

# **HUMAN CENTERED DESIGN (HCD) IN ACTION**

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## **Increasing Patient Access To Kidney Transplant**

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# What we learned

## RISK ASSESSMENT IS HARD

"There's a 1 in 5000 chance you're going to get HIV from a high-risk donor... your risk of dying on the way back to the south of DC might be about that."

I DON'T KNOW WHAT I DON'T KNOW

LOST IN TRANSLATION

## DIVIDED, WE FAIL

"That doesn't help my outcomes."

ALL CENTERS AREN'T CREATED EQUAL

CLINICIANS ARE HUMAN TOO

MIND THE (CARE) GAP

INCOMPLETE DEFINITIONS OF SUCCESS

## FIND YOUR WHY

"I'm retired, I want to jump on my motorcycle and just go on the road for four days. And you know, enjoy a glass of milk or a beer."

GOALS AS ANCHORS

LEAN ON YOUR NETWORK

## UNTIMELY FLOODS OF INFORMATION

"They all ask the same question: where's my name on the waiting list? You have to explain to them that there is no such thing as a waiting list, each kidney has its own waiting list."

INFORMATION OVERLOAD

WHO/WHAT DO I TRUST?

"WAITLIST" IS MISLEADING

GIVE IT TO ME STRAIGHT, DOC

## PATIENT OR NUMBER?

"I had nurses tell me, from my dialysis center, that I wouldn't be able to get a transplant...they were wrong, but they were telling me the best of what they knew."

HAVE WE MET?

US VERSUS THEM

CAN YOU HELP ME?

## COST IS PROHIBITIVE

"I know my body is a candidate for transplant, but my wallet isn't."

AS ALWAYS: TIME IS MONEY

CAN I EVEN AFFORD HIGH KDPI?

## WE'RE BETTER TOGETHER

"I get to see [a post-transplant patient], shake his hand, see how he's doing. That's so encouraging — that someone used to walk in my shoes."

YOU GET ME BECAUSE YOU'VE BEEN THERE

## 05. COST IS PROHIBITIVE


### Opportunities

## *How might we...*


... improve **communication about coverage policies** so that patients feel confident in their ability to afford treatment?




... inform the **patients about the financial costs** associated with transplant **earlier** in the process?



... **guide patients who feel demotivated by finances**, so that they can explore other options with confidence and get waitlisted?



... **reduce the financial burden or increase financial incentives** for patients who accept high KDPI kidney?



# Patient Mindsets

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- Drive
- Goal Orientation



- Technology IQ
- Health Literacy
- Support System
- Socioeconomic Status

# Patient Mindsets

## The Coachable

"I sat in the lobby of that transplant center until they would talk with me. I am a candidate for transplant, but my wallet isn't..."

**BARRIERS:** Trouble securing finances // BMI requirements // Access to info  
**CATALYSTS:** Well-articulated goals // Lots of engagement with care teams

### Resources

Technology IQ: ● ○ ○ ○ ○  
 Health Literacy: ● ○ ○ ○ ○  
 Support System: ● ● ○ ○ ○  
 Socioeconomic Status: ● ○ ○ ○ ○

### Motivation

Drive: ● ● ● ● ●  
 Goal Orientation: ● ● ● ○

## The Empowered (9% - 30%)

"I would rather be there to make things happen *for* me. When it comes to other patients, I always make time to chat."

**BARRIERS:** Communication gaps // Information decentralization // Lack of opportunities  
**CATALYSTS:** Engaging other patients // Meeting care teams // Community events

### Resources

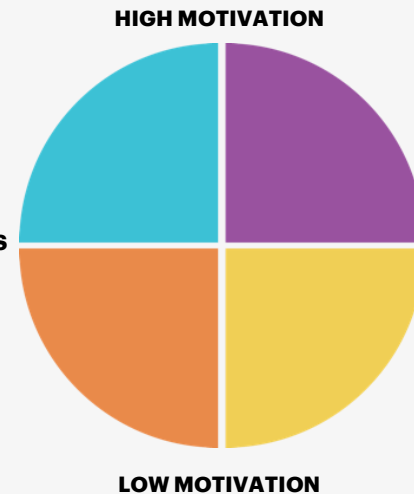
Technology IQ: ● ● ● ● ●  
 Health Literacy: ● ● ● ○ ○  
 Support System: ● ● ● ● ●  
 Socioeconomic Status: ● ● ● ○

### Motivation

Drive: ● ● ● ● ●  
 Goal Orientation: ● ● ● ● ●

LOW RESOURCES

HIGH RESOURCES



## The Surrendered (up to 20%)

"Transplant centers have no interest in opening their doors to me. It's a lot of work to get on that waitlist and dialysis isn't so bad."

**BARRIERS:** Emotional support // Finances // Lack of goals or meaning  
**CATALYSTS:** Major threat of death // Remembering pre-ESRD life // Seeing others thriving after a transplant // Receiving help

### Resources

Technology IQ: ● ● ● ○ ○  
 Health Literacy: ● ○ ○ ○ ○  
 Support System: ● ○ ○ ○ ○  
 Socioeconomic Status: ● ○ ○ ○ ○

### Motivation

Drive: ● ● ○ ○ ○  
 Goal Orientation: ● ○ ○ ○ ○

## The Complacent

"My life on dialysis is totally fine. I could do it, but I don't see that much of a benefit from surgery."

