

# Transplants.org Oracle Health

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# Project Overview

## Transplant Journey



## Objective

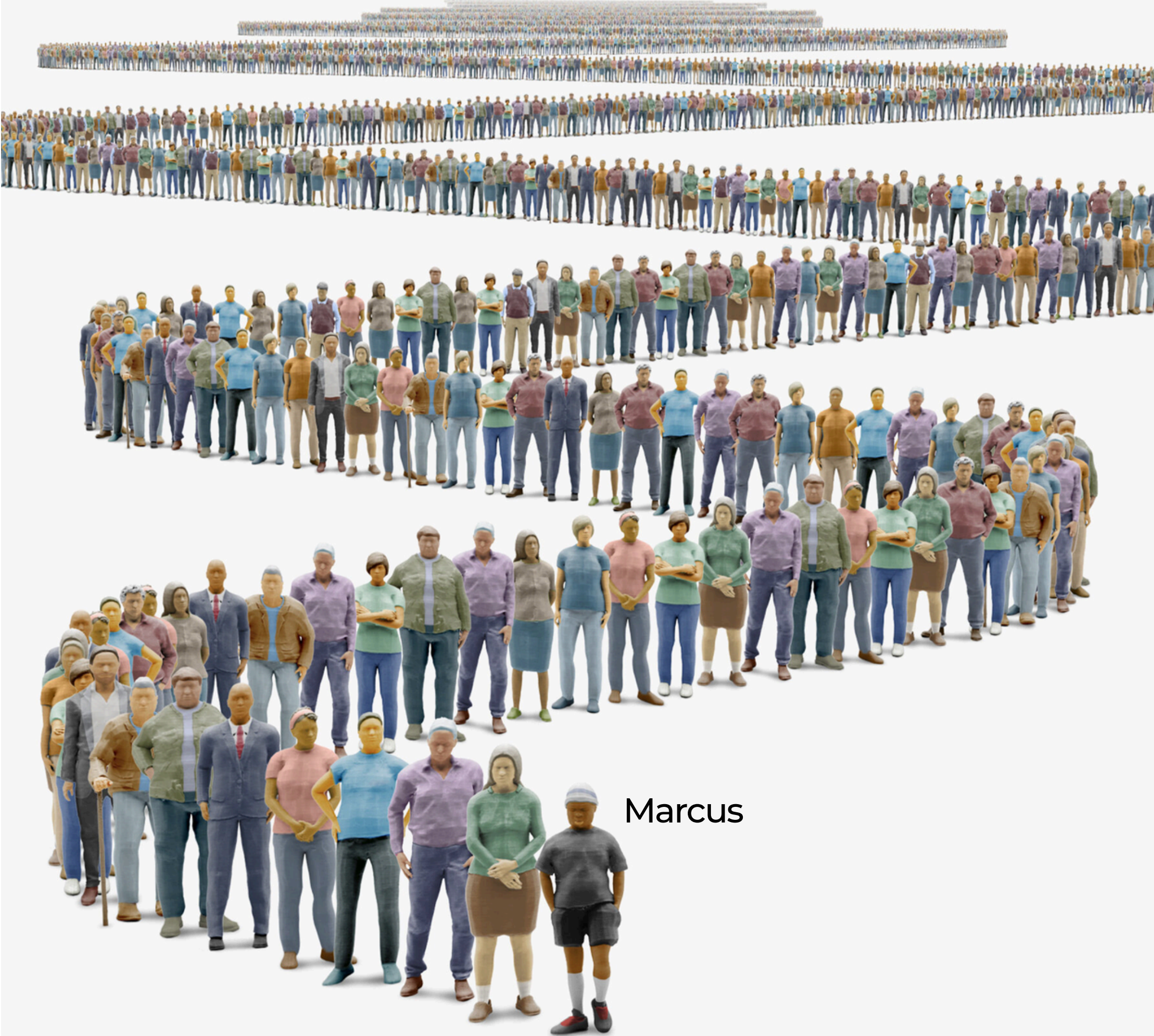
Transplant.org + Oracle + CMU combines nonprofit patient advocacy, enterprise cloud infrastructure, and academic research expertise. Our goal is to categorize and assess questions from thousands of social media conversations, starting with kidney transplant, to directly improve information access for patients and caregivers.

Marcus, 12 y/o



Marcus was at the top of the waiting list - the first in line.

Recipient

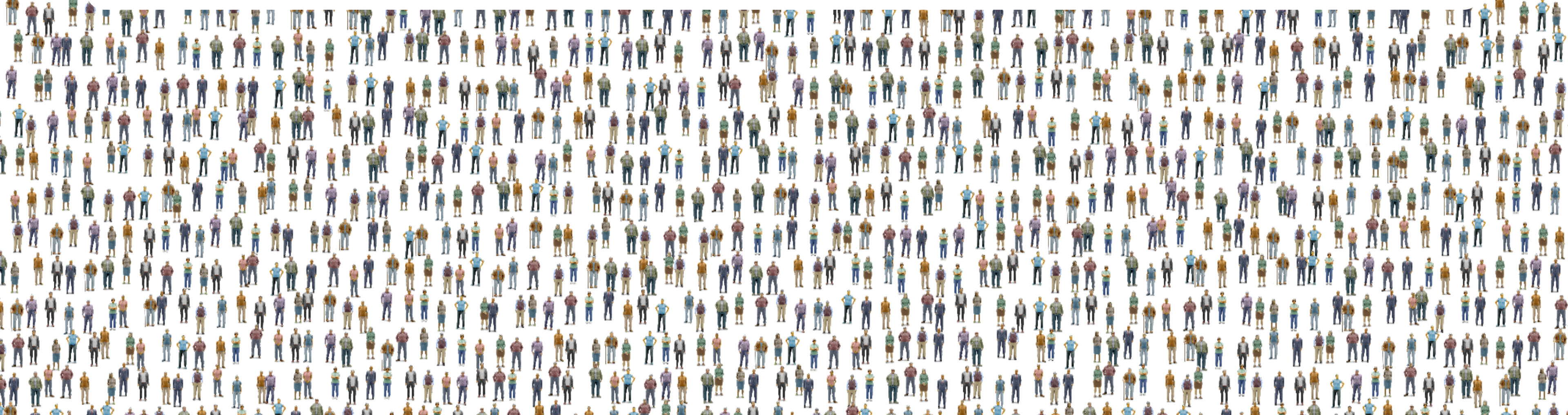


Instead, it went to a middle aged man  
3,557 spots further

Marcus



There are about **90,000 patients on the national kidney registry.**



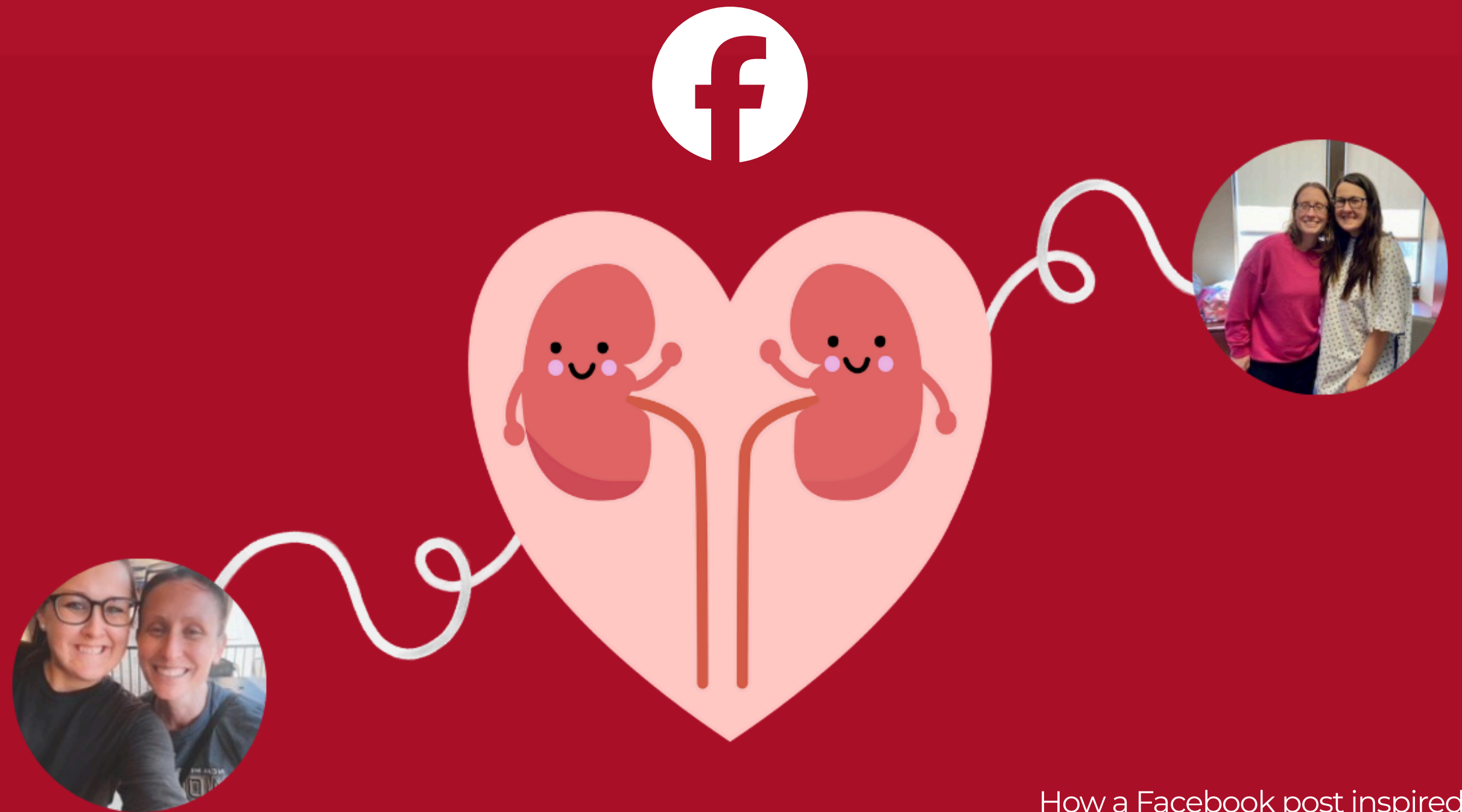
# Why This Matters?

