Project RED: Patient Personas
VERSION2 | 7-26-11
Observations and Interviews
Immersion into culture of the patient

**PEOPLE**
- Patients interviewed: 67
- Patients observed: 14
- Family interviewed: 21
- Care Team interviewed: 33

**LOCATIONS**
- CKD/DNC Clinics
- St. Mary’s Dialysis Unit
- Eisenberg Dialysis Unit
- NE Dialysis Unit
- Albert Lea Dialysis Unit
- Owatonna Dialysis Unit
- Decorah Dialysis Unit
- Onalaska Dialysis Unit
- Eau Claire Dialysis Unit (Thurs)
- Home Clinic

**AREA OF INTEREST**

**Team 1:**
- CKD/DNC Clinics
- Social Services Referrals
- Dietetics Referrals
- Patient Education Center
- Pre and Post-Visit Interviews

**Team 2:**
- In-Patient Dialysis In-Take
- Social Services Referrals
- Dietetics Referrals
- Multi-Specialty Interaction
- Discharge Interviews

**Team 3:**
- Physician Rounds
- Physician Appts
- Social Services Rounds
- Dietetics Rounds
- Dialysis Session Interviews
Observations and Interviews
Immersion into culture of the patient

OBJECTIVE
Define dialysis treatment through the eyes of the patient.

Identify untapped areas of opportunity within the Mayo Clinic dialysis treatment to improve the patient experience.

Create tools for the Mayo Clinic Project Red Team to navigate and incorporate the patient experience of dialysis treatment into the design and implementation of an accountable care system with processes to manage all care required by End Stage Renal Disease while realizing improved outcomes and managing to the bundled reimbursement.

INITIAL INSIGHTS OF PATIENT NEEDS
Shared Decision Making

Collaboration and Empowerment

Open/Honest Communication

Improved Education Intervals and Interpretation

Clarified External Relationships
Project RED Process Map
KEY CLINICAL EVENTS
**Personas**
A guide for the Future State

**PURPOSE**
Personas are not the “end all be all,” but they allow for representation of a larger sample of patients in regard to their personal traits, background, values, goals or characteristics. They can help mediate team discussion as a stand-in to help guide dialogue to support patient goals. Future state mapping can be continuously evaluated against the personas. Future state interventions may work for one, some or all of the personas.
81 Patient Interactions Translated into 8 Personas
HOLISTIC PERSPECTIVE
NARRATIVE

I started in the Diabetic Nephropathy Clinic a couple years ago. I hadn’t retired the last time I saw him, but I think my doctor will be happy with my appointment today. I’ve been taking better care of my health now that I have more time to spend on exercising. I like to go on bike rides with my granddaughters. I want to stick around longer for them. I want to show them how to take care of themselves. I never thought my health would get this bad. I had never really been sick all of my life. Now I know what it’s like to have to take care of myself. I like coming to the DNC clinic because they give me points when I come here. My other doctors don’t give me that feedback. I just wish they had better training plans. I’m doing better with exercise but my diet is still the same as before. I don’t know if its better to have smaller portions or completely change what I eat.

“I HAVE A NEW CAREER. MY HEALTH IS MY CAREER.”
NARRATIVE

I started dialysis in the hospital. I thought I was getting sick a couple months ago, but I didn’t have a primary care doctor. To be honest, I was afraid of the cost and never imagined getting so sick so quickly. Now I have a lot of hospital bills to pay, and I’m trying to organize my Medicare all at once now. It’s so confusing. I need to find a primary doctor that I like. I’ve been out for a couple months, but I’m just now understanding the process. Sometimes I have to skip dialysis, because of my work schedule. I know that it messes up my schedule, and that scares me. I don’t have a choice though. I have to put food on the table for my young kids. My wife is already doing most of the work. To pay for all of these pills and diabetes appointments, I have to work extra shifts when I can. Then on top of this, the care team wants me to exercise and diet. I have so much stress on my mind that I can’t imagine where I would find the time. I want to be a dad too. “I’LL CROSS THAT BRIDGE LATER.”
(voice of daughter, Victoria) My mother died years ago, and I try to get to see my dad when I can, but I can't manage it all on top of my personal responsibilities. I got a call from the hospital that he was admitted. He’s not very conscious or awake. I’m not sure if he knows where he is right now. I feel so guilty for not being here with him before. Now I have to make all these decisions myself. The care team told me he would die if he didn’t start dialysis right away. I don’t know what other options I have. Is this really the best thing for him? I guess I have to start him and then they said they could transfer him to a satellite clinic close to a nursing home for him. They are the professionals so I guess they would know best. I guess they are just going to organize this. He could leave the hospital now, but they said it may take a few days to get everything together. “I still don’t understand why they are trying to explain things like transplants and everything to me....
RICARDO (M)
AGE 64
CKD TO ESRD (FISTULA)
WORKS FROM HOME
MARRIED

