

# **Welcome ASTCT - NMDP Access Workshop Attendees!**

**Thursday August 24<sup>th</sup> – Friday August 25<sup>th</sup>, 2023**

**ASTCT Washington D.C. Headquarters**

# ASTCT NMDP ACCESS Initiative

## Second Annual Workshop

Washington D.C.

August 24 & 25, 2023

# ACCESS Initiative: Purpose and Vision

- **PURPOSE:**

- To reduce barriers to hematopoietic cell therapy and transplantation through implementation of changes in practice and policy by active, sustained engagement of the cell therapy ecosystem

- **VISION:**

- To advance, measure and sustain progress toward universal access in the initial focus areas of awareness, poverty and racial inequality

# ACCESS Initiative: Focus Area Committee Goals

## Awareness

- To improve access to HCT/CT by identifying areas for increasing awareness education and intervention for the patient, physician, and transplant program

## Poverty

- To identify patients at high risk of adverse outcomes due to socioeconomic adversity and develop patient-, center-, and policy-related initiatives to improve their access and survival

## Racial Inequity

- To improve equity in access and outcomes for all HCT/CT recipients regardless of their race or ethnicity

# ACCESS Initiative: Committee Leadership

**ASTCT  
Chairs**

## Awareness



Brenda Sandmaier

**NMDP  
Chairs**



Erica Jensen

## Poverty



Navneet Majhail



Jessica Knutson

## Racial Inequity

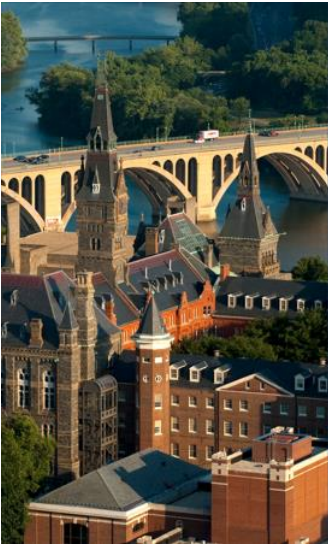


Eneida Nemecek



Rafeek Yusuf



# Inaugural ASTCT-NMDP ACCESS Workshop July 28 & 29, 2022 Washington, D.C.



**Georgetown | Lombardi**  
COMPREHENSIVE CANCER CENTER

**Intersectionality of Cancer,  
Aging and Disparities: A  
Biological Basis**

Lucile L. Adams-Campbell, Ph.D.  
Professor of Oncology  
Senior Associate Dean, Community Outreach and Engagement  
Associate Director, Minority Health & Health Disparities Research



Equal Outcomes for All

# 2023 Tandem Meetings Orlando, FL



**Staci Arnold, MD,  
MBA, MPH**  
Aflac Cancer & Blood  
Disorders Center  
Healthcare Disparities



**Warren Fingrut, MD**  
Memorial Sloan Kettering  
Cancer Center  
Access Disparities

**ACCESS  
INITIATIVE  
WORKSHOP**

**Saturday, February 18, 2023**  
12:30 PM - 2:30 PM EST  
World Center Marriott - Crystal NPQ

**OF ALL FORMS OF  
INEQUALITY, INJUSTICE  
IN HEALTH IS THE  
MOST SHOCKING  
AND INHUMANE.**  
-MARTIN LUTHER KING JR.

**THE ACCESS INITIATIVE  
NEEDS YOUR HELP.**

Join the American Society for  
Transplantation and Cellular  
Therapy (ASTCT™) and  
the National Marrow Donor  
Program (NMDP®) in the  
fight to increase ACCESS  
to transplant.



**ASTCT™**  
American Society for  
Transplantation and Cellular Therapy

**NATIONAL  
MARROW  
DONOR  
PROGRAM®** **BE THE MATCH®**



**Sumithira Vasu, MD**  
The Ohio State  
Comprehensive  
Cancer Center  
Patient & Caregiver  
Advocacy

Equal Outcomes for All

# ASTCT-NMDP ACCESS Initiative



## Transplantation and Cellular Therapy

ELSEVIER

journal homepage: [www.tctjournal.org](http://www.tctjournal.org)

### Position Statement

## The ASTCT-NMDP ACCESS Initiative: A Collaboration to Address and Sustain Equal Outcomes for All across the Hematopoietic Cell Transplantation and Cellular Therapy Ecosystem

Jeffery J. Auletta<sup>1,2,\*</sup>, Brenda M. Sandmaier<sup>3,4</sup>, Erica Jensen<sup>1</sup>, Navneet S. Majhail<sup>5</sup>, Jessica Knutson<sup>1</sup>, Eneida Nemecek<sup>6</sup>, Femina Ajayi-Hackworth<sup>1</sup>, Stella M. Davies<sup>7</sup>, on behalf of the ACCESS Workshop Team<sup>† †</sup>

<sup>1</sup> National Marrow Donor Program, Minneapolis, Minnesota

<sup>2</sup> Hematology/Oncology/Blood and Marrow Transplant and Infectious Diseases, Nationwide Children's Hospital, Columbus, Ohio

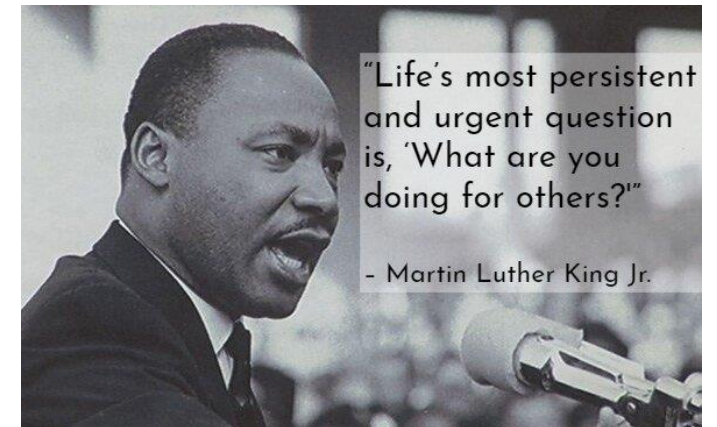
<sup>3</sup> Fred Hutchinson Cancer Center, Seattle, Washington

<sup>4</sup> University of Washington School of Medicine, Seattle, Washington

<sup>5</sup> Sarah Cannon Transplant and Cellular Therapy Network, Nashville, Tennessee

<sup>6</sup> Oregon Health Sciences University, Portland, Oregon

<sup>7</sup> Bone Marrow Transplant and Immune Deficiency, Cincinnati Children's Hospital Medical Center, Cincinnati, Ohio