1. Journey as "black box", confusion about priority systems, multiple lists, timing
2. No standardization between transplant centers, same question, different answers
3. Misinformation spreads unchecked, no single source for patient advice
4. Wrong information can be fatal, transplant decisions aren't lifestyle choices, they're survival decisions
5. Information overload like multiple handbooks overwhelm patients



An employee at the procurement organization readying a liver for transport.

# Role of Social Media



How a Facebook post inspired a living kidney donation

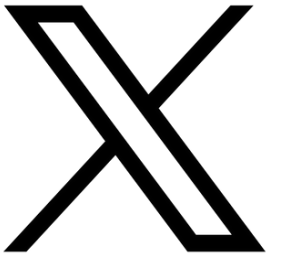
# Digital Health Communities

1. Patients use platforms to acquire health information and share their transplant experiences
2. Candidates and recipients rely on platforms as support systems throughout their journey
3. Helps patients navigate managing their lives and treatment post-transplantation
4. Keeps patients updated with latest transplant information and developments
5. Posts reveal what information gaps exist, helping improve transplant care services



# How Transplants.org can use Social Data

- Identifying unmet needs in the transplant community
- Improving education materials for transplant patients
- Coordinating effective outreach for clientele who face the most confusion in the transplant process (e.g., elderly recipients).
- Identifying public misinformation



reddit

# Data and Methodology

- Collected and anonymized 5,760 public Reddit posts made between January 2021 and October 2025
- Developed initial question taxonomy from existing literature and selected classification/ question extract (C/E) fields
- Refined and evaluated LLM prompts for C/E based on human-evaluated 200 sample posts
- Iteratively performed C/E on full dataset to update question taxonomy through automated topic modeling and human judgement (scalable to unseen data)
- Analyzed stages of transplant journey through C/E results and Reddit engagement data

The logo for Reddit, featuring the word "reddit" in a lowercase, sans-serif font. The letter "i" has a small orange dot above it.

Source of Posts



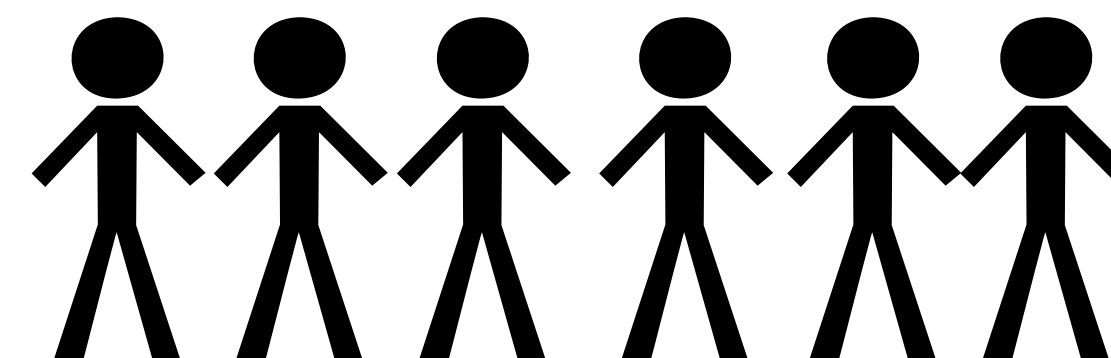
Microsoft Presidio

Package for anonymization



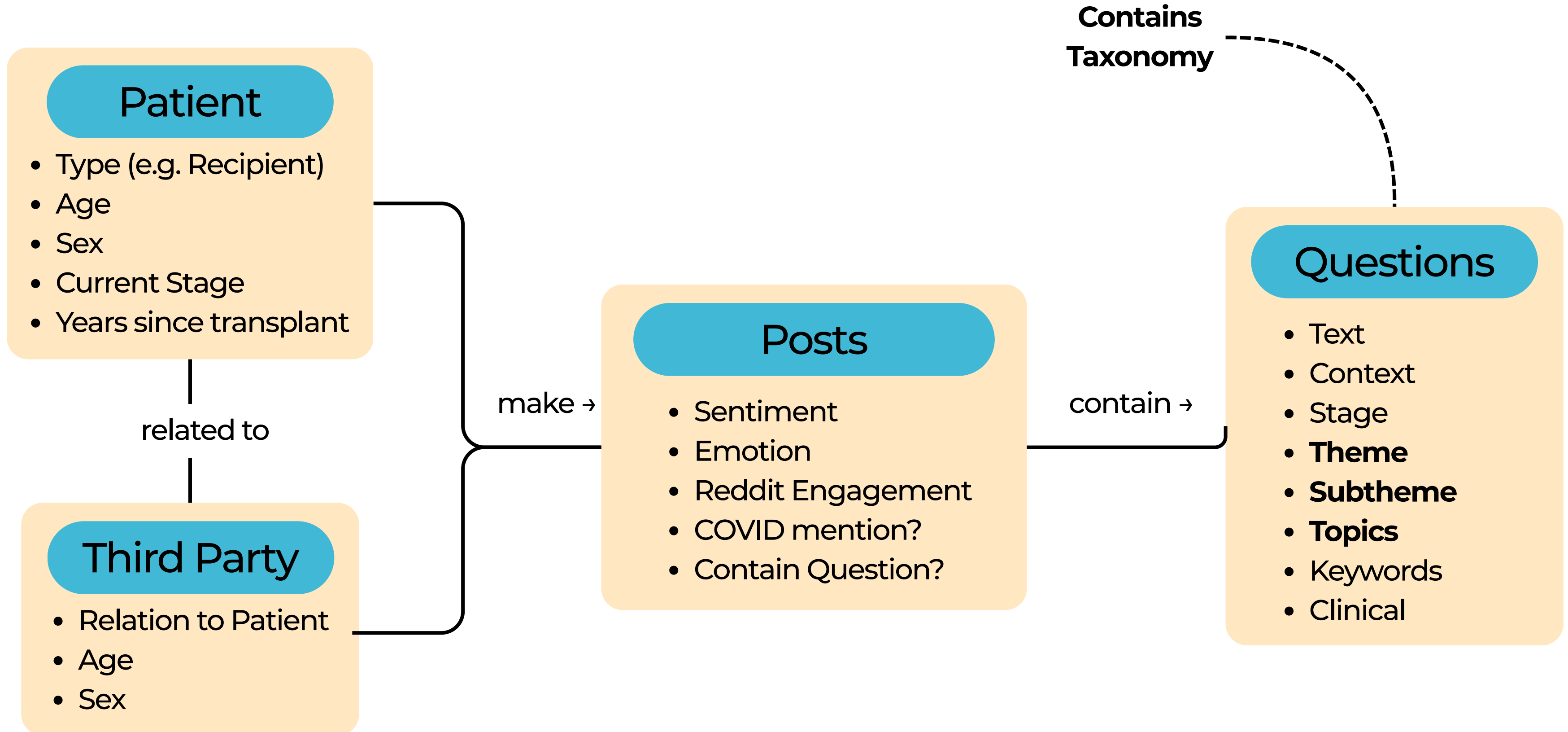
Gemini

Google Gemini LLM for C/E (not training on data)



