

Improving Transportation for Patients Receiving Dialysis Treatments

> A Report on Findings



January 2014

# **PART I: INTRODUCTION**

#### Introduction to Ride Connection

Ride Connection is a non-profit organization that has been providing transportation for people with disabilities and older adults for over 25 years. Our Mission is to link accessible, responsive transportation with community needs. In coordination with over 30 community partners, Ride Connection provides customer-focused, safe, reliable transportation options for individuals in Clackamas, Multnomah, and Washington counties in Oregon.

In Ride Connection's capacity as a coordinator and provider of transportation, we noted several indications of an existing need to address the difficulties associated with transportation for patients receiving dialysis treatment. First, we heard feedback from our riders from on-going rider surveys and from direct feedback that the current transportation options were not adequately serving the needs of these patients. Secondly, we heard from our transportation partners that the specific needs of patients receiving dialysis made transportation provision more challenging than for most riders. Finally, we were seeing an increase in trip requests for dialysis transportation, which was resulting in a shift in capacity to accommodate the requests. Transportation of patients to and from dialysis appointments presented both a challenge and an opportunity.

The findings of this report contribute to a growing body of literature that holds transportation as serving a function that is much more than merely moving people from point A to point B, but rather consider transportation to be intricately tied with greater quality of life and also for public health outcomes. Indeed, one study funded by the Transportation Research Board of the National Academies has shown that providing non-emergency medical transportation to those who are 'transportation disadvantaged' can significantly reduce emergency room and hospital expenditures, thereby leading to better health outcomes and a higher quality of life for patients, as well as reduced costs of medical services (Hughes, Cromwich et al., 2005). This same report included a cost benefit analysis of medical transportation services for patients with 12 specific conditions and concluded that, in the case of patients requiring kidney dialysis, providing transportation for disadvantaged patients would prove highly cost effective when we consider all of the improvements in the quality of life that result and cost savings that would result Although this report does not include a cost benefit analysis, the findings highlight numerous, additional ways in which the health outcomes of patients are directly and indirectly impacted by barriers or inadequacies in their medical transportation options, thereby suggesting that improved transportation options would not only improve health outcomes, but could potentially reduce overall healthcare costs by reducing medical complications for patients down the road.

# Our Approach to Inclusive Planning

In the summer of 2013, Ride Connection received a grant from the Administration for Community Living to conduct a participatory planning process that would address transportation for patients receiving dialysis treatment. This process set out to engage patients receiving dialysis treatment, caregivers, healthcare providers, and transportation service colleagues directly in information-gathering and problem-solving discussions. Information obtained from an advisory committee, surveys of patients and caregivers, focus groups and engaging the dialysis community in conversation resulted in identifying transportation challenges and informing specific changes that would not only improve the quality of transportation services, but ultimately would improve the health outcomes of patients receiving dialysis treatment.

Inclusive planning is part of the fabric of our organization. Ride Connection's services are all about meeting the transportation needs of each individual by offering a variety of transportation options. From public transit training to grocery shopping shuttles to transportation to medical appointments, our priority is to ensure every person has access to reliable and accessible transportation. While we typically conduct outreach to customers and survey those to improve our services, in this project we wanted a deeper understanding of the challenges faced by customers and to engage them in helping us identify solutions to address these challenges. We wanted to understand how our existing services – and those of other transportation service providers – could help improve our customers' lives.

Our values guide our decisions to ensure that we are not only going forward, but doing so deftly, always moving in our intended direction.

# PART II: KIDNEY DISEASE – BACKGROUND

Transportation can be challenging to coordinate for individuals receiving dialysis because of the unique treatment needs that patients with kidney disease require. This section describes kidney disease, how common it is, who it affects, and the unique transportation network in the Portland metropolitan area that works with patients and care providers to ensure patients are transported to and from their appointments.

#### What is Kidney Disease?

Kidney disease is a condition characterized by the loss of the kidneys' ability to perform life-sustaining functions leading, in some cases, to kidney failure which is a life-threatening condition. The kidneys are responsible for regulating salt and other mineral levels in the body by removing waste products and excess fluid from the blood, and excreting these through producing urine. Kidneys help regulate blood pressure, produce a form of vitamin D that supports bone health, and help regulate blood cell production through this process. In some cases, a patient's kidney can be replaced with a functioning kidney through a transplant. When a transplant is not possible or desired, there are several other ways to treat kidney disease. Most commonly, patients receive **hemodialysis.** This treatment requires the patient to attend dialysis treatment at a clinic approximately 2-3 times a week for a 4 hour period. This requires an access into the patient's blood vessels that doctors create through minor surgery. The patient's veins

are then connected to a dialyzer – a machine that artificially performs the function of the kidney by pumping blood out of the body, cleaning it, and pumping it back in. This treatment requires the patient to attend dialysis treatment at a clinic approximately 2-3 times a week for a 4 hour period.

Other patients receive **peritoneal dialysis**. This treatment can be performed at home or away from home, and does not require as many frequent visits to the dialysis clinic. This treatment requires the insertion of a plastic tube called a catheter into the patient's belly, creating an access to the abdominal cavity. The cavity is then filled with a dialysate fluid, which draws excess fluid and waste products out of the veins and into the dialysate fluid, which is then drained.

A third type of dialysis treatment is known as **home dialysis**, where a dialysis unit is brought into the patient's home, allowing the patient to administer their own dialysis treatment at home, usually with the assistance of a family member or other caregiver.

## Kidney Disease in Oregon and the United States

In 2010, the National Institute of Health identified kidney function as a national priority. Indeed, one in eight Americans have chronic kidney disease, while an additional 20 million Americans are considered to be at risk (National Kidney Foundation, website).

The total population of Americans with kidney failure, or "end-stage renal disease" (ESRD), has increased nearly tenfold since 1980. Some of this increase is attributable to population growth in the US as a whole, but still the prevalence of kidney failure per million people has risen during this same period from less than 300 to over 1800. Figure 1 demonstrates that Oregon's trends are comparable to the US.



Similarly, the number of new incidents of kidney failure reported each year has also risen steadily. Between 1980 and 2010, the number of new incidents of kidney failure reported annually rose from 76 to 365 per million (Figure 2). While Oregon's numbers have not been as drastic, they have continued to rise significantly nevertheless (Figure 2).



## An Aging Population Complicates the Kidney Disease Challenge

The population with kidney failure is not just growing in numbers; it is also getting older. Figure 3 shows that average age of the total population with kidney failure has increased from 49 to 59 over the past three decades. Figure 4 also suggests the proportion of new incidents of kidney failure are occurring more among the population aged 65 and older than the proportion of existing cases of this age.





One reason why the population of dialysis patients is both increasing and aging is simply because the population of the United States as a whole is getting older as the baby-boom generation starts to enter their 60s. Figure 5 shows the change in the population of different age groups as a proportion of the total population since 1980, compared to how these age groups have changed as a portion of the population with kidney disease over that same period. With the aging of the baby boomers, the population aged 45-64 is growing faster than any other group as a proportion of the total US population, and that the proportion of kidney dialysis patients in this age range is growing as well.

However, the aging boomer population can only partially explain why the population with kidney failure is older. Figure 5 also shows that the population aged 65-74 has not changed as a proportion of the total US population since 1980 and yet this age group now constitutes a larger portion of the population with kidney disease than previously. Further the proportion of kidney disease patients over the age of 75 has increased by 11 % since 1980 despite only increasing 2 % as a proportion of the total US population. This suggests that the population of older individuals with kidney disease is increasing at a rate faster than the general aging of the population.



Together, these figures suggest that kidney failure is occurring with greater frequency among the population overall, and that tending to occur later in life. We can therefore expect to see both the prevalence and the incidence of kidney failure continue to increase over the next several decades as the baby boom generation reaches an age when kidney failure occurs with greater frequency. Accordingly, the infrastructural capacity required to treat those with kidney failure - including the number of treatment centers and transportation options – will have to grow and improve to accommodate this growth.

#### **Dialysis Centers in Portland Metro Region**

Currently there are twenty-two dialysis centers in the Portland Metropolitan area. The highest concentration of these clinics is in downtown and in inner-Northeast Portland. In other parts of the region, such as the areas around Tigard and Happy Valley, there appears to be gaps in the geographic distribution of the clinics (Map1). Nineteen of these 22 dialysis centers are owned by two companies – Fresenius and DaVita Healthcare – each of which are large publicly-owned corporations who provide dialysis services for most patients in the region. The Gresham Dialysis Center and the Portland Dialysis Center are the two independently owned clinics in the region. Veterans Affairs is a government-run dialysis clinic.