I started in the Diabetic Nephropathy Clinic a couple years ago. My wife went to a couple appointments then, but she never comes anymore. She is busy with work. So when I got all the way to kidney failure, we had decided that I could stay in-center no matter what. She seems to get a little resentful, so I try not to subject her to a dialysis environment. It's not that fun. I feel good in-center though. I have a few friends that I know. We exchange friendly hellos and get to know each other a bit. My care team thinks I don't try too hard. They always reinforce diet and exercise. My wife does all the cooking, and in my culture, you eat the food given to you. How can I get my wife on board with my illnesses? With my co-morbidities get confusing though. I never know which doctor to go to. My side-effects and meds confuse me. Usually my Nephrologist will help me. I can't please everyone.

"I NEED A PLAN THAT FITS MY CULTURE, OR I'LL NEVER FIT INTO IT."
NARRATIVE

I’ve been on dialysis for a couple months now. I used to be at Eisenberg, but now they moved me out here to the NE clinic. It’s farther from my nursing home. Not that it matters, but I don’t know why they moved me. I take a shuttle and nobody meets me. I have no family, and I don’t know anyone else at dialysis. I hate it. I don’t have any options. I’m sad most of the time. I can’t even choose the food I eat at the nursing home. I don’t feel like myself anymore. I don’t know if I can stop dialysis or if that’s sacrilegious. I hope someone talks to me. Maybe I’ll tell my nurse. She talks to me the most. If they knew what I needed though, why wouldn’t they give it to me?

“I DON’T FEEL LIKE MYSELF ANYMORE.”
NARRATIVE

I started in the Diabetic Nephropathy Clinic a couple years ago. I'm an ESRD patient now. They placed a catheter for PD and I was able to start doing home PD. That worked for a couple years, but now I've had to change to home HD. My boyfriend comes to every appointment with me and helps me at home. I don't have any other health problems now, so it's much easier to manage. Now I have a steady routine and my care team is really pleased with me. I have been able to work and nothing can stop me. I don't know what I would do in the future if I had to change anything again.

“YOU JUST HAVE TO BE OPTIMISTIC.”

INFLUENCERS

- Shared Decisions
- Collaboration
- Communication
- Education
- Relationships
I've been on dialysis for a little over a year now. I started in the hospital and for the entire first year I was severely depressed and in denial. They just told me my life was changing. I couldn’t believe them. They never explained a lot to me, and so I took it upon myself to understand my own labs. I didn't trust the doctors to do everything right. I don’t find them easy to talk to. I would skip sessions, because I didn’t understand the entire scope of dialysis. The first year was the hardest with all of my diseases. I didn't know how to manage everything, and then it just got overwhelming. I’ve been in the ER seven times since February, because I can’t deal with it. I need help organizing.

“I JUST WANT TO BELIEVE THEM.”
NARRATIVE

I originally started dialysis years ago before I got a kidney transplant from my dad. I was in the hospital and then they moved me to Eisenberg until my dad finished his tests. I had his kidney for 7 years, but it's failing again, so they had to start me back on dialysis. I'm waiting for my fistula now. They put me back on the transplant list for a heart and a kidney, but I won't get it unless I get both at the same time. I just want to wait and not get a fistula. I'm too young for this. I'm having a hard time keeping hope. My parents have been giving me the most support. I guess it wasn't a surprise, but I was just hoping it wouldn't fail.

I'M SCARED.
Persona Themes

01. Shared Decision Making
02. Collaboration and Empowerment
03. Open/Honest Communication
04. Improved Education Intervals and Interpretation
05. Clarified External Relationships
01. Shared Decision Making

+ Patients want to have stable relationships with their providers, especially at EOL care.

+ Decisions can’t be an isolated activity, it’s something that is repeated and reassessed over time in a holistic approach.

+ Patients don’t know what they don’t know, therefore they can’t always triage questions or know what’s available to them.

+ Patients relate to goals, and prefer to be educated with pros and cons of actions rather than a paternalistic relationship.

+ Patients can’t predict how they will feel in the future. They think is goals and values.

+ Patients need to understand the trajectory of the disease and make decisions of pathways.

+ The care team can’t always predict outcomes, but they can map the “cone of uncertainty.”

+ Patients need a conduit to say what’s important to them. They seek conversation even if it is hard for them.

+ Patients experiences seasons of change and need proactive planning to make prompt decisions.

+ Patients want check-ins to continue the collaborative nature that is developed over time.

+ Some patients are enabled by the care team and need effective self-management plans.
**02. Collaboration and Empowerment**

+ Patients want to be treated as an expert in their own life. They all have different experiences and contextual backgrounds that are often overlooked.

+ Some patients feel they are told they are “wrong” in their behaviors, but they simply want to collaborate on new behavior change models that match their values and beliefs.