Project team as human reviewers

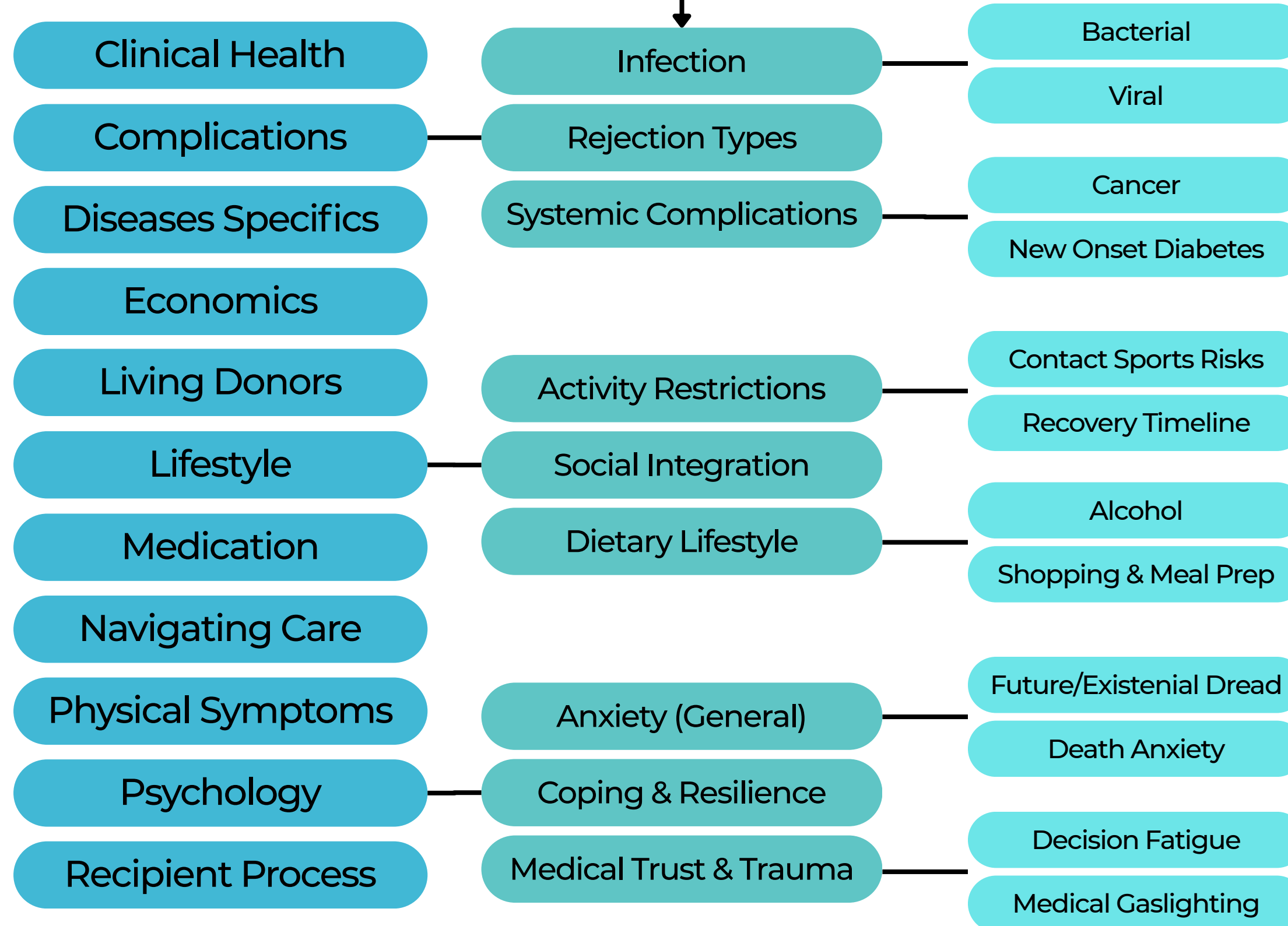
# Data Structure



# Question Taxonomy

Each with 3-4 Subthemes

Distinct Themes →



← Each with many topics

Updating taxonomy as simple as changing row in Excel file and clicking "Run" on Python script

# Stakeholders in the Data

## Patients

Those who are to be recipients during the transplant process, often make up the largest portion of online dialogue around transplants

**68%**  
of Questions Asked

## Caregivers

Caregivers are often an overlooked stakeholder group, providing post-operative care and emotional/physical support throughout the transplant process for patients.

**20%**  
of Questions Asked

## Donors

Both Living and Deceased donors comprise a valuable stakeholder group

**12%**  
of Questions Asked

# Online Segment Mapping – Age

The average age of patients we analyzed who posted on reddit was roughly 36 years old. When comparing that to the real-world data on transplant patient age, this presents an opportunity to evaluate which age range needs more targeted outreach

## Recipient Ages

**36**

Average age of  
transplant patients who  
posted on Reddit

**48**

Average age of  
transplant patients from  
the American Journal of  
Transplantation

## Donor Ages

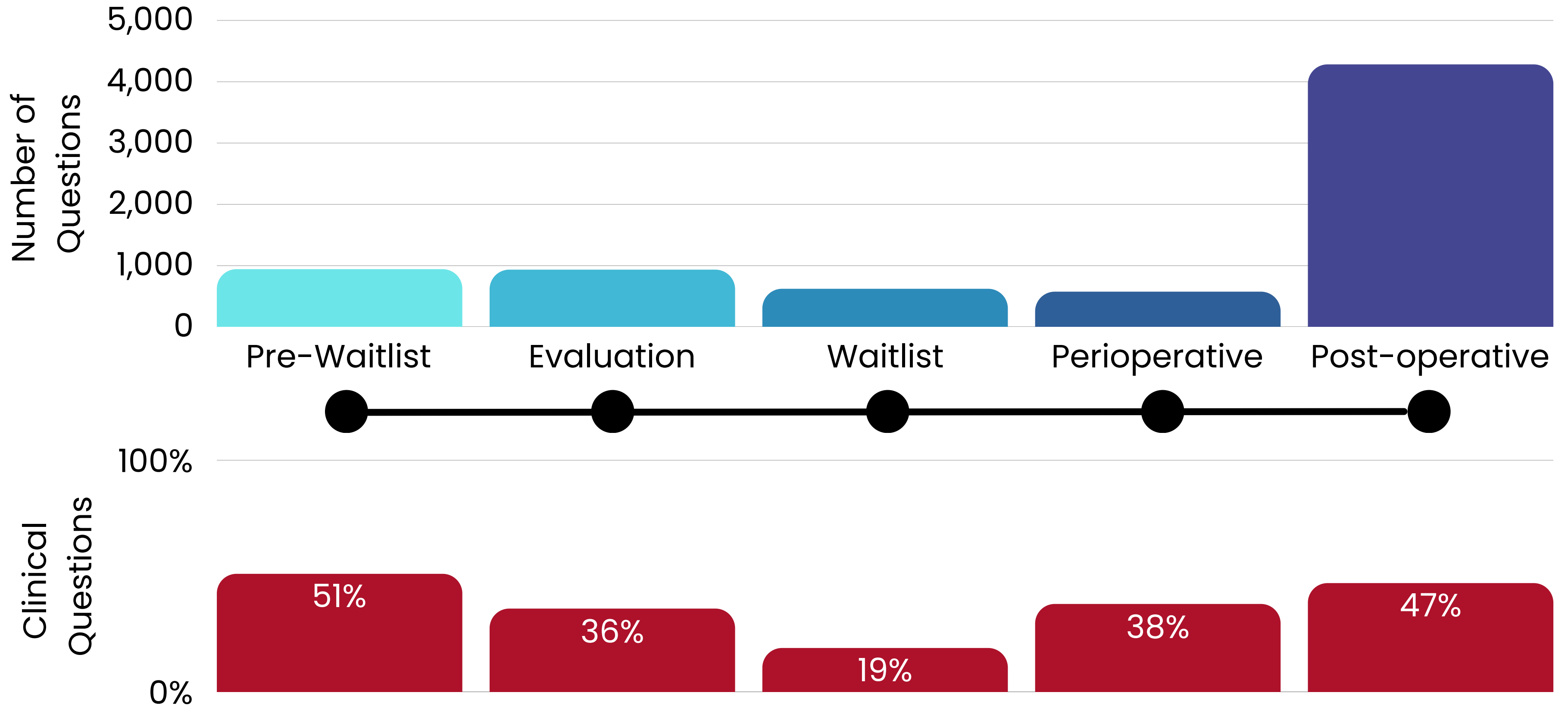
**30**

Average age of  
transplant patients who  
posted on Reddit

**42**

Average age of  
transplant patients from  
the American Journal of  
Transplantation