<u>Map 1:</u>



Table 1: Metro	reaion	dialvsis	clinic s	pecifications

Clinia Nama	# PATIENT STATIONS	IN-CENTER HEMO- DIALYSIS PATIENTS	HOME HEMO- DIALYSIS PATIENTS	NOCTERNAL DIALYSIS PATIENTS	PERITONEAL DIALYSIS
DaVita Hillsboro	13	14	3		
DaVita Lake Road Acutes	21	89	-	20	_
DaVita Meridian Park	14	38	4	-	9
DaVita Northeast Portland Renal Centre	15	94	21	5	4
DaVita Oregon Kidney Center	24	101	-	-	-
DaVita Sherwood	13	19	-	-	-
Davita Walker Road	16	2	-	-	-
DaVita West Linn	13	18	-	-	-
DaVita Willamette Valley Renal Center	10				
Fresenius Maywood Park	21	1	-	-	-
Fresenius Beaverton	25	128	-	-	-
Fresenius Clackamas	24	79	1	-	-
Fresenius Emanuel	5	10	-	-	-
Fresenius Hollywood Kidney Center	20	107	-	27	-
Fresenius Mt. Hood	12	71	-	-	-
Fresenius Raines	13	58	4	-	15
Fresenius Rose Quarter	25	127	-	-	-
Fresenius Tualatin	25	84	-	-	-
Fresenius Twin Oaks	24	74	-	-	-
Gresham Dialysis Center	12	57	-	-	-
Portland Dialysis Center	15	53	-	-	-
Veterans Affairs Medical Center	Not available				

# Transportation Options in Portland Oregon

The Portland Metro Region is made up of one large transit district and three smaller districts and the Portland Street Car.

Public Transportation:

TriMet Portland Street Car

Canby Area Transit (CAT)

Sandy Transit (SAM)

South Clackamas Transportation District (SCTD)

Other transportation resources for older adults and people with disabilities

Ride Connection – Provides transportation service to older adults and people with disabilities. Services include; travel training, door-thru-door to curb-to-curb services and community shuttles.

Transit District's ADA service - Provides transportation service for people who are unable to use buses or MAX due to a disability or disabling health condition.

TriMet Medical Transportation - Provides transportation to covered medical appointments for Oregon health Plan Plus members



Map 2: Treatment Centers with Public Transportation Overlay

Map 3: Ride Connection Service Partner Areas



Improving Transportation for People who Receive Dialysis Treatment

## Health Coverage Options

Transportation coordination for patients who receive dialysis relates to medical coverage of dialysis care because it determines how much of the costs of transportation provision are covered by the patient. Currently, there are three primary sources of medical insurance that provide coverage for kidney patients: Medicare, Medicaid, and private insurance plans. Typically, Americans must be 65 years of age or older in order to receive Medicare; however, since 1973, Medicare has been made available to individuals who have End Stage Renal Disease (ESRD) regardless of their age. Unlike Medicaid, Medicare does not cover the costs of non-emergency medical transportation like that needed by patients to get to treatment. As Figure 6 shows, over one quarter of new patients who receive dialysis in Oregon are covered by Medicare alone and, therefore, their transportation costs are out-of-pocket. Further, as the National Kidney Foundation has noted, "in order to qualify for Medicare ESRD benefits, one must contribute to the Social Security system for 40 guarters. Thus many individuals with kidney failure may not be eligible for Medicare" (National Kidney Foundation, Oct 2010). Consequently, as Figure 6 shows, 7% of patients are not covered by any insurance and thereby must also pay out of pocket for their transportation expenses. It is worth noting that due to current changes related to the Affordable Care Act, it is unknown how coverage for medical transportation will be affected in coming years (Rosenbaum et al., 2009). In addition, 80% of new patients are not eligible for Medicaid and therefore do not have transportation to and from dialysis treatment available through their insurance coverage.



# Figure 6: Medical Coverage for New Dialysis Patients in Oregon

Source: Centers for Medicare & Medicaid Services

# PART III: METHODS OF PARTICIPATORY AND INCLUSIONARY PLANNING AND WHO PARTICPATED

Ride Connection applied for and was awarded grant funds through the Inclusive Coordinated Transportation partnership Project Grant to develop an inclusive participatory planning process that would identify existing challenges related to transportation and how these challenges impacted individual's health. We used this opportunity to focus specifically on those that receive dialysis treatment at clinics and needed transportation. This section describes the methods we used to engage participants and the outcomes of each method.

Using a participatory planning process aligns with our value of providing safe, accessible and personalized services. Developing any protocol change to improve our services for those needing transportation to dialysis treatment had to include the unique knowledge and understanding of patients and their caregivers/healthcare providers in order to be effective. Inclusionary planning means including individuals most impacted by services in the design and delivery of those services for dialysis treatment. Also called "stakeholders" – participants are those who stand to lose or gain from a process – in this case a community of dialysis patients, their caregivers, transportation providers and healthcare providers.

- Participatory processes have several strengths we hoped to realize in this project. Involving individuals in designing or implementing a research or planning project can make the outcomes more relevant (Minkler and Wallerstein, 2003).
- Citizen engagement in planning and research can validate the knowledge and understanding of groups who might otherwise be left on the fringes of these processes.
- It can also result in new relationships and shared understanding among participants which can support outcomes that evolve from the project (Minkler and Wallerstein, 2003).
- Participation is important for encouraging citizens to understand the role and power they have in affecting society (Arnstein, 1969).
- From a health perspective, participating in this planning process could help build capacity among dialysis patients to improve their sense of independence and skills in supporting their own care (Minkler and Wallerstein, 2003).

Each of these aligns with Ride Connection's core organizational values.

We reached out to the individuals receiving dialysis treatment, caregivers, healthcare providers, transportation providers and other community members who were interested in this subject to ensure input from many different perspectives.. We engaged people from multiple agencies and backgrounds in conversations including Portland Kidney Group, Northwest Renal Network, the National Kidney Foundation, dialysis clinics, Ride Connection partners, medical transportation providers and TriMet. Outreach efforts consisted of phone calls, in person meetings, emails and the distribution of recruitment and education materials. All Advisory Committee members were offered transportation

and a financial stipend of \$20 per meeting in honor of their time and contribution. See Appendix A for sample communications.

At each stage of this project, participants helped to identify, document, and explore the transportation challenges for dialysis patients and inform specific changes that would not only improve the quality of transportation services, but ultimately would improve the health outcomes of dialysis patients (see Table 2). Ride Connection engaged the dialysis patient and provider community initially through an Advisory Committee) to develop the research questions and methods to answer them. We involved other members of this community to expand our understanding from the Advisory Committee through surveys and focus groups. Finally, we held a workshop inviting Advisory Committee members, focus group members, others stakeholders in the larger dialysis and transportation provider community to review findings and develop recommendations for next steps. Each of these participation methods and their outcomes are described in this section on the following pages.

Prior to beginning this process, we obtained approval from the Human Subjects Research Review Committee of Portland State University to assure the ethical integrity of our practices. We additionally ensured that every member of our project team acquired training and certification in human subjects' research. The project team included Ride Connection staff members, two research consultants, an intern, and a dialysis care provider who was also a member of the Advisory Committee. We reviewed the literature related to kidney dialysis, End Stage Renal Disease and non-emergency transportation prior to engaging with patients and caregivers in order to ensure that we had an adequate background and understanding of the issues.

Participant Input	Planning Process	Additional Input
Advisory Committee	Define research questions and scope of project	<ul> <li>AC responses by emails with clarifications and suggestions when the project encountered challenges</li> <li>AC member patient provided training on dialysis to project team and RC staff</li> </ul>
<ul> <li>Advisory Committee</li> <li>Focus Groups</li> <li>Interviews</li> <li>Surveys</li> </ul>	Provide information on transportation challenges related to dialysis	<ul> <li>AC member provider supported facilitators for focus groups</li> <li>AC members developed survey questions</li> </ul>
<ul><li>Advisory Committee</li><li>Workshop</li></ul>	Develop Recommendations and Next Steps	<ul> <li>AC members and workshop members willing to participate in next steps</li> </ul>

Table 2: How Participant Input Shaped the Planning Process

# Advisory Committee

We convened an Advisory Committee to guide the project team through the inclusive participatory process including designing the project scope and developing research questions under our large umbrella concern: How do we improve transportation services for individuals receiving dialysis treatment?