# Agenda: Day 1




- Committees should assign a notetaker for committee breakouts and for each committee group presentation
- Notetakers will submit electronic notes to Debbie Fernandez  
[dfernandez@francefoundation.com](mailto:dfernandez@francefoundation.com)

Thursday, August 24, 2023

1:30 PM – 2:00 PM

## Arrival/Refreshments/Welcome

1:45-2:00 Overview: Jeff Auletta, Stella Davies

2:00 PM – 3:30 PM 


## Committee Breakouts

Committees meet individually to review progress/ideas

3:30 PM - 4:00 PM

## Break/The France Foundation Presentation

10-minute break; 20 minutes The France Foundation Capabilities Presentation

4:00 PM – 6:00 PM 

## Committee Presentations

1. 4:00-4:40 pm Poverty Committee
2. 4:40 -5:20 pm Racial Inequity
3. 5:20-6:00 pm Awareness

6:00 PM - 6:30PM

## Wrap-up Day 1

7:00 PM

## Dinner

Chef Geoff's  
2201 M Street NW (202) 237-7800

7:45 PM – 8:30 PM

## Dinner Speaker

***Why Achieving Health Equity Takes trust and Courage***  
**Ray Bignall, MD, FAAP, FASN**

Chief Diversity and Health Equity Officer  
Nationwide Children's Hospital  
Director, Kidney Health Advocacy and Community Engagement (KHACE)  
Division of Nephrology and Hypertension  
Associate Professor of Clinical Pediatrics  
The Ohio State University College of Medicine

# Agenda: Day 2



- Each committee should assign a notetaker for each project deep dive
- Notetakers will submit electronic notes to Debbie Fernandez  
[dfernandez@francefoundation.com](mailto:dfernandez@francefoundation.com)

## Friday, August 25, 2023

8:00 AM – 8:30 AM

**Coffee and Breakfast/Welcome**

8:30 AM – 9:30 AM



**Pilot Project Deep Dive: Medicaid Scan**

Navneet Majhail, Jess Knutson, Ellie Beaver

9:30 AM – 10:00 AM



**Pilot Project Deep Dive: Kaiser Permanente Database**

Rafeek Yusuf

10:00 AM – 10:15 AM

**Break**

10:15 AM – 10:45 AM



**Pilot Project Deep Dive: Health Equity in Practice**

Delilah Robb

10:45 AM – 11:45 AM

**Group Discussion: One Year Later – Metrics of Success and Future Directions**

Jeff Auletta, Stella Davies

11:45 AM – 1:15 PM

**Working Lunch**

11:45-12:30 pm Patient Member Considerations

Emily Ward, Jackie Foster

12:30-1:15 pm Tandem Meeting Planning

Jeff Auletta, Stella Davies

1:15 PM – 1:30 PM

**Wrap-Up**

1:30 PM

**Workshop Ends; Depart for Airport**

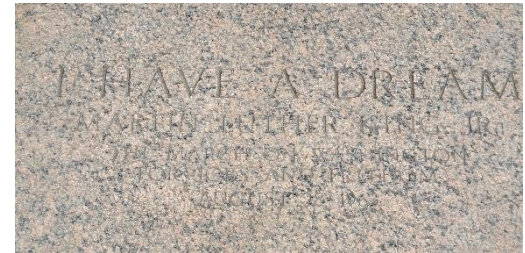
# Considerations

- What is going well?
- What adjustments are needed?
  - Committee structure
  - Goals
  - Pilot projects
- What do we need?
- Do we have the right people?
- How can we integrate patients into the Initiative?
- Industry partnerships

**Helping one person might not change the world, but it could change the world for one person.**  
– **Anonymous**

“I have a dream that one day this nation will rise up and live out the true meaning of its creed.”

-- August 28, 1963  
*on the steps of the Lincoln Memorial*



# Acknowledgments

- Amy Ronneberg, CEO NMDP
- Andre Williams, Executive Director ASTCT
- NMDP Foundation
  - Joy King, Angie Fitzgerald, Amy Connor
- ASTCT
  - Angie Dahl, Alycia Maloney
- France Foundation
  - Debbie Fernandez





# Committee Breakouts

## 2:00-3:30 PM

**Awareness:** Client Conference Center (CCC)

**Poverty:** Multi-Purpose Room (MPR)

**Racial/Ethnic Inequity:** Library

# **Break/The France Foundation Presentation 3:30-4:00 PM**

**3:30-3:40 PM – Break**

**3:40-4:00 PM – The France Foundation Capabilities Presentation**



# The France Foundation



# WHO ARE WE...

Founded in 1999

Award Winning – Collaborations and Educational Design



JOINTLY ACCREDITED PROVIDER™  
INTERPROFESSIONAL CONTINUING EDUCATION

Jointly Accredited Provider  
Accreditation Council for Continuing Medical Education (ACCME)  
Accreditation Council for Pharmacy Education (ACPE)  
American Nursing Credentialing Center (ANCC)

Recognized by Peers, Collaborators, and Others

Wholly-Owned Subsidiary of Smithbucklin

# WHAT WE DO...

- The France Foundation (TFF) has been at the forefront of planning, developing, and implementing certified medical education. TFF has implemented thousands of educational activities over the past 20 years.
- Our services include project management, content development, multi-media content development, in-house animation, accreditation, and outcomes analysis services.

# WHAT WE DO...Live Events



Grand Rounds



Immersive Workshops

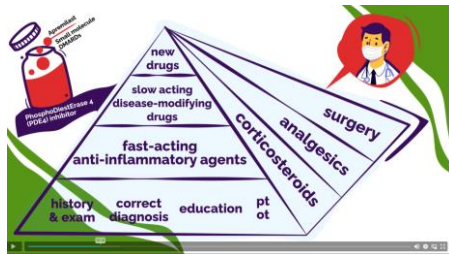


Specialty Symposia



Congress Sessions

# WHAT WE DO...Online Activities



rheic Arthritis?