# Transplant Stages in the Data



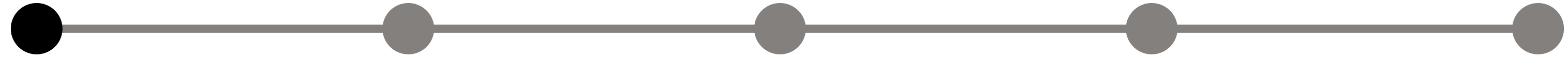
# Pre-Waitlist

Evaluation

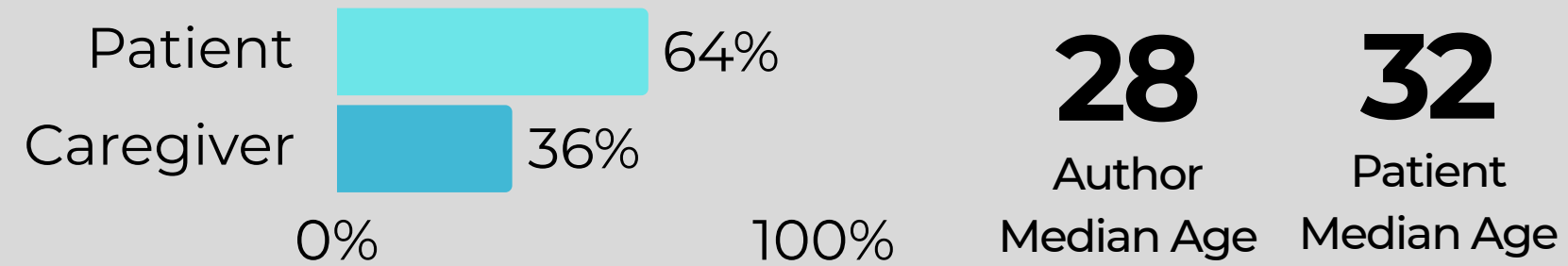
Waitlist

Perioperative

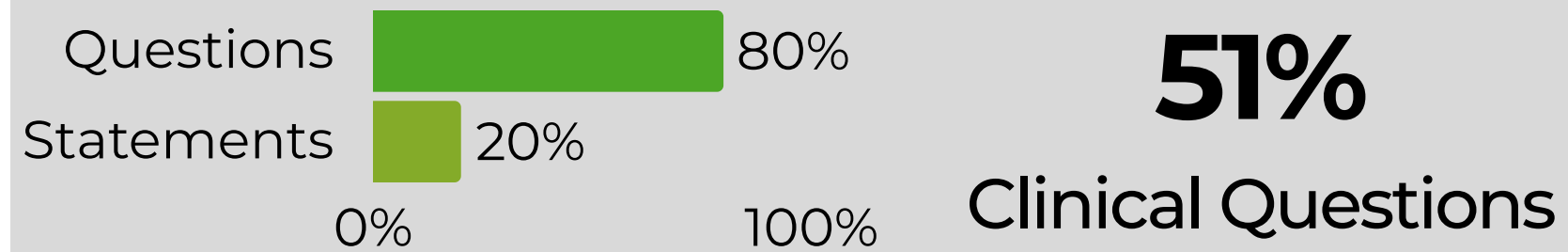
Post-operative



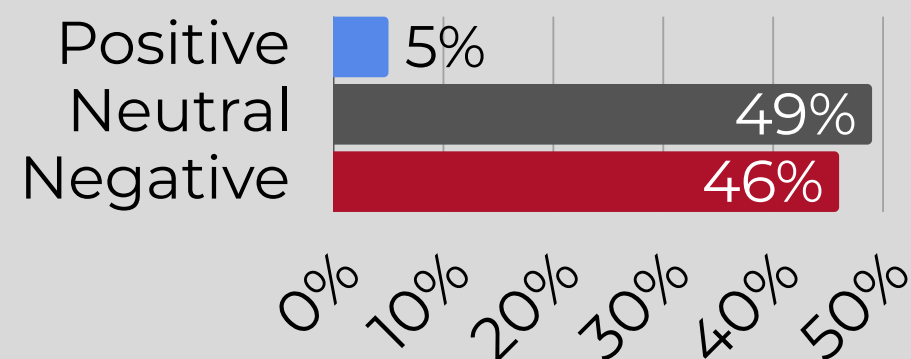
## Who is posting?



## About what?



## Feelings when they ask?



Sad

## What are they asking?

### Top Themes

**Clinical Health**

**Recipient Process**

**Psychology**

### Top Subthemes

**Lab Values (Blood)**

**What to Expect**

**Coping & Resilience**

### Most Engaged Questions

Does kidney disease predictably worsen significantly over time without a transplant?

How can I deal with the emotional challenges of stage 5 renal failure and the prospect of a transplant?

Why are medical professionals not providing preventative advice for my significant other's kidney condition?

Pre-Waitlist

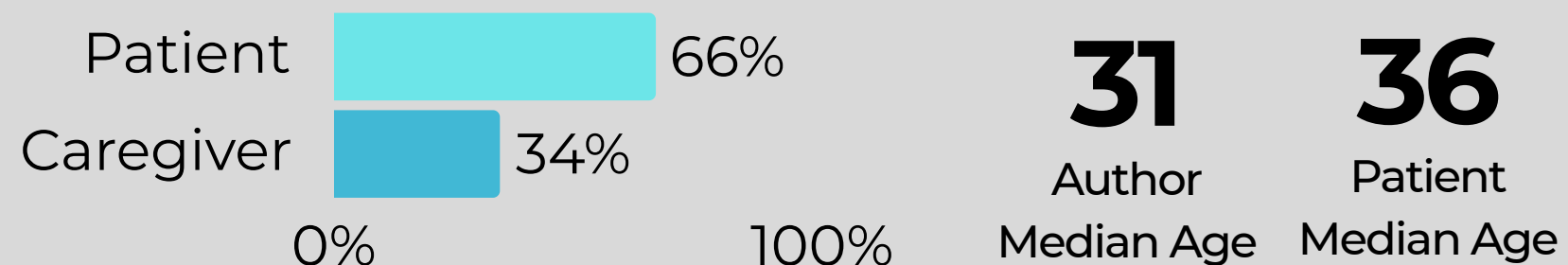
**Evaluation**

Waitlist

Perioperative

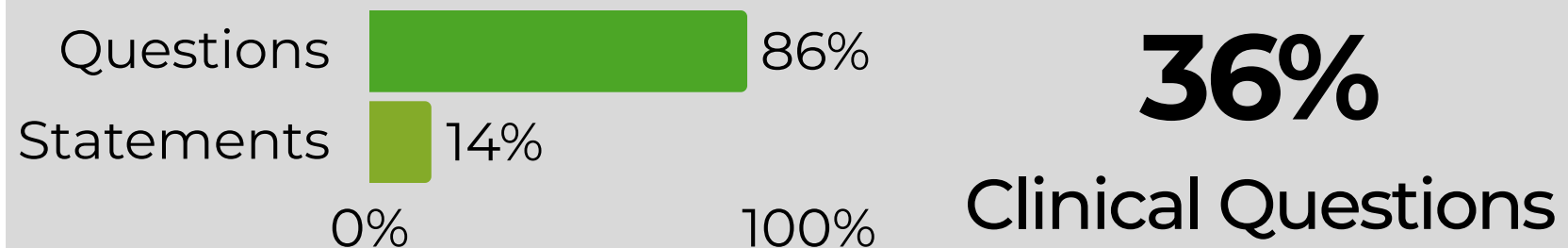
Post-operative

## Who is posting?



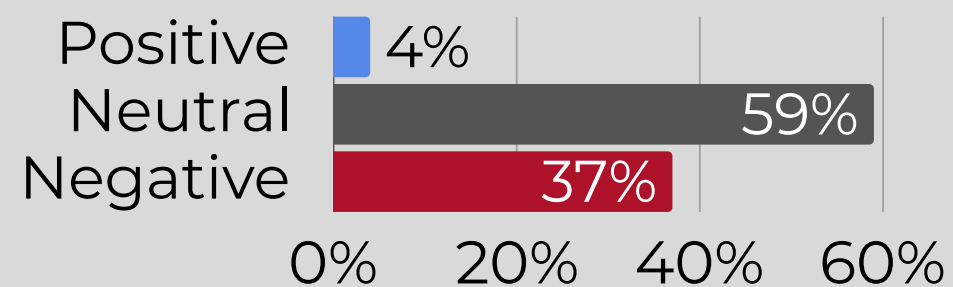
**31** Author Median Age  
**36** Patient Median Age

## About what?



**36%** Clinical Questions

## Feelings when they ask?



Fear

## What are they asking?

Top Themes

**Recipient Process**

**Navigating Healthcare**

**Clinical Health**

Top Subthemes

**Waitlist Strategy**

**Patient Adovacy**

**Lab Values (Blood)**

**Most Engaged Questions**

Is a kidney transplant truly worth the effort, considering my profound loneliness and fear of no change in my quality of life?