Our goal was to have diverse voices representing patients, caregivers and healthcare providers with at least half of the seats occupied by patients. To maximize our outreach, we identified "champions" who were invested in helping to spread the word further and encourage individuals to participate (Wynia & Matiasek, 2006). The project team developed a set of criteria to ensure we were meeting our goals of engaging a diverse group of voices by geography, age, income level, race and ethnicity, and mobility status. We screened those interested in participating to ensure that the conditions of participating were understood. We provided each potential member with a description of their responsibilities and asked each to sign a consent form agreeing to participate to stay within the protocols for professional participatory processes and our human subjects review protocol. The prescreening resulted in a list of candidates that were able and committed to participating, as well as individuals that were interested but wanted to take on a lesser role.

The Advisory Committee was ultimately composed of 5 individuals who were receiving hemodialysis, one caregiver, one transportation provider and 5 healthcare providers, and their participation remained committed and engaged throughout the process. We did encounter some barriers to participation along the way, however. For instance, many patients dialyze on a Mondays-Wednesdays-Fridays schedule and often do not feel well enough to attend the day of dialysis. We also communicated with Advisory Committee members using the telephone and postal mail in addition to email because not all members of the committee had regular access to computers. Advisory Committee meetings were held monthly from August through to November, and covered the following issues:

1<sup>st</sup> Meeting: Communication Agreements and Beginning of the Scope

- Our first meeting was primarily spent collectively establishing communication agreements. The group agreed that in order to create a successful process we needed to create an environment where every voice was heard. Collectively agreeing to the communication processes and defining expectations were critical to the success of the committee. See Appendix B for a description for the elements the group committed to for creating this environment.
- The Advisory Committee members began discussing how to answer the overarching question of "how to improve transportation services for dialysis patients." Advisory Committee members requested information to guide thinking in the next meeting including a map of existing dialysis clinics and a description of existing transportation services and their limitations. One patient also offered to provide Ride Connection staff and project team members with training on Dialysis to ensure they understood some of the topics patients would bring up.

2<sup>nd</sup> Meeting: Discussion of Dialysis Transportation Barriers, Scope Development Continued

- The Advisory Committee members dove into identifying broad themes in transportation changes for dialysis patients based on the experiences of the Advisory Committee. Initial themes they identified included: driver lack of knowledge conditions that affected those who are receiving dialysis treatment, transportation methods and logistics, patient stability following dialysis treatment, clinic scheduling challenges, insurance coverage of ride costs, geographic location of clinics, and timing of transportation and dialysis coordination.
- The Advisory Committee members used the discussion of broad themes to discuss how to find out more information on these themes through focus groups and surveys. The group suggested criteria to select clinics in order to have two sites and ensure different perspectives such as urban & rural, different forms of dialysis, economic diversity, and locations representing the main dialysis in the area would be involved, see the focus group section for more information.

3<sup>rd</sup> Meeting: Focus Group Site Selection and Question Development

 The Advisory Committee members discussed the Project Team's suggestion for which clinics to work with for focus groups and reviewed a first draft of a focus group script and survey questions to ensure they reflected the concerns the Advisory Committee had brought up and would be understandable to other participants.

4<sup>th</sup> Meeting: Review Findings and Develop Recommendations

- The Project Team presented findings from the focus groups and surveys.
- The Advisory Committee responded to RC staff draft recommendations. Advisory Committee members confirmed some recommendations and made suggestions to change or expand others.

The committee provided input into the research methodology to be used through the process, identified priority issues, developed survey questions, assisted with the themes to be discussed at focus groups, selected appropriate locations for the focus groups to be held, helped develop solutions that came from the focus groups and survey results and assisted with anything that was asked of them.

Some of the Advisory Committee members went above and beyond their initial commitment. For example, one Advisory Committee member, who received dialysis treatment, conducted training for transportation providers including Ride Connection staff and the project team describing what it is like to experience end stage renal disease. Another Advisory Committee member who is also a patient hand delivered and helped gather completed surveys from other patients. One Advisory Committee member provided information on kidney disease, and a caregiver Advisory Committee member volunteered to co-facilitate and support the focus groups.

#### Focus Groups

We contracted with two facilitators trained in working with vulnerable populations to facilitate focus groups with those receiving kidney treatment and caregivers.. The project team used the major themes identified in the Advisory Committee meeting to develop focus group questions that would help to expand our understanding of the barriers to transportation services for dialysis patients.

We used similar outreach methods to recruit focus group members. We relied on clinic staff to recruit and encountered similar challenges as with the Advisory Committee to engage patients. Additionally, caregivers did not respond to outreach. One patient who could not attend a focus group was interviewed one-on-one. We developed criteria from the Advisory Committee meetings and screened potential participants to ensure that a range of diverse voices and experiences with dialysis transportation would be represented in the process. We asked patients to fill out basic demographic information to help us understand more about their demographics.

We held two focus groups attended by eight patients and two caregivers, who described their personal experiences related to their challenges with transportation to and from dialysis care.

- The majority of patients were receiving Medicare (78%), with nearly one quarter (22%) on Medicaid and nearly half (42%) reporting supplemental insurance.
- Patients dialyzed at several clinics in the area including: Lake Road (suburban), Beaverton (suburban), Clackamas (suburban), and Irving (urban).
- Half of participants listed themselves as living in an urban area about one third considered themselves living in a suburban area, and some did not answer (8%).
- The most common shift they dialyze on is three times a week in the morning.
- Half of respondents were low-income earning less than \$15,600 annually, 42% did not answer and one individual's household income was over \$40,000 annually.
- Two-thirds of the participants were female.
- Three-quarters of the participants (76%) identified as white, 8% identified as African American, and 16% identified with other ethnic origins.

At the end of each focus group, the project team members and facilitators conducted a de-briefing of what they heard. The two facilitators analyzed the focus group notes independently to identify overarching themes. The two met with a third facilitator to discuss commonalities and differences (Armstrong et al, 1997). The two facilitators were in agreement regarding the general themes, however each person emphasized different elements or drew unique nuanced understanding from particular themes. The project team matched the focus group findings with the original themes identified in the Advisory Committee and used the two to develop recommendations.

#### Patient and Caregiver/Healthcare Provider Surveys

Two separate surveys were conducted – a survey of dialysis patients, and a survey of caregivers. The caregiver survey was an online survey that was distributed via clinics, advocacy networks, and transportation providers. A total of 26 caregivers/healthcare providers and 83 patients responded. These caregivers had been involved in the field of dialysis care between one and 30 years.



Figure 7: Caregiver/Healthcare Provider Survey Respondents

The patient survey was conducted both online and in paper format. Paper versions of the survey were distributed to clinics throughout the Portland Tri-county region. Eighty three patients responded to the survey. Approximately 59% of the respondents were male. Over 85% of respondents were 45 years old or older, and nearly half were between 45 and 65 years of age (Figure 8). 42% of respondents reported using a mobility device. One-third of patients who responded indicated that they earned less than \$10,000 per year, and two-thirds earned less than \$20,000 (Figure 9).

#### Figure 8: Modes of Transportation used by Patient Survey Respondents



Q2 Which of the following transportation options do you use to get to or from dialysis?

# Figure 8A: Age Range of Patient Survey Respondents



# Q17 What is your age range?

#### Figure 9: Approximate Annual Income of Patient Survey Respondents



#### Q16 What is your annual approximate income?

Survey results show that patients regularly face a wide range of issues related to their transportation needs. These issues are each addressed in greater detail in the Thematic Findings section below, however it is worth noting that many of these issues are encountered less often by patients who regularly drive themselves to and from the

dialysis clinic, as evident in Figure 10. Of course, patients who drive to and from dialysis face other challenges and complications; for instance, patients often do not feel well following their treatments and may be jeopardizing their safety by driving themselves home. However, as we discuss the primary challenges and complications throughout this report, we have chosen to primarily focus on the issues being faced by those patients who are not driving themselves. When we refer to non-driving patients throughout this report, this is the population that we are referring to.