**BARRIERS:** Complacency // Risk aversion  
**CATALYSTS:** Articulating goals // Seeing success // Hand-holding guidance

### Resources

Technology IQ: ● ● ● ● ●  
 Health Literacy: ● ● ● ○ ○  
 Support System: ● ● ● ● ●  
 Socioeconomic Status: ● ● ● ○

### Motivation


Drive: ● ○ ○ ○ ○  
 Goal Orientation: ● ● ○ ○ ○

## TRANSPLANTATION

6



## Patient Milestone Actions / Decisions



A horizontal timeline with seven white dots on a dark blue background. Below each dot is a text block describing a patient milestone action or decision.

I decide to pursue transplant

I choose to get listed at the transplant center that's best for me.

I sign the consent form for high KDPI and increased risk kidneys if it's right for me.

I stay active on the waitlist

I'm offered a kidney and I accept it.

I maintain the health of my kidney.

**I help other people get kidneys too.**

# Opportunity Areas

26 high priority concepts across 5 opportunity areas were derived for potential implementation and piloting moving forward. Each concept was supported with examples of similar projects happening today, applicable learnings, and an implementation plan.



## IMPROVING UNDERSTANDING & MOTIVATION

1. Kidney Classification Synonyms
2. ESRD Metaphor Playbook
3. Tradeoffs and Risks Visualizations
4. Transplant Mythbusters
5. Motivational Patient Stories
6. ESRD Influencer Campaign
7. Education at Time of Consent
8. Targeted Marketing
9. Transplant TV



## EMPOWERING INFORMED DECISION MAKING

10. My Compliance Tracker
11. High KDPI Consent Guide
12. Transplant Center Evaluation Guide
13. Transplant Orientation Template
14. Transplant Center Comparison Tool
15. Personalized Decision Tool



## COORDINATING INFORMATION SHARING

16. My Information Board
17. Transplant Hub



## INFLUENCING PROVIDER ACTIONS

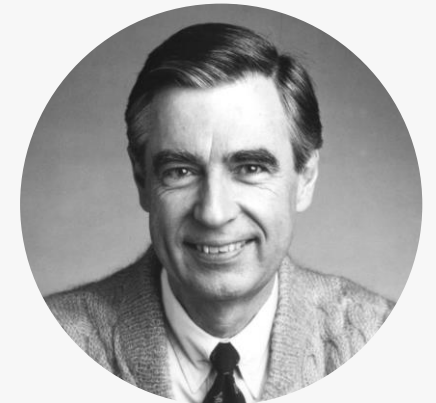
23. Best Practice Playbook
24. 2nd Ask for Consent
25. Patient-Centric Incentives
26. Kidney Offer Report



## LENDING A HELPING HAND

18. Certification Program
19. Activated Caregiver Network
20. Amplified ESRD Networks
21. Buddy Program
22. Professional Navigators

**“Look for the helpers”**







T H A N K   Y O U

**OFFER:**

*We are happy to do a deeper dive session on our work –  
the research, findings, and recommendations – with any  
interested committee members*

## 05. COST IS PROHIBITIVE

Patients often learn about regulatory requirements for insurance after they can do anything about it. Additionally, existing coverage policies can create barriers to transplant consideration when they are perceived to be too complex to comprehend or when there's a perception that a patient can't afford post-transplant care.

**AS ALWAYS: TIME IS MONEY**

**CAN I EVEN AFFORD HIGH KDPI?**

# As always: time is money

When weighing whether transplant is a viable option for a patient, both the patient and their care team assess whether they believe transplantation and follow-up care are affordable. Information about finances and insurance is not centralized and presentation is delayed. Timing can be a barrier to affording to get waitlisted and/or a barrier to patients' abilities to afford post-transplant medication.

## WHAT WE LEARNED

- Patients and care teams alike complain that information about coverage can be confusing and may come too late to be useful.
- Medicare only covers 80% of transplant costs; patients need supplemental insurance to cover the rest. Patients were generally unaware that their window of opportunity to sign up for supplemental insurance in the first 6 months following ESRD diagnosis, and if they miss that window, they cannot sign up until age 65.
- Transplant finance coordinators/advisors can act as unilateral decision makers for whether patients can get on waitlist, based solely on the patient's finances.

## WHAT WE HEARD

**"I know my body is a candidate for transplant, but my wallet isn't."** - Patient

**"The biggest issue is if a patient is Medicare only and doesn't realize they're responsible for 20%. ... [They] just didn't know that Medicare has a short window. If you miss that, you don't really get another opportunity to sign up until you're 65."** - Finance Coordinator

# Can I even afford high KDPI?

Post-transplant cost for high KDPI kidneys can be potentially higher. By introducing new problems, patients may need more follow-on care, meaning more expenses. This additional burden can be a barrier to patients in opting for high KDPI kidneys.

## WHAT WE LEARNED

- Patients perceived getting a high KDPI kidney as a risk for worsening their existing medical conditions.
- Adding complications that might be associated with higher KDPI kidneys can impose a financial risk, since medication regimens can become increasingly complex.
- The risk of complications rises with high KDPI, so there is the potential for an increase in ancillary costs, such as additional hospital costs and caregiver support.

## WHAT WE HEARD

**“Why is a second transplant covered but not medication? It doesn’t make sense!”** – Transplant center outreach coordinator

**At the end of the day, we don’t want to further complicate a patient’s situation and make them take more drugs. Adding even more non-generic medication can increase their care costs.** – Transplant and Finance Coordinators