## Animation Videos

## Video Modules

Advances in Multiple Sclerosis (AIMS) Primer: Third Edition

Factor	Relationship to Risk for MS
Vitamin D	Insufficiency is associated with increased risk for MS
Sunlight exposure	Decreased exposure may relate to vitamin D or other primary process
Geographic location	Latitude effect; geographic prevalence of disease with decreasing exposure to sunlight may be mediated by vitamin D, genetics, or infection
Epidemiologic studies	MS risk increases several fold following EBV infection

**What is TTP?**

**Form of thrombotic microangiopathy (TMA) characterized by:**

- Microangiopathic hemolytic anemia (MAHA)
- Neurologic damage (mainly brain, heart, kidney)
- Thrombocytopenia

**Rare Disease**

- Incidence: 2 to 6 new cases per million people
- Prevalence: 1.9 cases/million in US (Oklahoma registry, Dec 2015)
- More frequent in women than men (ratio approximately 2-3 to 1)
- Median age at onset approximately 40 years

**Triggers-Conditions that increase VWF Levels**

- Inflammation due to infection, surgery, autoimmune disorders, or cancer
- Pregnancy

**Unmet Need**

- Mortality: 15%-20% with treatment
- Exacerbation: occurs in up to 50% of acute events
- Ineffective treatment: sometimes refractory to standard treatment
- Thrombotic complications: major complications may occur during acute events
- Long-term consequences: microthrombotic events in first 2-5 days
- Risk of recurrence: 30%-40% of cases

**EMPAT**  
Effective Management of Pain at Treatment of Hematology

**SCREEN FOR PAIN AT EVERY ENCOUNTER**

- In patients with hematologic malignancies, pain is reported in:
- Patients should be screened at every office visit

Ongoing pain is observed in 33% of patients during survivorship and 60% of patients receiving treatment. Thus, these patients should be screened for pain at every healthcare visit.

Click on the arrows to learn more.

Autoplay: On

HIDE TEXT

CHALLENGE US

## Primers and Downloadable Guides

## Adaptive Learning

# OUR PARTNERS...

- TFF has been a trusted partner for many years, working closely with today's leading societies and associations in oncology and hematology, to implement innovative education with the objective of ultimately improving the care that clinicians provide.




# RECENT WORK WITH ASTCT...

## Project ECHO Series and Online Modules

SERIES 1 of 4

### Identification of **RELAPSED ALL**



Reshma Ramtal, MD, FACP  
Associate Professor  
Hematologist/Oncologist  
University of Kentucky  
Markey Cancer Center  
Lexington, KY




SERIES 2 of 4

### Treatment of Ph+ Relapsed/ Refractory Acute Lymphoblastic

SERIES 3 of 4

### Treatment of Ph- Relapsed/ Refractory Acute Lymphoblastic Leukemia (ALL)

BEGIN ACTIVITY

## Program Description - Live

The education will be delivered using the PROJECT ECHO model which includes a series of 4 virtual mentoring discussion sessions at each hub.

### Virtual Sessions

- University of Kentucky Markey Cancer Center
  - 09/08 | 12:00 pm EST - Identification of Relapsed ALL (Topic 1)
  - 10/13 | 12:00 pm EST - Treatment of Relapsed/Refractory Ph+ ALL (Topic 2)
  - 11/10 | 12:00 pm EST - Treatment of Relapsed/Refractory Ph- ALL (Topic 3)
  - 12/08 | 12:00 pm EST - Managing the Adverse Effects of Newer Therapies for ALL (Topic 4)

### Oregon Health and Science University Knight Cancer Institute

- 09/12 | 3 pm EST - Identification of Relapsed ALL (Topic 1)
- 10/17 | 3 pm EST - Treatment of Relapsed/Refractory Ph+ ALL (Topic 2)
- 11/07 | 3 pm EST - Treatment of Relapsed/Refractory Ph- ALL (Topic 3)
- 12/05 | 3 pm EST - Managing the Adverse Effects of Newer Therapies for ALL (Topic 4)



# RECENT WORK WITH ASTCT...

## Interactive Online Module Series

Diagnosing and Assessing  
**Chronic  
GVHD**

BEGIN ACTIVITY ▶



Principles of Management of  
**Chronic  
GVHD**

BEGIN ACTIVITY ▶



Emerging Treatments in  
**Chronic  
GVHD**

BEGIN ACTIVITY ▶



# RECENT WORK WITH ASTCT...

## Project ECHO Series and Online Modules in Partnership with ASH

**CAR T-Cell Therapy Consults:**  
NAVIGATING A NEW LANDSCAPE

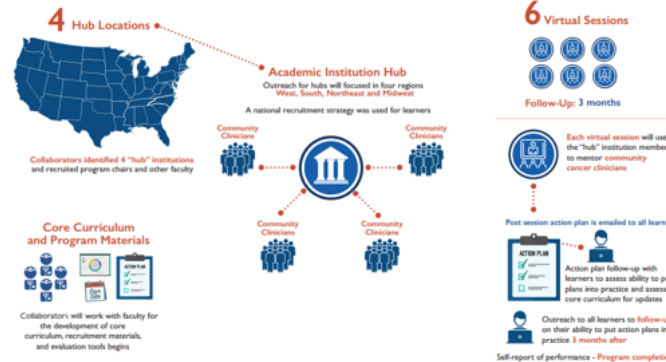
**BEGIN ACTIVITY**

ASTCT  
The France Foundation  
ECHO

Live

## Program Description-Live

The education was delivered using the PROJECT ECHO model, which included a series of 6 virtual mentoring discussion sessions at each hub



### Virtual Sessions

1. CAR T in B-ALL: Introduction and Identification of Patients-Deciding When to Refer (Topic 1)
2. CAR T in B-ALL: Treatment, Short- and Long-term Follow-up (Topic 2)
3. CAR T in Multiple Myeloma: Introduction and Identification of Patients-Deciding When to Refer (Topic 3)
4. CAR T in Multiple Myeloma: Treatment, Short- and Long-term Follow-up (Topic 4)
5. CAR T in BCL/DLBCL: Introduction and Identification of Patients-Deciding When to Refer (Topic 5)
6. CAR T in BCL/DLBCL: Treatment, Short- and Long-term Follow-up (Topic 6)





Questions?

[tbruno@francefoundation.com](mailto:tbruno@francefoundation.com)

# Committee Presentations

## 4:00-6:00 PM

**4:00 – 4:40 PM: Awareness**

**4:40 – 5:20 PM: Racial Inequity**

**5:20 – 6:00 PM: Poverty**

# ASTCT-NMDP ACCESS Initiative

## Awareness Committee

Washington D.C.