#### Figure 10: Frequency of Transportation Related Problems Encountered over a 3 Month Period (September – November, 2013)

We designed this multi-pronged participatory approach to ensure a diversity of voices was heard at each step of the process. The Advisory Committee played a critical role in sharing their experiences to develop preliminary factors on transportation challenges for dialysis patients. The focus groups expanded on that base and the surveys effectively confirmed some of the experiences shared in the Advisory Committee and focus group discussions.

missing my ride catch my ride home trouble in the vehicle

I had to leave the I was rushed to catch My transportation I was sent from the I was left waiting at

because I was

bleeding or had

another medical complication

a result, I had

(bleeding, fainting,

etc.)

unwilling to take me and had difficulty

provider was clinic to the hospital the clinic without a

coordinating my

ride home

I shortened my

appointment was shortened because I treatment because I clinic before I was my ride home and as

was late for my was worried about ready in order to

home

My treatment was

appointment

The process was unlike any inclusive planning project that Ride Connection has previously undertaken. The level of commitment, the importance of this issue, the devotion and expertise in the Advisory Committee and level of engagement encouraged and motivated us to go beyond our thinking about only our internal protocols. The project team brought up the content of this project in regular staff meetings, encouraged staff to attend the patient-delivered training on dialysis, and we have embedded these efforts into our organization even before the project reached the recommendations

5%

0%

I missed a dialvsis

appointment

find a ride

I missed a dialysis

appointment

because I could not because my ride was cancelled because I

show up

cancelled or did not was late for my

My dialysis

appointment

stage. Staff played a large role in thinking through the findings to develop draft recommendations for feedback from the Advisory Committee – a key indication of how Ride Connection used information every step of the process.

Prior to the announcement of the Administration for Community Living inclusive planning grant, we were working with community representatives, public health agencies, and hospitals to study and plan for improvements to medical transportation. This project has reinforced our desire to remain engaged in these efforts and build on them, as described further in the Recommendations section, below.

This project is limited in scope and scale: we could not ensure we gathered every possible experience related to transportation challenges on dialysis and we did not survey a statistically representative sample of dialysis patients. Therefore, these findings should only be used to guide Ride Connection and partner practices, not used to draw conclusions about all dialysis patient experiences in the tri-county region or in Oregon.

# PART IV: THEMATIC FINDINGS

Each stage of the participatory process revealed different – and similar – issues related to transportation barriers for dialysis patients. Issues that originally came up with the advisory group were reiterated in the focus groups and confirmed during the patient and caregiver survey process. The project team grouped themes as "major" if they came up repeatedly by multiple individuals in both focus groups and the Advisory Committee or when more than one person heavily emphasized themes as a priority. The project team designated themes as "minor" if the issue came up less frequently by fewer individuals or were not as strongly emphasized. The limitation to this method is that a different composition of participants could have emphasized different things. However, triangulation of our evidence across our sources - the Advisory Committee, the two focus groups and the two surveys – ensures confidence that these are issues that matter. Seven major theme areas and 5 minor themes emerged as shown in Table 3.

MAJOR Themes	Advisory group	Focus group	Patient survey	Caregiver survey
Flexibility and dependability	1	1	1	1
Waiting and indirect routes	1	1	1	1
Missed rides home	1	1	1	
Late rides affect dialysis treatment and health conditions	1	1	1	1
Affordability		1	1	
Geography and clinic choice	✓	1		
Drivers/dispatchers	1	1	1	1
MINOR Themes				
Nocturnal Shift or Peritoneal Treatments Are Ideal – and Patients May Not Be Able to Do Them	1	1		
Dialysis Patients Value Independence		1	1	
Dialysis Patients May Also Be Isolated		1		
Clinic Staff	✓			

Table 3: Major and minor themes and planning method where discussed

Each of the following sub-sections describes a main theme and provides quotes from the focus groups and relevant quantitative findings from the surveys.

# 1. Major Theme: Patient Need For Flexibility And Dependability In Dialysis Treatment Transportation

Discussions with Advisory Committee members and the results of focus groups and surveys each corroborate the importance of ensuring affordable access to different transportation options that are both dependable, and flexible enough to meet patient needs. As one patient noted in a focus group, "(the) ideal would be have them pick me up on time, get me there on time, and pick me back up and get me home without sitting around for 2 hours waiting for them, same day service, without calling my rides on Friday... We got other things to worry about instead of worrying about how to get dialysis and get back home." Among the surveyed participants, 42% of the patients who did not primarily drive themselves to the clinic indicated that thinking about their transportation was a source of stress in their lives (Figure 13).

In focus groups, patients emphasized how greatly they depend on their transportation – and especially affordable transportation – as a critical healthcare need. Multiple participants in the focus groups expressed that they are not able to get to their treatment on their own either because they live too far away from their clinic to walk home on their own, or because they have mobility restrictions due to health conditions or mobility concerns. As one patient remarked, "From where I live, [there is] no way to walk to or from dialysis and I've fallen a few times."

Further, patients' needs often vary day to day in relation to their health. Some days, patients require unanticipated procedures and care - when transportation is inflexible and scheduled rides cannot be easily changed to fit patient's changing needs, this can create barriers to accessible and reliant transportation.

One way of addressing patient need for flexibility is by ensuring that diverse transportation options are available for patients. Results from our patient survey indicated that there are, indeed, many different modes of transportation currently being used by patients to and from their dialysis treatment. Our survey provided 9 different transportation options and demonstrated that patients use all of them (Figure 11). Approximately 30% of patients indicated that they drive themselves, with one-quarter indicating that driving themselves was the most frequent transportation option that they used. Thirty percent of respondents also indicated that they use TriMet Lift services – the public paratransit service of the Portland Metro region. The next most frequently indicated option was being driven by a friend or family member (23%). Less than 4% of patients walked to dialysis.





Still, despite the many transportation options that exist, not all of these options are available and accessible to all patients. In fact, survey respondents were asked to indicate every form of transportation that they use to get to and from dialysis treatment and nearly two-thirds of respondents only reported using one form of transportation (Figure 12). Further, nearly half (45%) of non-drivers indicated that they do not have a reliable transportation backup in the case that their primary mode of transportation fails through. Of the non-drivers, 19% responded negatively when asked if their transportation provider is patient and flexible (Figure 13). Additionally, 17% of non-driving patients surveyed indicated that they have missed an appointment at least once in the past three-month period because they could not find a ride, while 25% missed an appointment because their ride was delayed or cancelled. Each of these figures provides evidence that despite the many possible transportation options, these options are not equally accessible and, consequently, the transportation of some patients remains tenuous.

Caregivers who completed our survey also indicated that transportation flexibility remains a problem. As one caregiver noted:

[Transportation] service should be based on the individual care needs of each patient, and not the scheduling needs and/or financial gain for the transportation company. Each entity should have designated individuals who work collaboratively on an ongoing basis to design ride schedules which have to be flexible and include allowances for movement of times based on patient needs.

Another caregiver who took the survey noted that "Reliability and flexibility is a big issue-if just a few minutes late, a lot of transporters refuse to wait."

Information gathered from Workshop participants indicates that there may be confusion related to the "5 minute window" and how it is understood and implemented consistently. Regardless, the effect is an impression by patients and caregivers of inflexibility in the system.





# 2. Major Theme: Patients Experience Waiting And Indirect Routes In Transportation To And From Dialysis

A second major theme to emerge was patient frustration related to having to wait for a long time in being transported to or from a clinic. . Indeed, 27% of non-driving patients noted that they had been stuck at the clinic without a ride home at least once during the previous three-month period (Figure 10). In a focus group session, one patient stated, "what I don't like [is to] have to sit around from 9:30 until 11 waiting for them to pick me up and I only live 5 minutes from dialysis from my house. It's ridiculous."

Patients also indicated that they wait long periods of time during the ride home. Of the non-driving patients, 12% disagreed when asked if their transportation provider "gets me to dialysis in a reasonable amount of time (Figure 13). In a focus group session, one patient noted that "Last year I spent 2.5 hours on LIFT [a TriMet ADA service], they passed my house, then we went downtown, then to Hillsboro or Beaverton and then home." Another noted, "they pass your house multiple time [in drop off]."

