual TxDOT Coordinated Call for FY 2014 discretionary rural and small urban funds typically released in June or July each year will be delayed pending study of MAP-21, the federal transportation legislation signed into law by President Obama last week that replaces SAFTEA-LU. A discussion of MAP-21 was tabled for the next Stakeholder meeting.

B. The next Regional Transportation Coordination Stakeholders' meeting is scheduled for August 16, 2012 at 10:00 AM MDT at the El Paso MPO.

#### **VI. Adjournment**

The meeting adjourned without motion at 12:20 PM.