August 24 & 25, 2023

# 2022 ACCESS Working Group Committee: Awareness



- ASTCT Chair: Brenda Sandmaier
- NMDP Chair: Erica Jensen



Vice Chair: Jennifer Holter Chakraborty

# Challenge

A key barrier to increasing ACCESS to therapy is lack of awareness

## Providers

- Lack of knowledge of rapid advancements and changes in treatment options
- New standards of care, including referral guidelines that often are not disseminated to community physicians or even physicians at academic institutions that do not offer HCT/CT

## Patients

- Lack of knowledge of HCT / CT treatment options
- Access to available care and support information

# Physician Education and Access to Research



**Subcommittee Chair: Jennifer Holter Chakrabarty**

Subcommittee Members:

- Taha Aljuhaishi
- Pashna Munshi
- Tania Jain
- Sam Watters

# Physician Education and Access to Research

**Goal: Update information physicians reference for the latest information**

## Accomplishments

- ✓ Identified target areas for improvement in physicians reference in HSCT
  - ✓ Target areas identified include Determining Eligibility for HSCT highlighting early HLA testing, improvement in expansion/safety in older adults, expansion access in ethnically diverse patients
  - ✓ Highlight improvement in quality of life and outcomes in mismatched and matched donors
- ✓ Incorporation of HCT Consultation Timing Guidelines in UpToDate topics including AML, MDS, ALL
- ✓ Incorporating Donor and Cord Blood Unit Selection Guidelines in Donor Selection
- ✓ Incorporating new GVHD/Outcome date in Early Complications of HCT
- ✓ Updates in Overview of AML, ALL in children and Adolescents, and treatment of high or very high risk MDS to incorporate early referral for Allo evaluation

# Physician Education and Access to Research

**Goal: Update information physicians reference for the latest information**

## Coming Up

- Early discussion with ASTCT Education and Content Committees for Highlight of ACCESS initiatives
- Identification of Diversity and Equity Highlights with Content Committee for “ASTCT News Daily”
- Nucleus Spotlight on Access/Equity
- Identification of Dr. Munshi and Dr. Al-Juhaishi to lead updates in Auto and Car-T for UpToDate with ASTCT lead
- Work with MMRF and other foundations/patient groups for expansion of educational scope.



# Community Physician Awareness



**Subcommittee Chair: Anna Cincotta (Interim Chair, Emily LaMonica)**

**Subcommittee Members:**

- Dr. Beth Stenger (CHOA)
- Dr. Staci Arnold (CHOA)
- Dr. Tania Jain (Johns Hopkins)
- Dr. Alexandra Gomez Arteaga (Weill Cornell)
- Dr. Heather Stefanski (NMDP)
- Dr. Steven Devine (NMDP)
- Ruth Phillips (Blue Spark Technologies)
- Karen DeMairo (LLS)
- Emily LaMonica (NMDP)
- Sam Watters (NMDP)
- Becca Groebner (NMDP)

# Community Physician Awareness

**Goal: Develop partnerships and connections with community physicians**

## **Objectives:**

- ❖ Target high unmet need areas and engage community providers that do not have well established relationships with their regional transplant and cell therapy network
- ❖ Create peer-to-peer networking space around disease theme
- ❖ Spark collaborative discussion around shared challenges
- ❖ Highlight latest research and high priority clinical trials

*Thank you to Ruth Phillips (Blue Spark Technologies), Dr. Stenger & Dr. Arnold (CHOA), Dr. Jain (Johns Hopkins), Dr. Gomez Arteaga (Weill Cornell), Karen DeMairo (LLS), moderators Dr. Stefanski and Dr. Devine and our NMDP Local Provider Partnership team who facilitate these regionally.*

# Community Physician Awareness

**Goal: Develop partnerships and connections with community physicians**

## Accomplishments

✓ **NJ/NYC Peds SCD Physician Exchange Aug 17**

- Hackensack                      - NYP Columbia                      -Cohen Children's Medical Center of NY
- NYU Winthrop                      - St Joseph's Health                      - NYP Brooklyn Methodist

✓ **GA Peds SCD Physician Exchange Aug 22**

- CHOA                      - MUSC
- Navicent Health                      - Medical College of GA                      - Memorial Health/Children's Hospital of Savannah

## Coming Up

- Adult MDS Physician Exchanges (coming Fall 2023)

# Partnerships to Increase Patient Awareness



## Subcommittee Chair: Becca Miller

### Subcommittee Members:

- Mary Hengen, NMDP
- Katie Schoepner, NMDP
- Anna Cincotta, NMDP
- Bri Springer, NMDP
- Karen DeMario, LLS

# Partnerships to Increase Patient Awareness

**Goal: Build / strengthen partnerships with national disease specific groups and health focused community organizations**

## Accomplishments

- ✓ Collaborating with American Cancer Society on opportunities to increase awareness of resources through their relationships with community physicians and patient support resources
- ✓ Partnering with LLS to increase access to transplant in the Hispanic Community
- ✓ Working with STAR (Sickle Cell Transplant Advocacy and Research Alliance)
- ✓ Sickle disease roundtables in NE and SE
- ✓ Met with Deloitte on how to help educate CGT leaders on patient access issues

# Partnerships to Increase Patient Awareness

**Goal: Build / strengthen partnerships with national disease specific groups and health focused community organizations**

## Coming Up

- **LLS Collaboration Opportunities**
  - LLS/NMDP Regional Hispanic Community Engagement: Local Clinical Ops Partner in Chicago to join LLS on a video for patient education along with a TC physician and a patient. It will focus on engaging the Hispanic community of joining the registry and share information about the support for donors and the services for patients from diagnosis to survivorship.
  - In person panel for sponsored by LLS at Malcolm X College. Include live Q&A, donor recruiting, and patient services awareness.
  - Both programs will be in Spanish with the intent to target multigenerational households. Opportunities to do this outreach in other regions.
- **Engaging with CGT leaders on Patient Access to new therapies**
  - Patient Services and Health Equity Leaders participating in a panel to represent access barriers for CGT patients at Deloitte's NextGen Therapies Industry Working Group in September 2023.
- **Discovery on additional partnership opportunities**
  - International Myeloma Research Foundation including the M-POWERed Initiative to improve outcomes in African American patients
  - Myeloma Crowd (HealthTree Foundation)
  - Epic (social determinants of health data) and other technology companies that could support patients
  - Expand collaboration opportunities with LLS, ACS and other organizations on driving patient awareness and education

# Awareness Future Exploration

- Focus on: Myeloma, AML and MDS
- Investigate Patient advocacy communication / resource opportunities with industry partnerships (Google, WebMD, top search returns)
- Add fellows as key audience to educate
- Assess ASCO opportunity
- Advocate for telemedicine outreach and other key community barriers
- Explore education / coordination with IHS (possible intersection with other committees)
- Creation and dissemination of standardized diagrams of treatment roadmaps
- Realign goals around key opportunities with CPE / Fellow education and connection and patient awareness

# ASTCT-NMDP ACCESS Initiative Poverty Committee Update

Washington D.C.