The project team attributes some of this waiting time to rides being shared with other eligible rides on the same vehicle. Multiple participants complained about the lack of

prioritization of riders who weren't feeling well. In our caregiver/healthcare provider survey, one of the respondents emphasized the importance of ensuring efficient transportation, especially upon returning from dialysis, noting that "patients are tired after dialysis, so less able to tolerate a long ride, which is a built-in feature of the Tri-Met system." Regardless of the reason, we heard that when rides take a long time getting patients home, this can adversely affect the rest of a patient's day and can potentially lead to negative health impacts by disrupting regular sleeping and eating cycles, which are of particular importance to those patients who suffer from the two most common causes of kidney disease - diabetes and hypertension. As one patient explained, "when I'm late, my lunch isn't at noon, it's at 2pm, then dinner is supposed to be at 5, then have to move it back, being a diabetic then shots and other things at the wrong times, [my blood sugar] it's too low"; and another, "if I have to wait, my sugar goes up so that stresses me." A respondent to the caregiver/healthcare provider affirmed this assessment: "They feel terrible after their treatment and are forced to wait an excessive amount of time (often greater than 4 hours) before another ride will pick them up. They miss meds, meals, and needed recuperative (rest) time."

Research shows that the mental and physical health of dialysis patients can be improved, and that mortality rates are reduced, when transportation distances are lessened (Diamant et al, 2010; Moist et al, 2008, Tonelli et al, 2007).

# 3. Major Theme: Missed Rides Home

The third issue that arose from our investigation was patients missing rides and finding themselves stranded at the clinic with no ride home. At least two focus group participants explained that they had been stranded late at night without a means of returning home other than walking or riding home in their wheelchairs. Others reported that, even though their health requires them to use a door-to-door service, they have had to take the fixed bus route when they missed a ride and had no other options – a choice that not only causes more inconvenience, but which can also cause more physical health complications. Several participants noted feeling unsafe if they miss a ride and are stranded or have to wait until the next available transportation option. As one focus group member recounted, "If I forget to call in my ride {within} 24 hours, my only way is to drive my power chair all the way to the dialysis – about 20 blocks. I live on [address] and it's on [address] scary when [I] have glaucoma and can't see."

The Project Team attributes missed rides to several factors and scenarios. One factor is the variability and unpredictability of treatment end times. Many patients share the impression that TriMet will only wait 5 minutes past the scheduled pick-up time before leaving, and so when their treatment goes longer than expected or scheduled, that they will be left without a ride. One patient who participated in a focus group described this scenario, stating: "I worry about when [I] start late, if I'm off too late for them then they'll take off and leave me, the only way I can get home then is with a scooter and if I forget to charge my battery [then I] don't have enough charge to get home."

Another scenario occurs when patients complete their treatment, but do not have enough time to stabilize after treatment and therefore are still bleeding from their access site when they leave the clinic. Drivers are not permitted to transport them. Indeed, our survey confirmed that 13% of non-driving patients had experienced this scenario at least once during the three-month period prior to our study. One patient that, "I always have a problem, my arm always bleeds after dialysis and have to wait - they [drivers] don't want to wait. [It] happens once a week."

Information gathered in focus groups and surveys indicate that there is some confusion with patients about being stranded at clinics. Wait times for rides that must be called in (i.e. will call rides) can be significant. Patients do not have the stamina to wait for long periods of time to be transported home. All transportation providers in the region guarantee rides home but do recognize that will call return rides can mean a long wait time for rides.

# 4. Major Theme: Late Rides Affecting Dialysis Treatment And Health Outcomes

When a patient arrives late for dialysis treatment, even when it's for reasons beyond their control, healthcare providers may be able to accommodate that lateness in certain regards, but not in others. Of the non-driving patients who were surveyed, 16% indicated that their clinic would not accommodate them if they arrived late. Lost time on dialysis treatment at the beginning of an appointment may not mean more time to make up for this at the end of the appointment. Based on input from the Advisory Committee and focus group participants, what often happens is that lateness in getting to the clinic results in less time on the dialysis machine. As one of the respondents stated in the caregiver/healthcare provider survey, "There are no good options if the patient is not ready to go home exactly when scheduled. Frequently something happens and the solution is to cut treatment time which adversely affects patient health." The reduction in treatment time is not always a decision taken by the clinic - often times the patient themselves decide to cut their treatment short out of fear of missing their return ride. As another caretaker notes, "They most often shorten their treatment time because they know they won't be able to get a return ride that would allow them to receive their full treatment."

Regardless as to whether the patient decides to shorten dialysis time, it appears that lost treatment time due to lateness occurs frequently – 33% of non-driving patients had shortened treatment due to being late at least once over the 3-month period prior to our study, while 9% reported having had an appointment cancelled during this time as a result of arriving late. As noted by the respondent above, less dialysis time results in negative health consequences for patients. For example, when dialysis is shortened, the patient may not have reached their 'dry weight' (their weight when excess fluids have been removed), which results in more toxin and fluid build up in the body, and means that the patient cannot eat or drink as much between dialysis treatments – which can affect nutrition and sugar levels. Another potential impact of late arrivals that based on feedback from the Advisory Committee is that delays can result in rushed clinic technicians readying the machines, which creates a greater likelihood of errors being made in treatments.

In addition to shaving time off treatment, a late arrival can also result in a reduction in stabilization time following treatment, often in order to ensure that they can catch their

ride home. When a patient finishes a dialysis treatment, their blood pressure is low and they can feel fatigued and experience muscle weakness – a condition that some referred to as "dialysis drunkenness." Patients are generally given time to stabilize prior to leaving the clinic, however when the patient's stabilization time is cut in order to catch a ride home, they may leave the clinic with low blood pressure which can result in the patient fainting, or the patient could have difficulty clotting which can result in bleeding. Again, this scenario seems to occur relatively frequently, with nearly one in four (23%) of non-drivers reported having to leave the clinic before they were ready at least once during the past three month period prior to our study, and 17% reported trouble in the vehicle related to being rushed to catch their ride. One respondent to the caregiver/healthcare provider survey described this scenario, stating, that:

Sometimes patients need extra time to stabilize after treatments. It can be difficult to maintain a schedule when you provide service to dialysis patients. Patients can also have medical issues on the way home from treatment, this can become very frightening for the drivers and also may cause a potentially dangerous situation for the driver or other passengers.

Some patients reported that, in order to ensure that they arrive on time and to avoid the consequences of being late, patients will schedule rides for earlier than they actually need to be picked up to create a "cushion". This strategy shows some creative adaptation to the inadequacy of the transportation and health coordination systems. However in this case the patient still has to choose between the possibility of a longer wait if they arrive early or the possibility that their health could be compromised if they arrive late.

Patients who participated in a focus group explained how late arrivals compound with other issues discussed above to ultimately result in a stressful scenario for the patients:

"If [I] arrive late, then the techs can't hook us up until later so can't take us off until later and if you've scheduled a ride with TriMet at 10 and they can't reschedule then, "we're leaving you." I've had them leave me before, they [the clinic] have to make sure that your blood pressure is up and not too low, and if it's too low then [you] have to sit there and drink chicken soup before [you] can get up and leave the building, if you're 5 minutes late then they [the driver] gotta leave."

"I feel frustrated or angry because can't do anything to change it. Dialysis is very stressful anyway, hard time dealing on a daily basis, if ride not there or shows up late, not fair to us, we may have to wait even longer, at time when extremely weak."

"I worry about when [I] start late, if I'm off too late for them then they'll take off and leave me, the only way I can get home then is with scooter and if I forget to charge my battery I don't have enough charge to get home."

"It makes me mad. I tell the nurses and techs. If we aren't off by a certain time, we only have 5 minutes to wait for Trimet or it counts against us. I tell the clinic

to call TriMet if I need more time. You only get 3 missed rides. Sometimes my blood pressure is too low."

Research indicates that patients that shorten treatment pose a significant risk to mortality and hospitalization.