+ Some patients feel they need to make all long term changes at once, and find it unrealistic and lose stamina. Some may not even be in control of certain aspects of their life.

+ If a patient’s workload is higher than their capacity to achieve then they are set up to fail.

+ Self-discovery is important for patients. They need their own knowledge, because many patients only realize the disease when they have physical complaints.

+ Patients feel the need to know how they fit in the community, be met on their level, and have mental and psychosocial needs met promptly. They seek support at Mayo and trust the Mayo brand.

+ Change is hard for patients when they get comfortable, have planned their life around care and become reliant on the care team. They are scared for new changes.

+ Many patients want to know the trajectory and what they may be feeling is normal for that stage. It gives them support that may be lacking in other areas.
03. Open/Honest Communication

+Patients overhear other patient conversations and wonder why they don’t get the same conversations or resources. They seek standardization.

+Patients want to know the truth upfront. They don’t appreciate getting education on topics that are not options for them. It leads to false hope and confusion.

+Some care team members aren’t comfortable having certain conversations with the patient, which makes the patients feel uncomfortable as well. They don’t want to initiate the topics.

+Patients need mental models and feedback loops to constantly keep them communicating.

+Some patients refer to their most trusted care team member. And often, the first conversations are the most meaningful.

+Death is framed as a negative outcome. This scares patients.

+Patients want to know cost. It’s a primary concern.

+Patients need outlets for cognitive, language, and physical communication barriers.

+Some patients are getting moved through the system before even knowing if they want dialysis.

+Patients often come as a unit of care, which begs the need for families to communicate effectively.
04. Improved Education Intervals and Interpretation

+ In CKD clinic, learning styles are acknowledged but not acted upon.
+ Patients need information interpreted for them in a way that is broken down by values and learning style.
+ Patients will search elsewhere for information if it isn’t given to them.
+ Patients can’t see the dialysis trajectory early on, which could lead to decisions they don’t want.
+ Sometimes when physicians try to share decision making, patients still don’t always understand the clinical side. They want to pick within a range that is decided by the doctor.
+ It’s easier for patients to create new habits than to break old ones.
+ Satellite clinics tend to have less educational options than Rochester, MN.
+ Some patients would prefer to review education annually to refresh their memory.
+ Some patients learn actively and reactively.
+ Not all questions can be answered in the Patient Education Center which is frustrating to patients.
+ Educational brochures tend to look similar to patients, and confuses them.
+ Education can’t stand alone. It pours too much on the patient, and they quickly become overwhelmed.
05. Clarified External Relationships

+ Patients don’t always know how to triage their questions, especially if they have co-morbidities.

+ Some nephrologists act as primary care and some don’t. This is confusing to patients.

+ Some patients want separation between the clinical setting and their home setting. Some even feel guilty of being a burden on their home life.

+ Some patients seek out more of a community at dialysis and choose in-center because of this.

+ Patients want to know the roles of the care team members, but it isn’t always obvious to them.

+ Some patients don’t see evidence of integrated care, because of communication issues around transitions.

+ Family involvement can be positive or negative.

+ Some patients have had bad experiences at non-Mayo sites, which brings in confusion.

+ Patients are willing to go to primary care, but they place more trust in their nephrologists.

+ Patients often come as a unit of care, which includes relationships with their families and friends.

+ Sometimes patients experience conflicting advice from other specialties and primary care.
Quotes:

“I started dialysis in the hospital. The doctor just said that if I wanted to live then I would have to go on dialysis”

“The beginning conversations were the scariest. I had nothing to gauge”

“The first three months were the worse, I was very depressed. Peter the social worker was great help; I straightened out”

“My very first conversation with the doctor stood out the most, but the nurses explained the ropes”

“Education was, here’s a book, go read it and come back”

“I don’t want to get an arm access if I don’t have to. I just hope my kidneys begin working”

“I am looking forward to be fortunate enough to receive a transplant”

“I would have needed someone to put needles in me at home. That was not my cup of tea and I would not do that myself”

“My wife and I are not confident enough about [PD] to try it”

“I would not advice anyone to do [HD] at home”

“Death is not something I have not heard about”

“My wife and I have to be fairly upbeat, because this is what it will be like for the rest of our life”

“Her family does not come to see what she is going through. Maybe if her family came, then they would realize her pain and that she does not want to be on dialysis” “I have already planned for a future funeral”

“I woke up with a catheter in my chest, my family wasn’t even here yet”

“I had to start dialysis right away in the hospital, but they didn’t discuss options. Just life or death”
Future State Mapping Exercises

Risk in Future and back story
Transition points
Pt. Acuity
Possible future pathways
Patient Screening
Acuity and Response Symmetry
Fixed Pressures and Variable Pressures
Entry and Exit Points
Design Principles
Concept Framework with Subteam charts