Should I risk a transplant if it might only offer a short period of 'normal' life before potentially returning to dialysis?

Is the transplant experience, including its many trials and tribulations and immunosuppression, truly worth enduring?

Pre-Waitlist

Evaluation

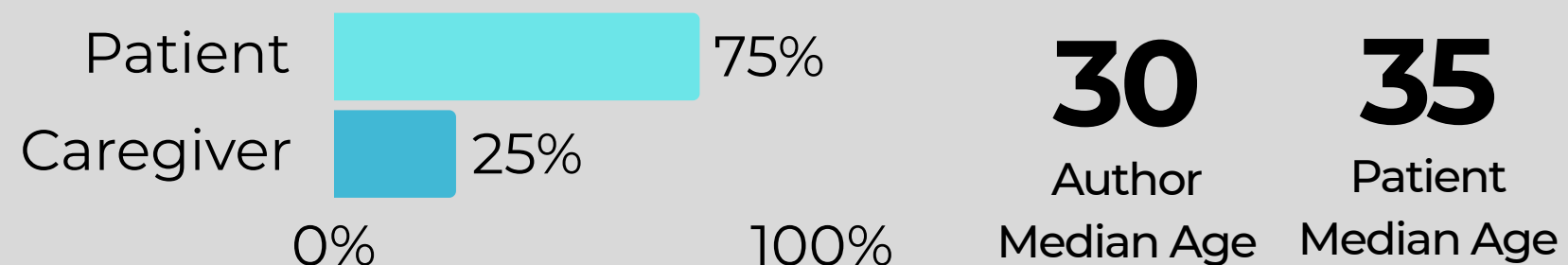
**Waitlist**

Perioperative

Post-operative

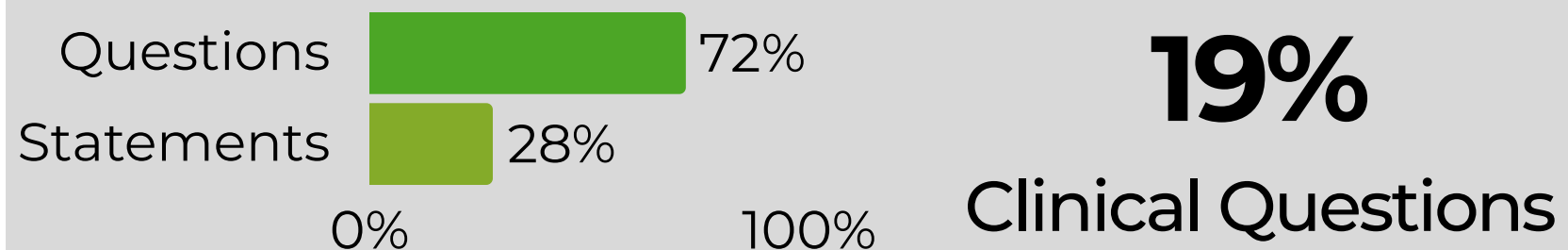


## Who is posting?



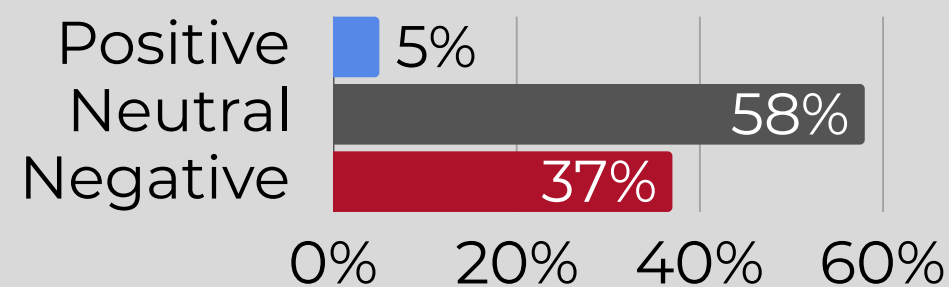
**30** **35**  
 Author Patient  
 Median Age Median Age

## About what?



**19%**  
 Clinical Questions

## Feelings when they ask?



Anger

## What are they asking?

Top Themes

**Recipient Process**

**Psychology**

**Navigating Healthcare**

Top Subthemes

**Waitlist Strategy**

**Interpersonal Dynamics**

**Patient Advocacy**

Most Engaged Questions

Why is living donor transplantation not an option for more people?

Why don't more states allow or offer living donor transplant centers?

How many calls did other recipients get before receiving a viable organ?

Pre-Waitlist

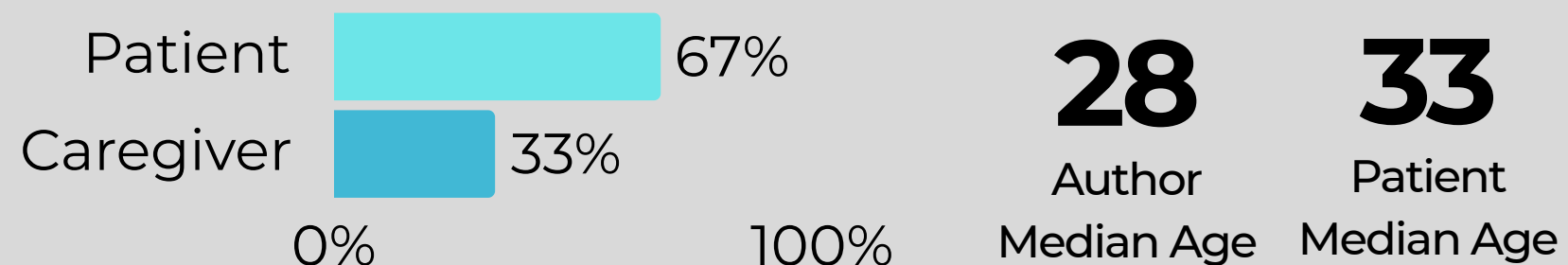
Evaluation

Waitlist

**Perioperative**

Post-operative

## Who is posting?



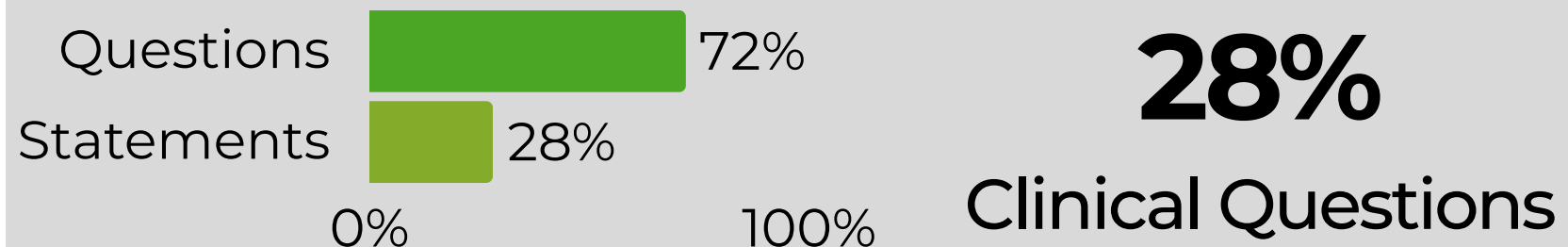
**28**

Author  
Median Age

**33**

Patient  
Median Age

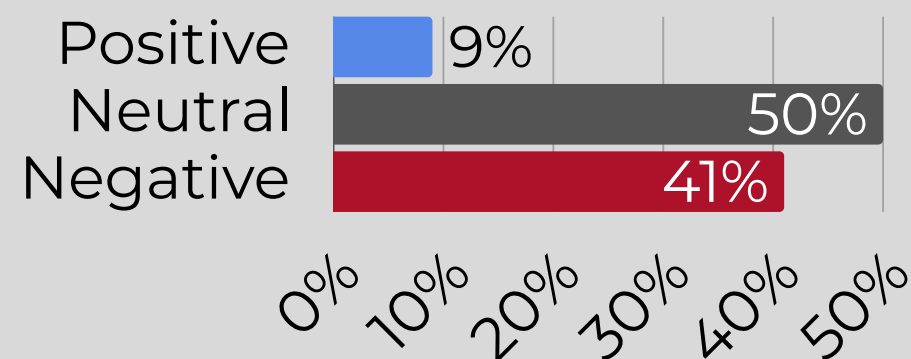
## About what?