"Although several factors (for example, the dialysis prescription and access choice) can affect the delivered dose of dialysis, patient behavior also plays an important role. Patients who shorten or skip their treatments are reducing their time on dialysis, and, by definition, the amount of dialysis they receive. <u>There is no question that shortening and skipping poses a significant problem.</u> About 20% of patients shorten treatments and about 6% skip treatments (Gordon, NNJ, 4/03). Data from the Dialysis Outcomes and Practice Patterns Study (DOPPS) demonstrated that skipping one treatment per month is associated with a 30% greater risk of mortality and a 13% greater risk of hospitalization. Shortening treatments, even by 10 minutes a month, was also associated with increased risks." (In Control A Medical Education Institute/Life Options Publication Vol1 No 3 9/04)

# 5. Major Theme: Patients Are Concerned With Transportation Affordability and Cost

As noted above, the majority of patients that we surveyed are low-income, with onethird earning less than \$10,000 per year and two-thirds earning less than \$20,000. Further, more than 1 in 3 (37%) of survey respondents reported having dependents that they have to support on these low incomes. Any cost that patients must incur for medical transportation can act as a significant burden if not a barrier to their medical care, and over half of the patients who responded to our survey indicated that they have to pay out-of-pocket expenses for their medical transportation.

The necessity for affordable transportation options was emphasized in focus groups. In some cases, focus group participants indicated that they must chose between paying for transportation to and from dialysis and other basic necessities such as food or rent. Patients were also concerned that the cost of transportation is rising rather than becoming more affordable. One patient commented that, "When [I] moved here, it was \$56, [the] next year [it] jumped up, now it's \$72, next year it will be \$84, then more later.... My friend pays \$100 a monthly fee and she's not disabled. [I'm] struggling to pay \$72, and [I'm on] Social Security and disability every month." Another patient added, "when they raise (the price) and I can't afford it that scares me, I don't have more income coming up, I don't have that kind of money."

One patient explained that due to the lack of synchronicity between their Social Security income and the monthly bus passes, she is left having to pay out of pocket for two/three days a month – an economic burden that she cannot afford. She has to choose between borrowing money from her daughter for a day pass or skipping treatment.

## 6. Major Theme: Disconnect between Resident Geography and Clinic Choice

Several patients described receiving dialysis treatment very far (across town or in another township) from their homes. This locational mismatch between home and care results in transportation providers having to crisscross town following indirect or inefficient routes, and contributes to the delays and waiting that patients experience in the transportation system.

Multiple patients said they have to wait as a rider a long time while drivers drop off people across town even if their home is located near the clinic. Several patients in both groups agreed that they would not mind sharing a ride with individuals in their neighborhood, especially if it limited the necessity of having to drive back and forth across town, which lengths the amount of time spent in travel before arriving at their home. As noted above, some of this back and forth and across-town transportation is attributed to some transportation providers not granting priority for drop-off to those with medical conditions.

Further, some patients also appear to be under the impression that they have no choice as to where they receive dialysis care, or are fearful of requesting a transfer. One focus participant noted, "[if miss a ride] I freak out, can't afford to call a cab, they're very expensive, my dialysis is Milwaukie I'm in Kaiser Permanente and they assigned me, that's a frightening thought for me, I don't have a family here, I live in near the Lloyd center [its] very convenient here, but if go outside of that I'm very fearful." This impression may reflect a lack of information however, as one advisory committee member and caregiver informed us that patients are able to choose their clinic. Other barriers to transferring clinics that were mentioned included uncertainty about whether certain medical insurance plans were available at all clinics, and the difficulty of transferring patient files.

Regardless, when focus group facilitators inquired about switching clinics in order to be closer to home, this was met with some hesitation by patients. Although many new patients may want the option of receiving care close to home, for patients who are more established at a specific clinic, the stress and burden of switching locations can be considerable. As one focus group patient noted, "I could move but then have to make new friends and relationships." Multiple focus group members discussed feeling comfortable and confident with the support staff at their current clinics. In other cases, when options of receiving treatment closer to home are not available, patients may opt to change the location where they live; one focus group participant made reference to a patient who had to sell his house in order to live closer to where he was receiving treatment.

#### 7. Major Theme: Patients Describe Challenges With Drivers And Dispatch

In focus groups, patients noted that they appreciate when drivers are considerate and treat them "like a regular person." However, several patients in both groups suggested that drivers and transportation systems are not compassionate with patients: "operators have good or bad personalities. Sometimes their personalities come off that patients

need them, 'you depend on us not we depend on you,' condescending, 'we'll get to you when we can when it's convenient for us as drivers.' or 'come on let's go, I got things to do'." Focus group patients also noted that they felt disempowered when drivers would not listen to their knowledge, such as how to get to the proper place to pick someone up. Another issue that was raised was a feeling that drivers lack knowledge about dialysis, however only 10% of non-driving patients felt that their transportation provider did not understand their needs. Patients also questioned whether a First Aid kit was kept on board in case of bleeding, whether it is mandatory for drivers to be trained in Frist Aid and CPR. Still, patients expressed an understanding that drivers would like to make accommodations for the needs of dialysis patients, but that rules and protocols do not allow that. For example, one focus group participant remarked that "The drivers know, if they had their way if had any control over it, would like to take dialysis patients home first and let shoppers/others wait, but they can't."

# 8. Minor Themes

Several additional themes were brought up during the course of our research that we considered 'minor themes' either because they were either not raised as frequently, or were not as strongly tied to the central research questions.

# i.) Dialysis Patients Value Independence

Several participants in both focus groups rely on their social networks including family and friends for rides. While this is convenient for them, several expressed not liking having to depend on others and suggested they feel some level of guilt about potentially burdening their social networks. Only 10% of surveyed patients reported relying on a friend or family member as their primary mode of transport. As one focus group participant noted, "its frustrating to depend on another service, frustrated because they are late, cancel things late, get angry about it."

Another patient noted, 'My husband, don't like to because can't put electric wheelchair in the car, when have to use a regular wheelchair and it's a pain in the butt have to depend on him to push me everywhere we go."

# ii) Dialysis Patients May Also Be Isolated

The flipside of patients not wanting to burden their family and social networks is a feeling of isolation and not having people available to support them. One participant mentioned being alienated for neighbors and friends. Focus group participants in one session discussed who lived where among the group to see if there was any potential for socializing such as through group shopping close to home. Given the relative stress related to dialysis care, having social networks of fellow patients could potentially be beneficial to client emotional stability.

#### iii) Nocturnal Shift or Peritoneal Treatments Are Ideal, but not Available to all Patients

Peritoneal or home dialysis methods may be preferred options by patients in relation to independence. The individuals attending the focus groups indicated that the level of "capability" required for this option was higher than it is with in-center dialysis treatment. Barriers inhibit some patients from receiving peritoneal or home treatments. Some

noted that peritoneal and home dialysis patients must be more self-reliant and able to take care of themselves better. It was also discussed in one of the focus groups that the payment reimbursement system was not set up to allow for caregiver support for peritoneal treatment. In the words of one participant, "you have to be able to do it yourself with your own eyes if you have peritoneal." Some patients also acknowledged that nocturnal dialysis would be a preferred option, but that a lack of transportation options at night posed a barrier. At least one study indicates that self-care treatments increase patient autonomy and sense of control (Meers et al, 1996).

#### iv) Healthcare Providers

In focus groups, several issues were raised related to clinic staff. One participant expressed an impression that late arrivals can lead to clinic techs rushing and chaos described earlier. Another participant described people standing outside on the curb waiting for rides that clinic staff may be unaware of:

Elderly people that don't talk and absolutely they can't move or look or talk nothing, sit there waiting for bus, they've missed it, no one paying attention, could just be sitting there. Because I'm a talker I talk with them in the waiting room, let the ladies at the front desk, they wouldn't say a word to say missed bus, or maybe not the mind to know missed their bus, more people watching out for others would be nice. People don't' get involved about people, they have their life, and just sit there.

Focus group participants also noted that patients often ask clinic staff to call their transportation provider in order to cancel or reschedule rides, and that the staff's response to this request varies. In some cases staff respond, but patients note that in other instances staff are distracted by other urgent issues and forget. This is an issue because patients are concerned that if they call to cancel a ride, it counts against them and they could lose their subscription service. Subscription service is a term used to describe ride requests that are called in to the service in advance for reoccurring rides.

#### Interpretation of Themes

In presenting findings to Ride Connection staff and the Advisory Committee, the project team and participants developed several general conclusions as a basis for developing recommendations.