August 24 & 25, 2023



# ACTIONABLE PRIORITIES

- **Identify** HCT and cellular therapy recipients at high risk of adverse outcomes due to socioeconomic adversity and **develop patient-, center-, and policy-related initiatives** to improve their access and survival

# FOCUS AREAS

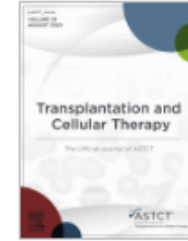
- Reducing barriers to access through Medicaid
- Understanding access barriers using Kaiser dataset
- Developing TCT advocacy *swat posse*





# Transplantation and Cellular Therapy

Available online 12 August 2023

In Press, Journal Pre-proof [?](#) What's this? [↗](#)



## Assessing Medicaid coverage for hematopoietic cell transplantation and chimeric antigen receptor T-cell therapy: A project from the ASTCT-NMDP ACCESS Initiative

Jeffery J. Auletta<sup>1,2</sup>  , Nandita Khera<sup>3</sup>, Patrick DeMartino<sup>4</sup>, Amar H. Kelkar<sup>5</sup>,  
Rafeek A. Yusuf<sup>1</sup>, Stella M. Davies<sup>6</sup>, Jessica Knutson<sup>1</sup>, Ellie Beaver<sup>1</sup>, Alycia Maloney<sup>7</sup>,  
Navneet S. Majhail<sup>8</sup>



# Medicaid Coverage for Cell Therapy Patients: Day 1

Ellie Beaver, Sr. Manager, Health Policy

---

# Agenda

---

- Day 1
  - Overview of Medicaid scan results
  - Key takeaways
- Day 2
  - Policy intervention proposals
  - Top intervention targets
  - Engaging ACCESS members
  - Accelerating Kids Access to Care Act (AKACA)



# Medicaid Policy Analysis

---

# Background

---

- The ACCESS Workgroup, a collaboration between NMDP and ASTCT to address non-HLA barriers to transplant, commissioned a 50-state + DC scan of state Medicaid programs for the following coverage policies.
  - Coverages policies for allogeneic and autologous stem cell transplant
  - Coverage policies for FDA-approved CAR-T therapies
  - Travel and lodging benefits
  - Payment methodology for donor search and cell acquisition costs
- Manatt Health was contracted to execute the scan.
- The scan was completed in May of 2023.
- Results were presented to ACCESS Workgroup members over the summer of 2023.

# Background

---

The ACCESS Workgroup, a collaboration between NMDP and ASTCT to address non-HLA barriers to transplant, commissioned a 50-state + DC scan of state Medicaid programs for the following coverage policies:

Coverages policies for allogeneic and autologous stem cell transplant

Coverage policies for FDA-approved CAR-T therapies

Travel and lodging benefits

Payment methodology for donor search and cell acquisition costs

- Manatt Health was contracted to execute the scan, completed in May 2023.
- Results were presented to ACCESS Workgroup members over the summer of 2023.



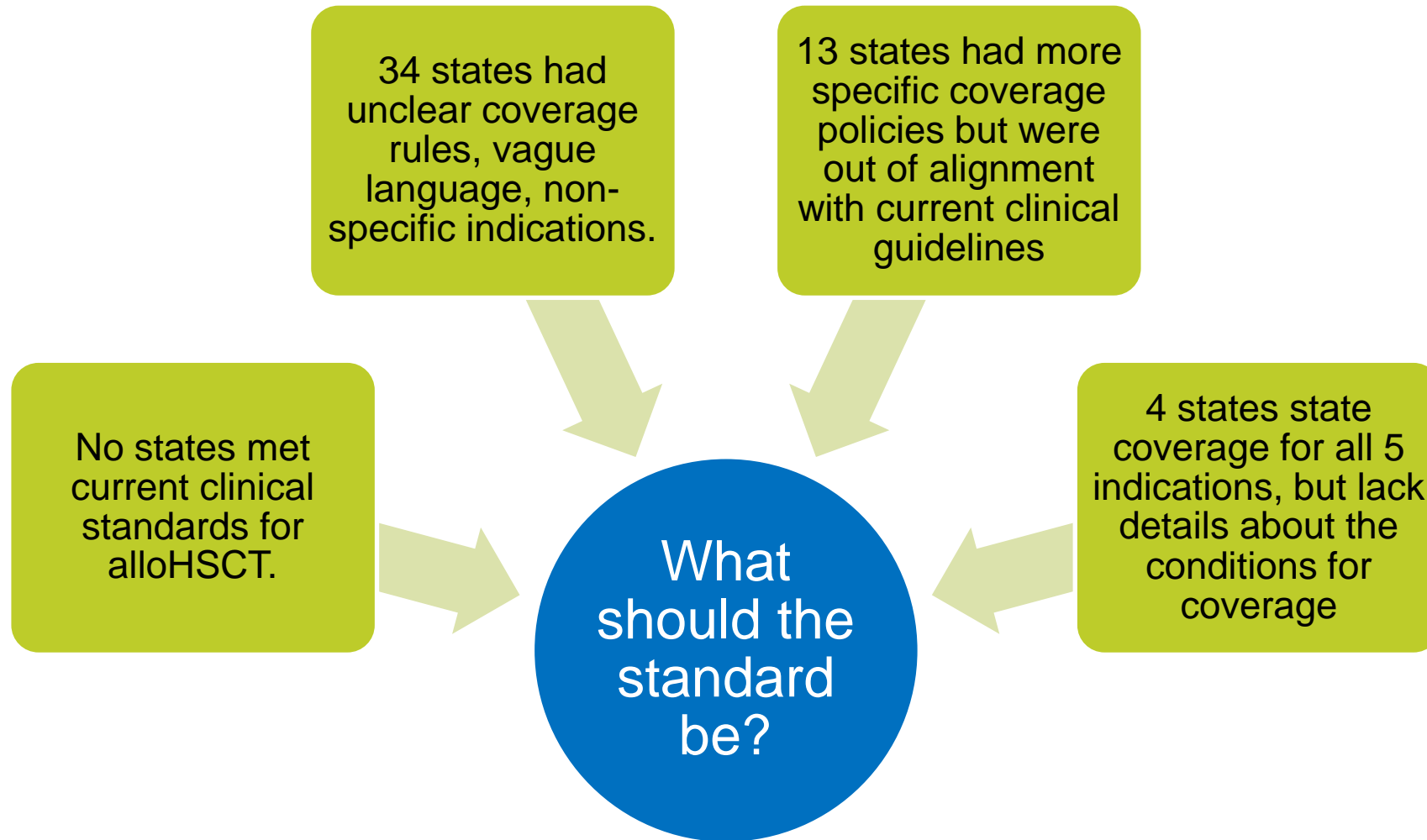
# Manatt analyzed key state *Medicaid fee-for-service (FFS)* coverage and reimbursement issues related to stem cell transplants and CAR T-cell therapies

## Research Scope

- Coverage of **stem cell transplants** for the following indications:
  - Allogeneic and Autologous
    - ◆ Acute Leukemia (AML, ALL)
    - ◆ Lymphoma
    - ◆ Multiple Myeloma
  - Allogeneic
    - ◆ Sickle Cell Disease
    - ◆ Myelodysplastic Syndrome (MDS)
- How coverage compares to the FDA label for certain CAR Ts used to treat **multiple myeloma, pediatric ALL and lymphoma.**
- Travel expenses, lodging expenses, meal expenses and companion expenses.
- Limits on such coverage (such as dollar caps) and whether enrollees must pay for the services out-of-pocket and seek reimbursement.
- Additional payment for donor costs for allogeneic stem cell transplants.
- Methodologies for determining the amount of such additional payments.