**28%**

Clinical Questions

## Feelings when they ask?



Fear

## What are they asking?

Top Themes

**Recipient Process**

**Physical Symptoms**

**Complications**

Top Subthemes

**Recipient Surgery**

**Pain & Sensation**

**Rejection Types**

Most Engaged Questions

What was it like waking up after the transplant surgery?

What items should I bring with me to the hospital for the transplant?

Are there any other suggestions for things I might need or general advice for the transplant experience?

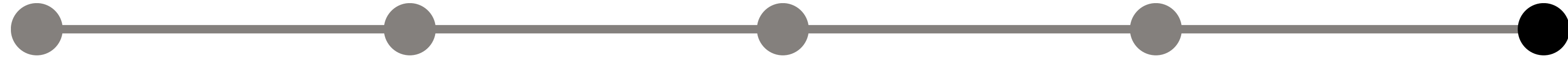
Pre-Waitlist

Evaluation

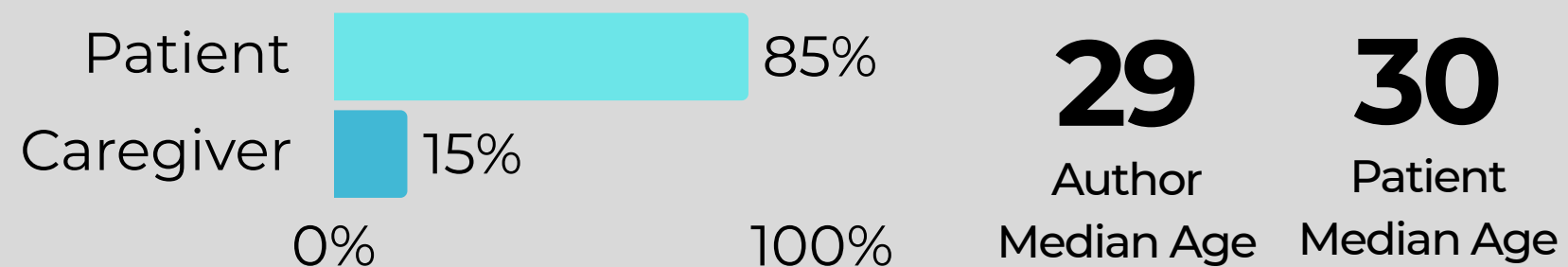
Waitlist

Perioperative

**Post-Operative**



## Who is posting?



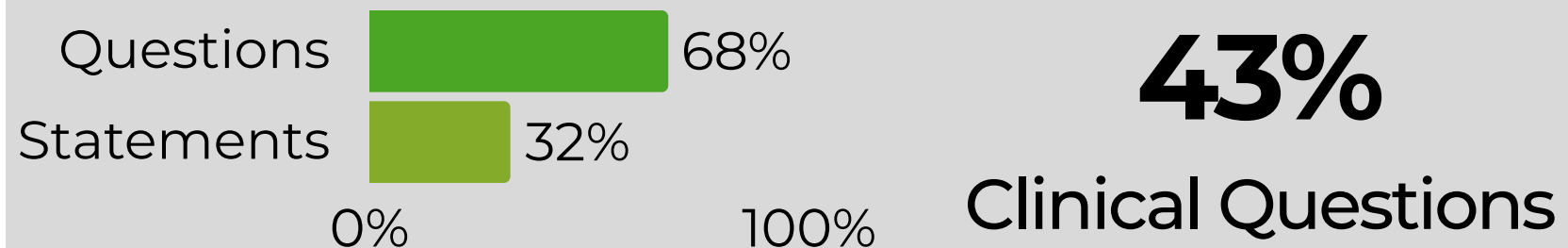
**29**

Author  
Median Age

**30**

Patient  
Median Age

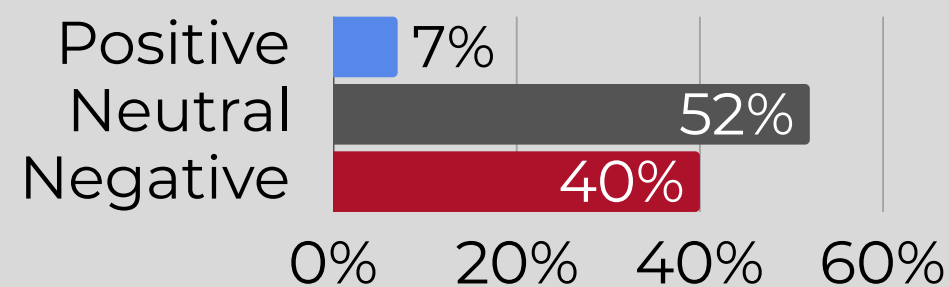
## About what?



**43%**

Clinical Questions

## Feelings when they ask?



Joy

## What are they asking?

Top Themes

**Lifestyle**

**Medication**

**Complications**

Top Subthemes

**Diet**

**Safety/Interactions**

**Infections**

Most Engaged Questions

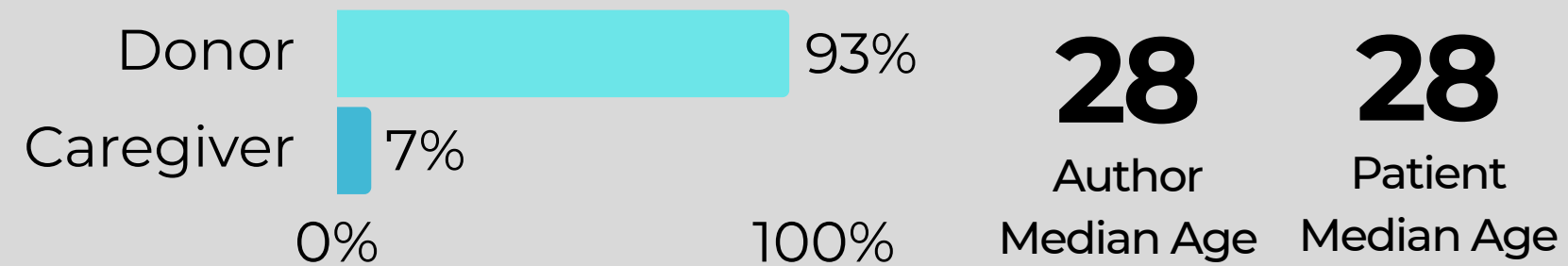
How have other patients successfully managed to balance college, employment, and their transplant experience?

What specific things should I have the dermatologist check for and what should I tell them when I schedule my appointment?

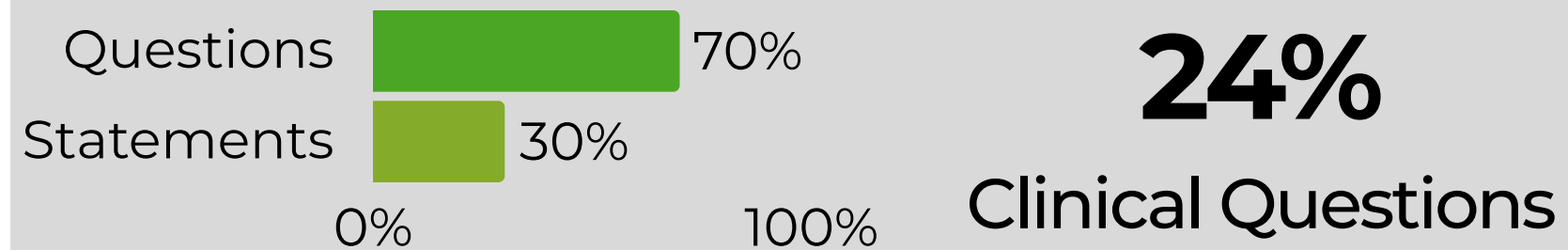
What is the post-transplant experience like for individuals with OCD, particularly regarding anxiety about accidentally skipping medications?

# Special Case: Donors

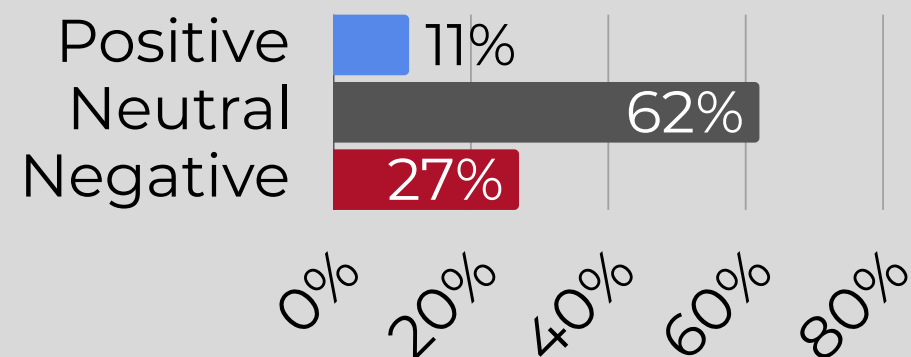
## Who is posting?