First, education and increased awareness is needed for every major player in the coordinated system: for example patients, drivers, clinicians, social workers and hospital discharge planners. This can ensure everyone who works to coordinate care and transportation for dialysis patients has the same information about what is possible and the potential consequences of situations such as delays or missed rides. For example, patients would benefit from knowing the options they have in terms of selecting a dialysis clinic closer to their home, drivers would benefit from understanding more about what to do if a patient begins to bleed after being picked up, and hospital discharge individuals could benefit from knowing different transportation options available to patients. This type of information can be empowering for patients who are able to self-advocate and can lead to reductions in stress from delays or missed rides.

Second, while there is already a degree of coordination of transportation with dialysis care, there may be innovations that transportation providers and clinics could pilot to reduce delays affecting patient dialysis and health outcomes. For example, the disconnect between clinic location and patient home likely contributes to delays and closing this distance either by clinic choice or by ride delivery could improve patient's ability to stay on time for appointments and the rest of their daily activities.

Third, transportation providers such as Ride Connection can revisit their existing protocols to find ways to help address dialysis patient transportation challenges. Some protocols such as training and awareness-raising is covered in the conclusions above.

Finally, engagement with other stakeholders such as clinic administrators is important for identifying future solutions. While this process emphasized hearing from patients, the project team recognized that hearing more of how dialysis clinics are able to meet their patient's needs would be helpful.

# PART V: RECOMMENDATIONS AND OUTCOMES

# **Recommendation Development**

The project team presented Ride Connection staff with the findings and asked them to develop workable solutions to the challenges that had emerged through the participatory process. The project team presented these initial solutions to the AC and asked them to further develop and refine the solutions. The project team used information from the AC meeting to revise the draft recommendations before holding a public Workshop inviting the larger transportation and dialysis community.

Nineteen stakeholders participated in a public workshop to further vet the list of solutions and prioritize solutions that would most benefit patients. Stakeholders included patients from both focus groups, caregivers, care providers, Advisory Committee Members, transportation providers, drivers, NEMT Administration and a Coordinated Care representative. The project team used information from the Workshop to refine the recommendations.

The following recommendations address patient concerns identified in the major and minor themes described in the previous section. The three categories of solutions are:

Ride Connection protocol changes Education, advocacy, recruitment and outreach Transportation pilot project – new programs and collaborations

# **Ride Connection Operational Protocols**

- Fact sheets
  - For RC customers on dialysis: explains what Ride Connection can and cannot do as a transportation provider – sets expectations
  - For RC drivers: explains dialysis patients' rights and responsibilities
- Increase return trip flexibility
  - Talk to partners about flexibility parameters and inform patients and clinics. Identify funds for a backup option.
- Guaranteed return trip
  - If RC has scheduled a return ride for a customer, they will get it, even if they are late. Inform customers.
- Allow will-call return
  - Set standards for flexibility of will call
- Re-evaluate no show/late cancel policy
  - Policy should take into consideration health conditions or emergency situations
  - Provide TriMet with information about our updated policy and suggest changes be made universally

- Improve scheduling protocol
  - Ensure condition of riders is considered when scheduling each ride
- Clearly define and prioritize 'life-sustaining' trips
  - Currently includes dialysis, radiation and chemo therapy
- Expand service hours
  - Analyze cost needed to support early morning ride requests
- Increase training options for RC drivers who transport dialysis patients.

Outreach, Advocacy, Recruitment and Education

- Create an open dialogue campaign about the needs of dialysis patients. Engage:
  - Network Partners
  - All Transportation stakeholders in the area
    - i.e. TriMet, Committee on Accessible Transportation
  - Veterans Administration
  - Dialysis clinics (management)
  - Coordinated Care Organizations
  - New Health Innovators
- Enhance other driver training programs
  - Incorporate key components of training into DMAP driver training
  - Offer this to TriMet LIFT drivers
- Develop training for dialysis support staff:
  - o RC Travel Navigators, Travel Coach and Travel Trainers
  - RC all-Staff, network partner staff
  - DMAP (medical transportation) staff
  - TriMet Staff
  - o 211, ADRC and Helpline staff
- Develop transportation options fact sheet that includes level of service, eligibility and cost for clinics/social workers/nurses/hospital discharge staff and patients
  - Should include specifics by program (i.e. MTP 5 minutes window can be extended for medical reasons)
- Volunteer recruitment

- Recruit a pool of drivers who are using their own vehicle and those able to provide one-way rides to dialysis
- Publish a education/position paper
  - Promising practice recommendation for dialysis transportation
- New patient support
  - Work with physician offices/clinics/discharge staff when patients are newly diagnosed. Travel Coaches could meet with patients and explain options available and assist in registration.
- Patient advocacy trainings
  - For patients and drivers so they know patient rights and can advocate for them
- Find an advocacy group to tackle the bigger picture.
  - Portland kidney group only local support group
  - Align with other support groups (i.e. diabetes, hypertension, neuropathy)
- Address monthly TriMet LIFT pass versus 30 day or other options
- Slow SAT (Specially Assisted Transportation) permit process for cabs
  - Work with the City of Portland to advocate for new process for cab drivers to become certified
- CCO coordination of transportation could produce new rules or changes to protocol for Medicaid eligible riders

#### New Program and Collaborations - Transportation Pilot Project

- RC Pilot Project focused on: reliability, affordability, friendless and <u>flexibility</u>.
   Focused on one location
  - Choose a dialysis clinic that would be willing to take part
  - Include Ride Connection, TriMet LIFT and TriMet Non-emergency transportation program
  - RC, TriMet and clinic work together to better serve patients to potentially include:
    - group rides by neighborhood for the go trips (shared rides).
    - Ensure rides are flexible for the return ride.
  - OTREC (OR Transportation Research and Education Consortium) could evaluate pre and post pilot
  - Find funds for cab ride home as back up and same day ride requests (additional funds will be requested through state formula process)
  - Coordinate services between providers
  - Coordinate rides by area

- Look for opportunities to turn some group dialysis trips into regularly scheduled routes directed from certain neighborhoods to clinics
- Look at all transportation providers as part of a single network
- Enhance same day communication changes can social workers at dialysis clinics email transportation provider of changes.

### Recommendation implementation

The project team presented the Ride Connection Board with the findings and solutions who supported moving them forward.

The project team also shared the findings with Ride Connection's network of partners to vet the list and to identify what solutions were best for patients and were most feasible.

Ride Connection protocols that have been immediately

- 1. No-show/late cancel policy : Medical condition is taken into consideration when no show/late cancel is counted.
- 2. Guaranteed return trip: no rider will be left at a clinic
- 3. Driver training: Enhance to include more in-depth information about conditions that affect dialysis patients
- 4. Education: Developed fact sheets for riders, drivers, and clinics that outline service expectations and dialysis patients' rights and responsibilities
- 5. Scheduling protocol: Condition of rider must be considered when scheduling each ride, especially when rides will be shared

Ride Connection plans to address the issues identified in our research by advocating for broader change in the transportation system as a whole. With the continued direction from our advisory committee and the support of others from the dialysis community, we intend to develop tools for dialysis education, outreach, advocacy, and volunteer recruitment. We will continue to utilize the methods learned in this process to truly engage dialysis patients and caregivers in <u>all</u> aspects of the implementation process. Our intension is to also partner with clinics and other transportation partners to create a pilot project that would guarantee flexible, reliable, and affordable rides to dialysis. We have applied for grant funding to support the continued inclusive process and for operations of the pilot project. Our goals moving forward will be:

- To improve dialysis transportation for patients with End State Renal Disease.
- To create a pilot that can be replicated.
- To create a model for inclusionary planning.

We intend to meet these goals in the following way:

## Education, Outreach, Advocacy, Recruitment and Implementation

We intend to contract with two patients from our advisory committee who have been involved in this project from the beginning. These patients will help us: design educational and outreach materials related to best practices in transportation for dialysis patients that can be shared with other transportation providers in our region to encourage broader system-wide protocol changes; assist in developing a volunteer driver program specific to creating flexible transportation options; assist in outreach and advocacy related to the implementation of the transportation pilot project, and engage additional stakeholders to support the cause. We will also explore the possibility of creating a new patient support advocate that can guide a newly diagnosed patient through the myriad of steps needed to be accomplished, including transportation planning.