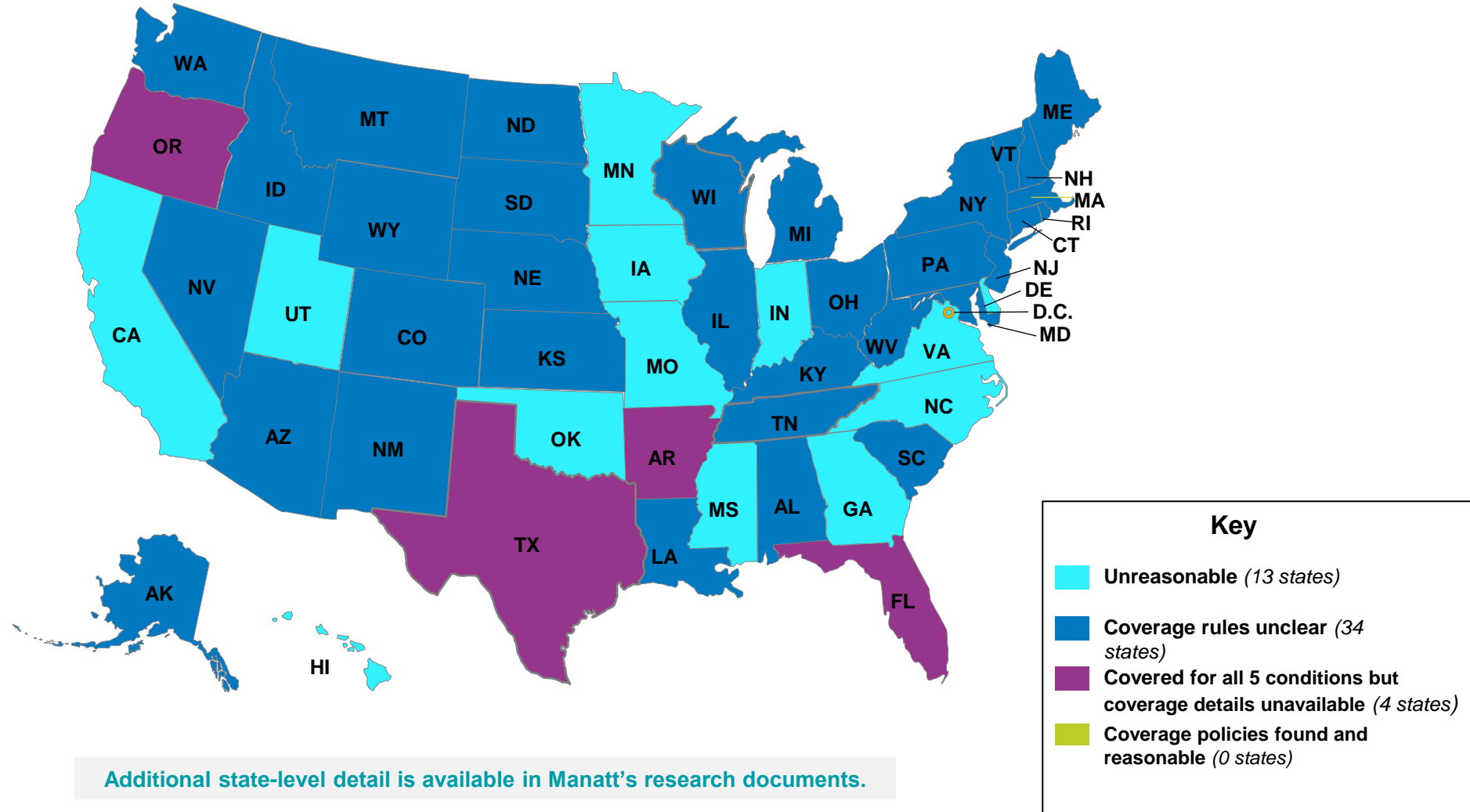
Note: Manatt's analysis focused on state policies, not those developed by or applied to Medicaid managed care organizations. CAR Ts examined consisted of Yescarta for lymphoma, Carvykti for multiple myeloma, and Kymriah for pediatric acute leukemia.

# Scan Findings: Coverage for alloHSCT



# AlloHCT Coverage Policies Overview

Of the states that had fully developed coverage policies, **all** had at least one unreasonable coverage condition.



# CAR T Therapies Coverage Policies Overview

---

- Most state CAR T coverage policies\* were reasonable, more so than the stem cell transplant policies
- Many states cover CAR T therapies in accordance with the FDA label
  - Some states have unreasonable restrictions not based on the FDA label
    - E.g. Prohibition of coverage if patients previously received a CAR T or had undergone a stem cell transplant
- Additionally, some states had discriminatory usage requirements, such as no coverage for those with HIV or hepatitis B or C