## About what?



## Feelings when they ask?



Fear

## What are they asking?

### Top Themes

**Donor Experience**

**Lifestyle**

**Psychology**

### Top Subthemes

**Surgery & Recovery**

**Activity Restrictions**

**Interpersonal Dynamics**

### Most Engaged Questions

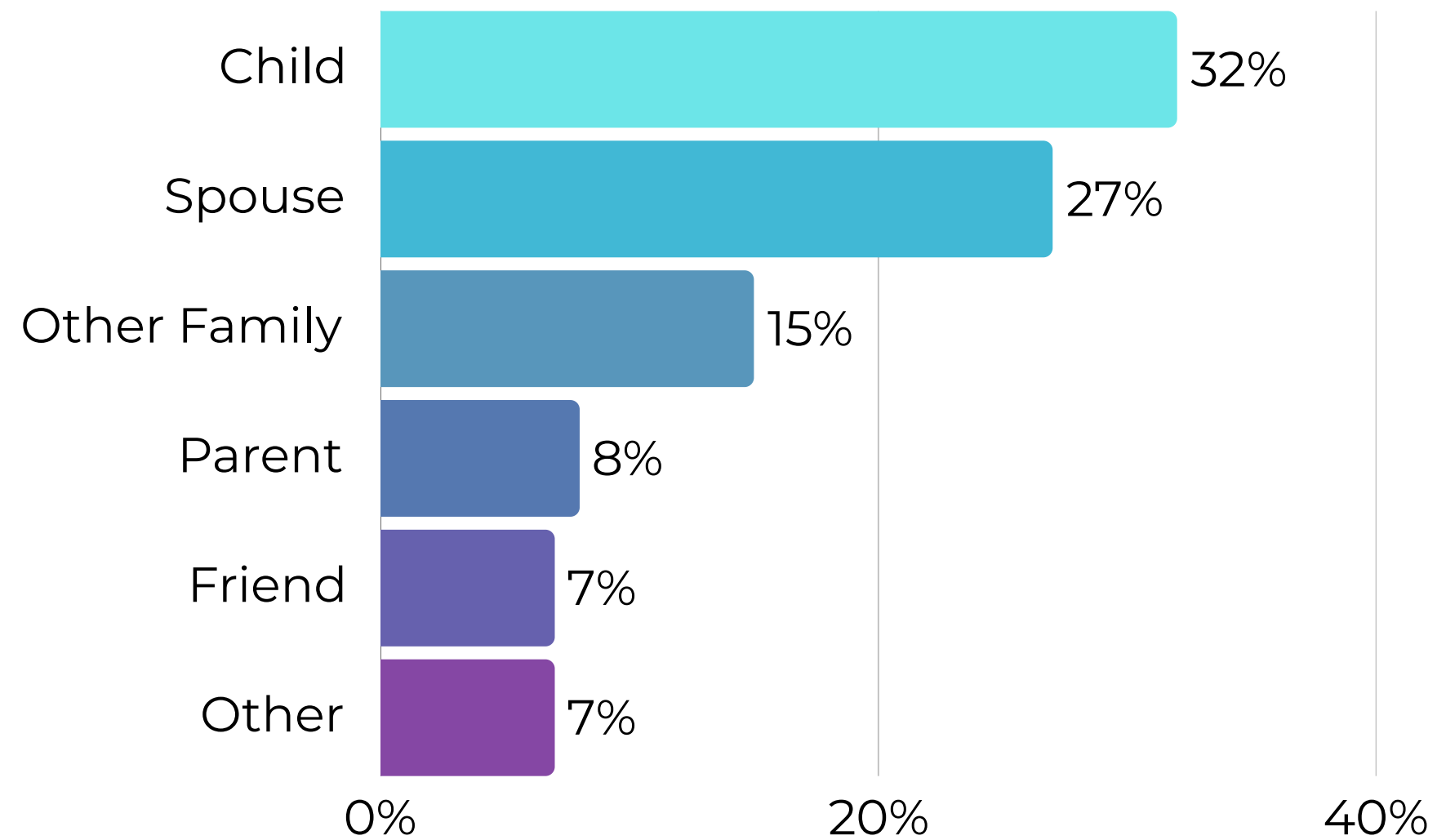
Should we offer a tax credit to encourage more people to donate kidneys, knowing only 2% complete the donation process, or let Americans continue to die from kidney failure due to the kidney shortage?

What are some things you wish you knew before donating?

Do you have any regrets about donating?

# Additional Analytics

## If not the recipient or donor, who's posting?



NOTE: Child is age agnostic. It could refer to a 30 year "child" posting about their 57 year-old recipient parent.