## Pilot Project

Working in partnership with our advisory committee, a dialysis clinic, TriMet, Health Share and our network of transportation partners, we will develop a pilot project at the selected clinic that would model the best in flexible, reliable, and affordable transportation services for patients. The pilot model will be informed by the information we gathered in Round 1. Best practices that this pilot will model include: grouping rides by neighborhood for trips to the clinic; providing flexible return trips allowing patients to change pickup times as needed; and allowing same-day ride requests. Our goal is to work collaboratively with TriMet, identifying strengths and weaknesses of each system and making adjustments to service delivery modes by sharing customers, capacity and resources. Through this pilot we will evaluate which of these practices work best for the patient, have positive effects on their health and what the costs are needed to sustain the level of service required. We have applied for other funds to support the operations of this pilot.

# Participant satisfaction

Participants were asked how satisfied they were with the process. Of the nine responses received, 22% were satisfied and 78% were very satisfied. When asked what aspects of the process they liked best;

- "The openness of the ride connection staff to learning and understanding patient needs."
- "Very inclusive of everyone. Good identification of issues."
   "Just that overall they were asking patrons about their likes and dislikes about the service. The fact that they would even ask, and care. That means something. And that they might do something about it."

When asked what aspects of this process could have been better, participants responded;

- "I wish there had been more patrons there."
- "More resources for implementation."

"Nothing. The research project seemed like a new endeavor for everyone involved and the entire process seemed well thought out and focused."

#### **Challenges**

The health of individuals with ESRD fluctuates daily. This has created challenges in attendance to meetings and focus groups. As a result, we have offered over the phone or in-person interviews. Due to HIPPA rules, we have had to work with the social workers at clinics to have them recruit patients. We are therefore relying on a go-

between to get people knowledgeable about what we are doing and interested in participating. We worked diligently to identify social workers that understood the transportation challenges of those that they served to assist us We had some push back from the corporate entities that own a group of the dialysis clinics. We are in the process of providing them information about the program and are enlisting our champion social workers' support to get them on board. Portland State was not able to start the cost benefit analysis as intended. We have begun working with them to establish a baseline so that we can evaluate during the implementation phase for this project.

#### Plans for the future

Since the end of the grant period, we have applied for additional inclusive planning and implementations funds and operations money for the pilot project. We have reached out to additional stakeholders to ask for their support for operations funds. TriMet has agreed to collaborate with Ride Connection in moving forward with a pilot project. We have been asked to present information about our findings to TriMet's Committee on Accessible Transportation, Health Share's Citizens Advisory Council, Elder in Action's Transportation Sub-committee and the Special Transportation Funds Advisory Committee who is responsible for the Coordinated Human Services Transportation Plan and funds to support the plans goals. We will continue to keep stakeholders engaged in this topic.

# APPENDIX A: SAMPLE COMMUNICATIONS

Invitation Email to Advisory Committee Members: I am writing on behalf of Ride Connection to inform you about a research project that we are currently beginning that will explore ways of improving transportation for people who receive dialysis treatment. We are currently recruiting stakeholders to participate in an advisory committee that will help to guide the course of this research.

The advisory committee will meet no more than 5 times between August and November. We would like the committee to consist of doctors, nurses, patients, family members, social workers, clinical administrators, and transportation providers. Based on what we know of your experience in the field, we were wondering if you might be interested in participating.

In case you are not available to participate, perhaps you know of other medical professionals, patients, or family members who might like to participate. I would like to send you our outreach email – it would help us immensely if you could distribute it to any contacts who might like to participate in the research – either as advisory committee, focus group participants. Please call me or any further questions.

More information about our study is also available here: www.rideconnection.org/ride/AboutUs/DialysisResearch.aspx

Many Thanks,

Survey Recruitment Email to Social Workers:

I just wanted to drop you a line about our focus groups on transportation – we held two on Wednesday: one at the Milwaukie Center in the afternoon and one in the evening at Ride Connection in NE PDX. We got some really great info from both groups and now we're working on compiling and writing up all of that info.

Also – as the project progresses, we're gathering info via patient and caregiver surveys... Please feel free to pass these links around! And take the caregiver one yourself if you have time! We will continue to collect responses for a few weeks:

For Patients: <u>https://www.surveymonkey.com/s/YHF9NPZ</u> For Caregivers: <u>https://www.surveymonkey.com/s/dialysiscaregiver</u>

Thank you again for all of your help with this project. I'll be really excited to share the final result with you when we're finished!

Best, Lydia Corran

## IMPROVING TRANSPORTATION TO DIALYSIS FOR PATIENTS WITH KIDNEY DISEASE

#### Focus Group Participants Needed

We are looking for dialysis patients and those who work in the renal care field to participate in one of two discussion groups about transportation needs and challenges.

Wednesday, October 30 1:00-2:30pm Milwaukie Center 5440 SE Kellog Creek Dr. Milwaukie Wednesday, October 30 6:00-7:30pm Ride Connection Office 847 NE 19<sup>th</sup> Ave, Suite 200 Portland

Refreshments will be served. Ride Connection will provide \$20 compensation for your participation. Transportation will be provided if needed. We offer mileage reimbursement for those who drive.

> Contact Lydia Corran to participate: 503.528.1761 or <u>lcorran@rideconnection.org</u>

About Ride Connection

As a nonprofit focused on transportation options for the Portland Metro area, independence and community livability is important to Ride Connection. We believe our mission to link accessible, responsive transportation with community needs helps ensure that older adults, people with disabilities and low income individuals are empowered to actively participate in their communities. We work on a neighborhood scale to coordinate services tailored to the specific needs of each community served. Learn more at <u>www.rideconnection.org</u>.

# APPENDIX B: ADVISORY COMMITTEE OPERATING AGREEMENTS

### ADVISORY COMMITTEE ROLES AND COMMITMENTS

We are very grateful for your interest in participating on Ride Connection's Advisory Committee for our study on End Stage Renal Disease!

Roles of the Advisory Committee include:

- Providing advice on the methods and process used to carry out this research project;
- Helping to ensure that a diversity of voices and experiences with ESRD are represented in our study and in our focus group;
- Making recommendations that will help to shape actual service changes at Ride Connection, and may also inform recommendations to other agencies to help improve non-emergency medical transportation for ESRD patients.

Commitments of Advisory Committee members include:

- Attend up to five one-hour meetings of the project advisory committee plus one two-hour planning workshop, during the period from August to November 2013;
- Meetings will be scheduled at a time and location that is convenient for the majority of advisory committee members (assistance with transportation to meetings is available upon request).
- Advisory committee members who complete each advisory committee meeting will receive compensation in the form of a cash stipend of \$20 for each meeting.

# COMMUNICATION AGREEMENTS

What makes for a good meeting?

- Clear take homes
- what are we supposed to think about in the next, at end of meeting need a synopsis so can be prepared next time, want to make progress, want clear take homes and to-do's, summaries?
- Make sure all hearing similar things; all on the same page
- Helpful make sure everyone has opportunity to participate draw folks out if don't talk as much – Every voice is heard
- Timeliness start on time, end on time if do 1.5 hours attention span so need a break – Stay on task
- Attempt to be concise, to the point
- Like that everyone go around to share
- One person speak at a time, no interruptions
- Check ins at the end of topics is good
- No distractions cell phones turned off! (two votes for this)
- The facilitator should be tough this is the time frame, cut off folks who are talking a lot/limit

# APPENDIX B: ADVISORY COMMITTEE OPERATING AGREEMENTS (Continued)

What makes for good communication?

- Show respect to others mutual respect
- No put downs, can be easy to be intimidating in these situations, we're all on the same page, great that doctors in the room/patients in room/drivers, etc.
- Feel free and open to share
- Be clear that all working for helping transportation patients
- Nothing is a stupid question
- Appreciate objectives, time frame, staying on task is great

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#### Thank you:

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Administration for Community Living Community Transportation Association of America Health Share of Oregon Oregon Department of Transportation TriMet Upstream Public Health

#### **About Ride Connection**

Ride Connection is a non-profit that has been providing transportation for people with disabilities and older adults for over 25 years. Our mission is to link accessible, responsive transportation with community needs. In coordination with over 30 community partners, Ride Connection provides customer-focused, safe, reliable transportation options for individuals in Clackamas, Multnomah, and Washington counties in Oregon.

> www.rideconnection.org 503.528.1720