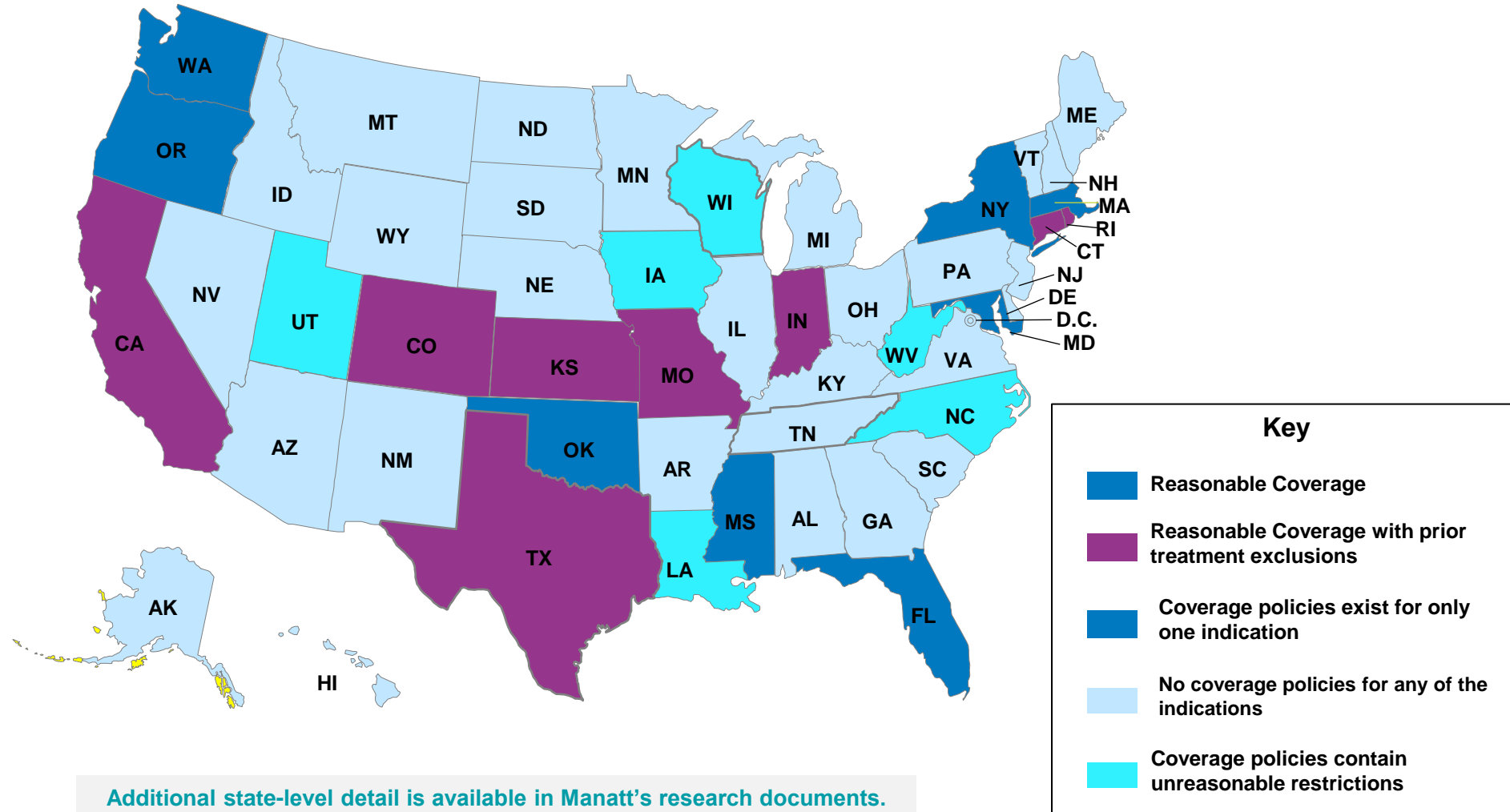
\*The data analysis was based on Yescarta for lymphoma, Carvykti for multiple myeloma, and Kymriah for pediatric acute leukemia

# CAR T Therapies Coverage Policies Overview

Most state CAR T coverage policies were **reasonable**.

However, several states did have coverage restrictions that ASTCT clinicians identified as **inappropriate**.

In addition, many states **prohibit coverage of CAR Ts if a patient had previously received another CAR T or had undergone a stem cell transplant**, a restriction that is not in the FDA label.



# Scan Findings: Medicaid Travel Benefits

All states cover transportation to Medicaid-covered services. The type of transportation offered varies by state and is dependent on cost-effectiveness and the Medicaid beneficiary's needs.

- Every state **covers out-of-state travel**, though some have more stringent requirements that must be met.
  - In Alabama, Medicaid beneficiaries must have their provider justify the need for out-of-state services and provide evidence that such services cannot be obtained in the state.
  - Georgia only allows out-of-state travel for treatments that are not normally provided by in-state medical providers.
- **Nearly all states say they cover airfare**; others may also cover travel by commercial airplane but do not specify this in their policies.
- **Most states provide mileage and gas reimbursement** for travel by personal car when the Medicaid beneficiary, their attendant or another volunteer can drive to the appointment or treatment.
  - Iowa will cover car rental expenses when it is the most economical choice given the Medicaid beneficiary's needs and the Medicaid beneficiary is able to drive themselves or has someone who is available to drive them.

# Scan Findings: Medicaid Travel Benefits

## All states cover transportation to Medicaid-covered services.

- Type of transportation offered varies by state and is dependent on cost-effectiveness and the Medicaid beneficiary's needs.

## Every state covers out-of-state travel.

- Some states have more stringent requirements that must be met.
- In Alabama, Medicaid beneficiaries must have their provider justify the need for out-of-state services and provide evidence that such services cannot be obtained in the state.
- Georgia only allows out-of-state travel for treatments that are not normally provided by in-state medical providers.

## Nearly all states say they cover airfare.

- Some states may also cover travel by commercial airplane but do not specify this in their policies.