## A few insights...

**4**

Median Years since Transplant

**13%**

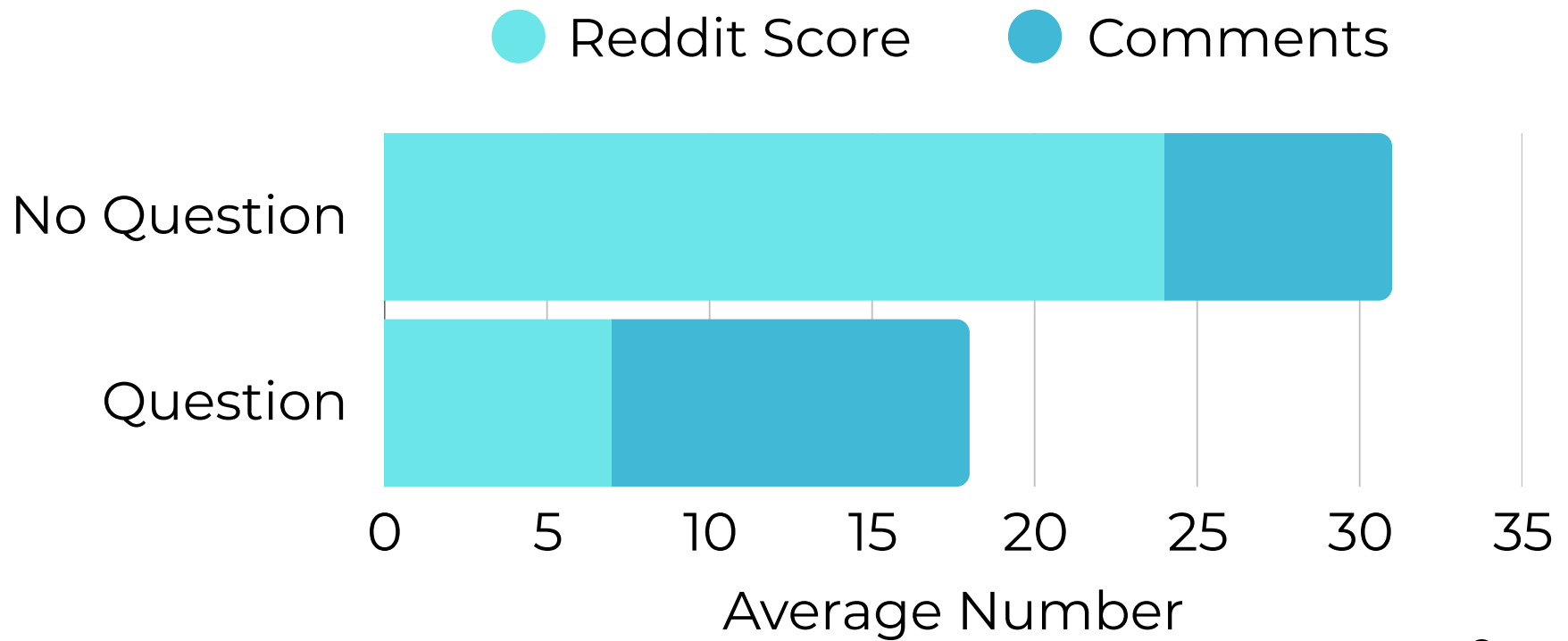
Posts mention recipient and donor

## Posters are in the moment or looking forward..

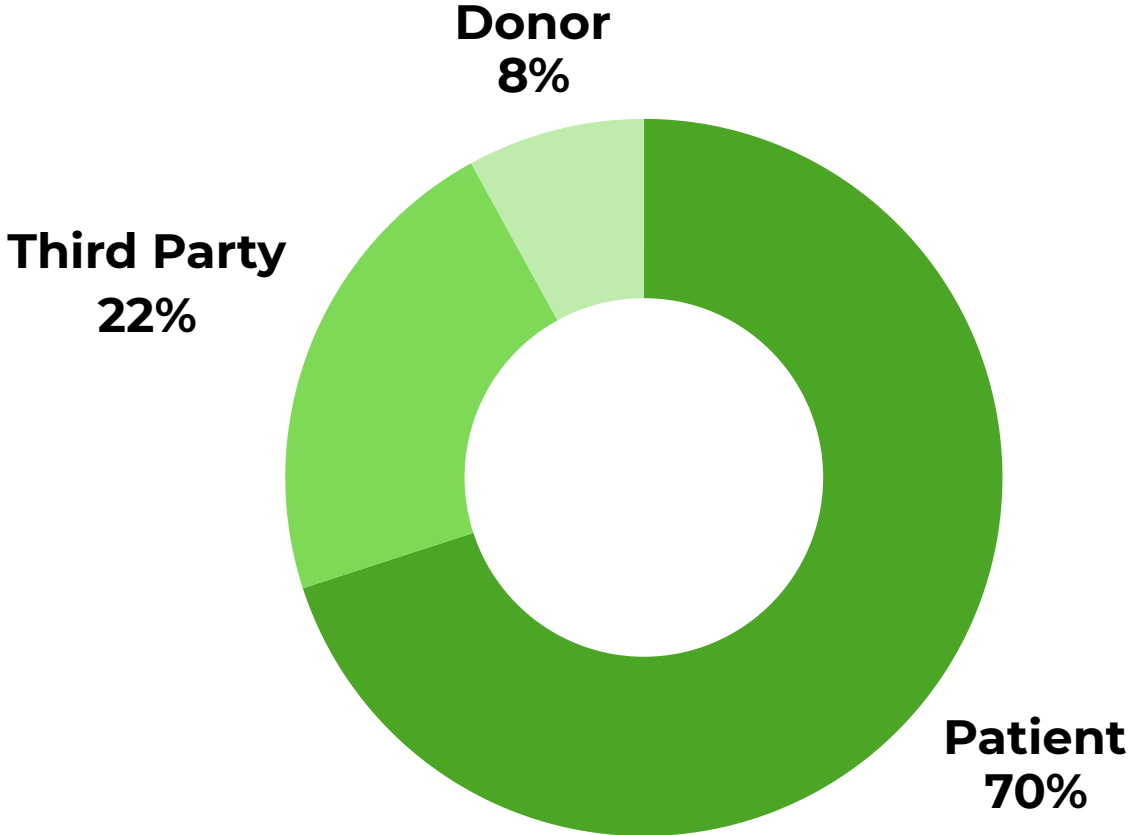
While most questions for a stage are asked while the author is in that stage (>80%), the next highest proportion (10-15%) come from when the author is in the directly preceding stage.

# What if it's not a Question?

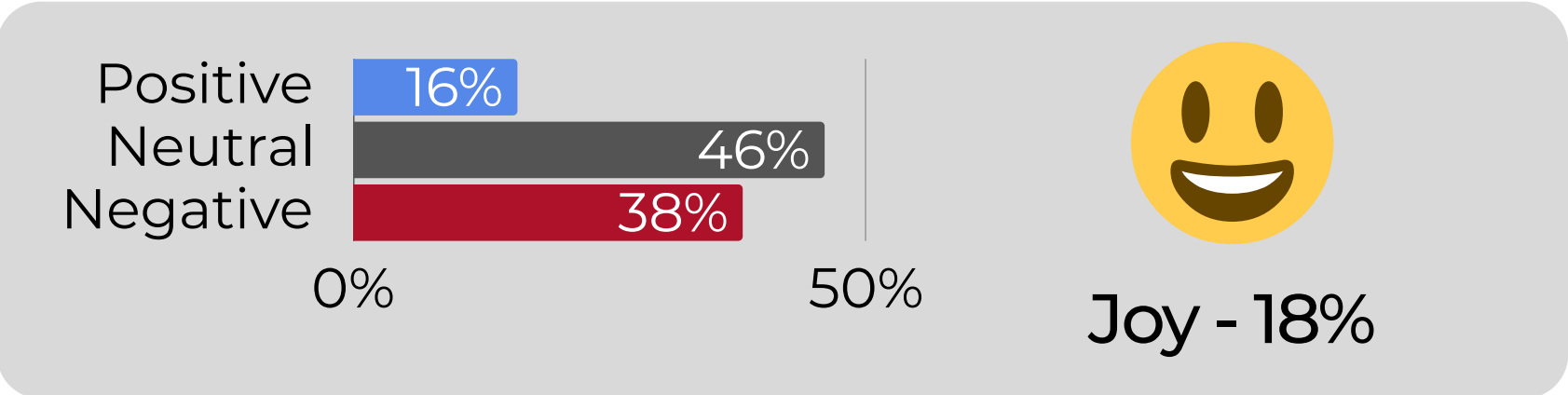
## More but Different Engagement



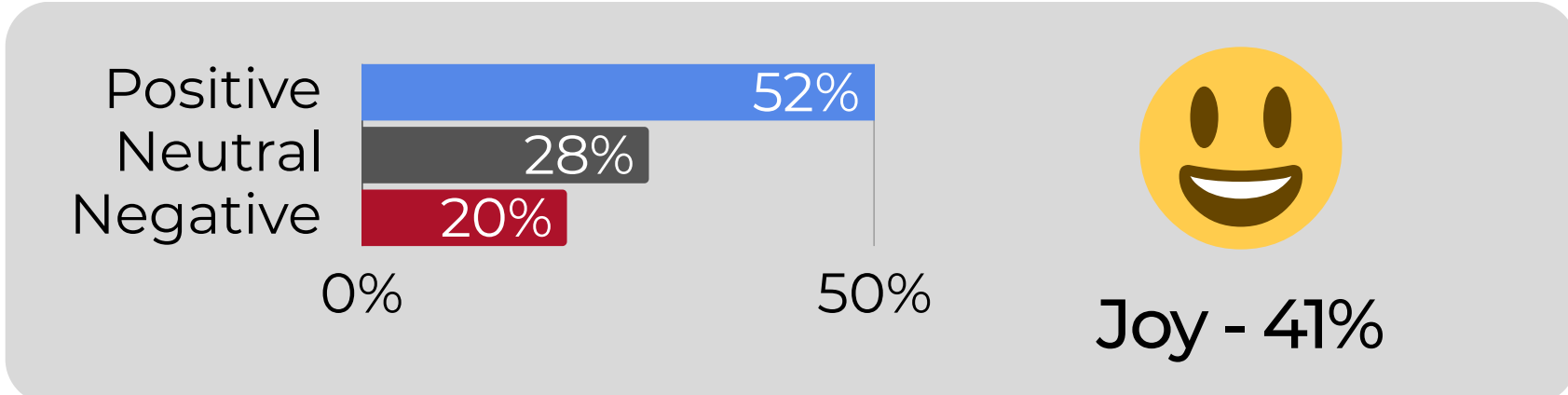
## Mostly Still Patients (and post op)



Quite joyful!



Brandwatch Analysis



Unverified LLM Analysis

# RECOMMENDATIONS

## Now/ Quick Wins



1. Answer the highest-volume, highest-confusion questions first
  - Focus first on **Post-Operative stage** (the largest cluster across all five stages)
2. Create Dedicated Donor & Caregiver Resource Pages
  - Provide **simple, accessible guidance** (“How to support someone in X stage”)
3. Incorporate Sentiment Insights Immediately
  - Include **“What is normal”** + **“When to worry”** micro-guides
4. Review Workflow
  - **Clinician review** for high-risk themes (drug interactions, infections)

# RECOMMENDATIONS

Next

- Validate the taxonomy with experts and stakeholders
  - Refine **themes and subthemes**
- Incorporate a structured Q&A format to the first version of Transplants.org
- Access data from private groups
  - Understand differences between **public vs private queries**
- Create content governance + review SOPs
- Set up early analytics & success metrics
  - **Measure engagement** + whether sentiment changes after viewing responses



# RECOMMENDATIONS

## Later Vision

- **Extend our validated methodology to other organs**

Scale taxonomy + workflow to heart, pancreas, liver, lung

- **Community matching (“People Like Me”)**

Connect users with peers who share similar journeys (eg, living donors)

- **Build a research & advocacy signal pipeline**

Identify recurring questions without clear medical consensus

- **Annual “State of Transplant Questions & Emotions” report**

Track which questions grow or shrink over time





# Risk and Limitations

Dataset Limitations

Trust and Credibility Risks

LLM Specific Limitations

Bias and Coverage Gap

Scope Limitations



# Potential Future Projects with CMU

- This dataset could be used to create an internal LLM for Transplants.org to properly answer patient questions and guide them to effective resources
- Further develop methodology to classify and extract questions, sentiment, and dialogue to explore the relationship between AI and the patient experience

**Thank You.**

Any Questions?