## Most states provide mileage and gas reimbursement for travel by personal

car when the Medicaid beneficiary, their attendant or another volunteer can

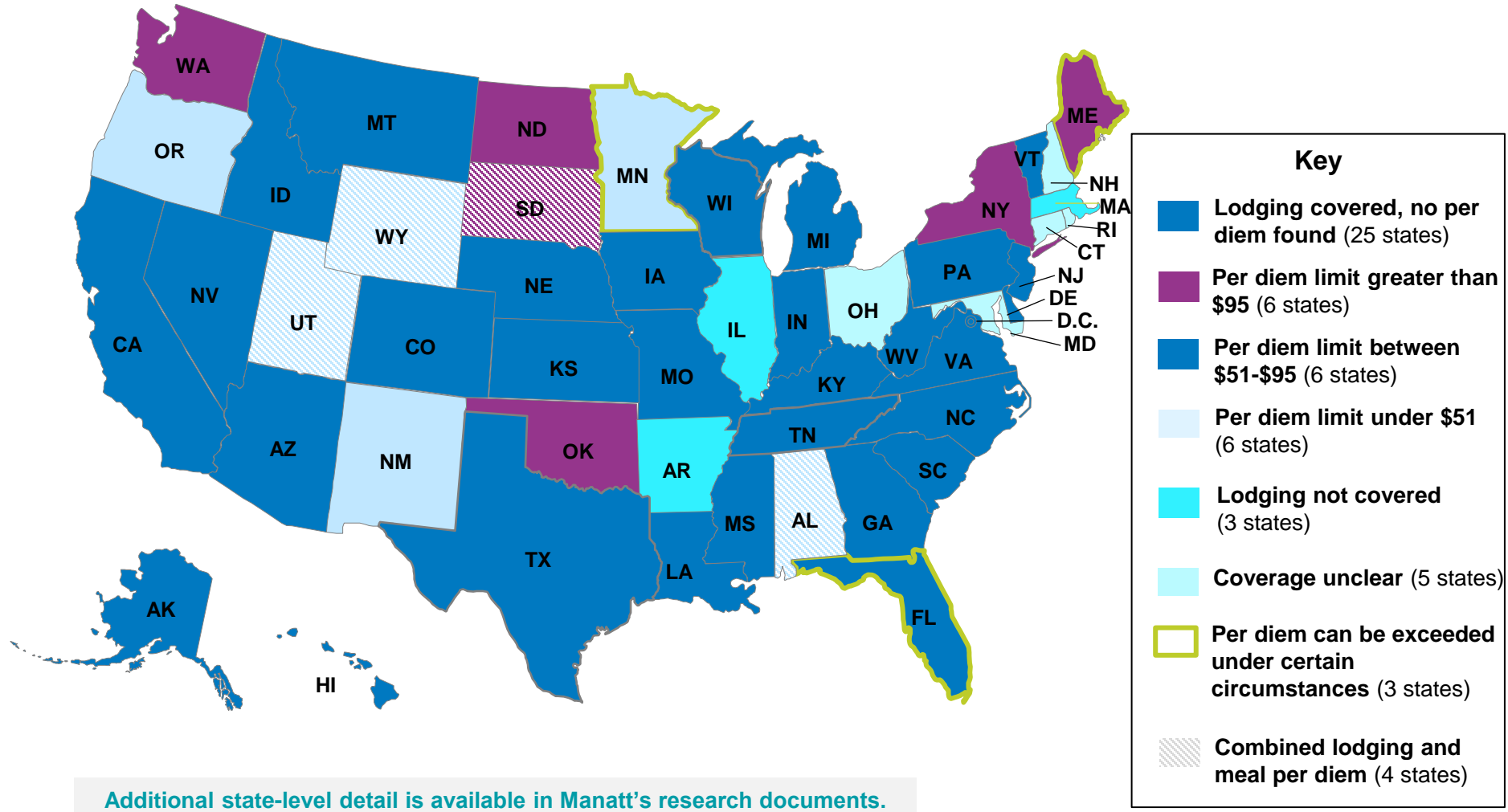
drive to the appointment or treatment.

- Iowa will cover car rental expenses when it is the most economical choice given the Medicaid beneficiary's needs and the Medicaid beneficiary is able to drive themselves or has someone who is available to drive them.

# Lodging: Per Diem Limits

Nearly all states cover lodging expenses related to travel for Medicaid-covered services.

Lodging reimbursement is often limited to instances when lodging is **more economical than additional round trip transportation** to the medical facility or the **beneficiary needs to be nearby the medical facility.**

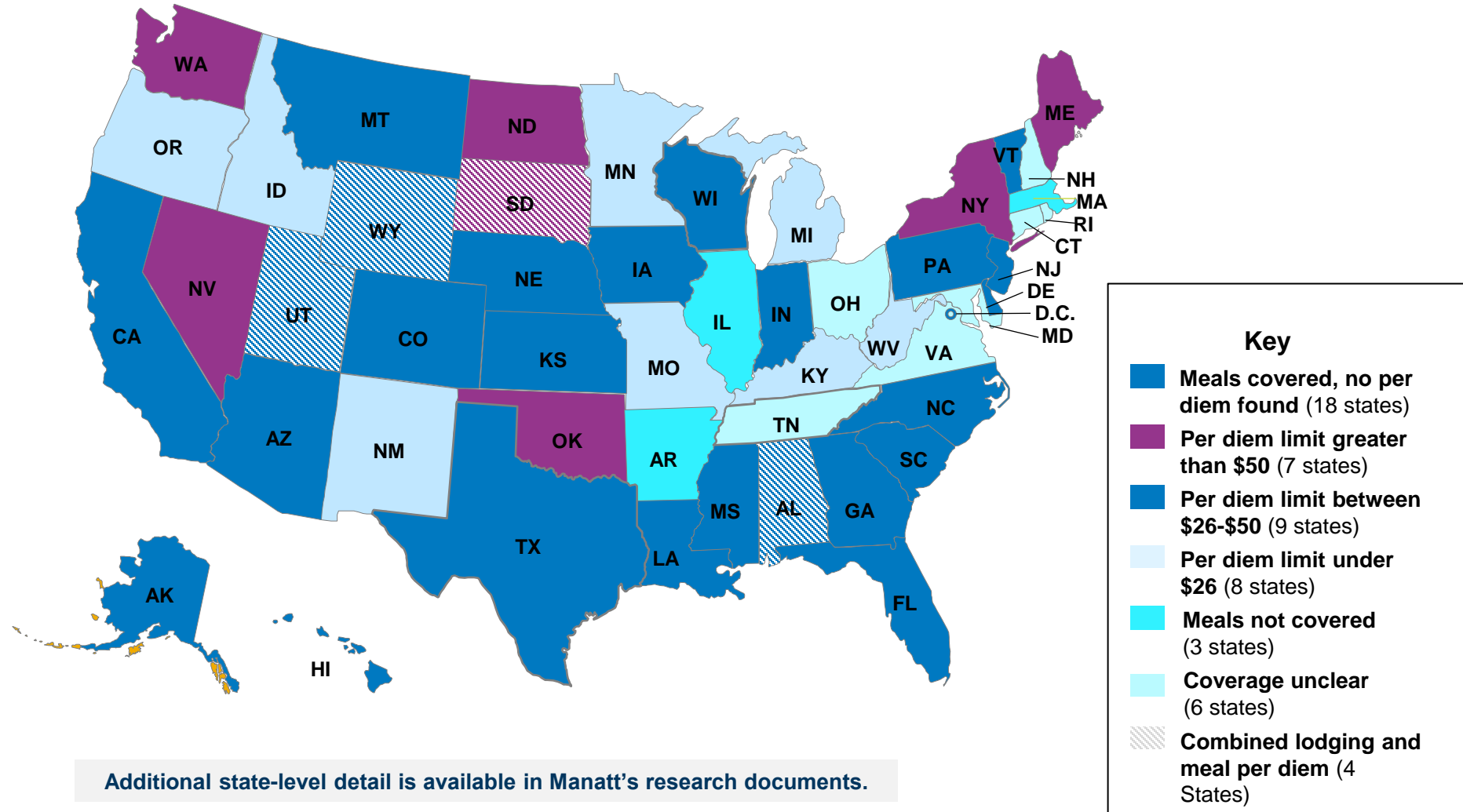




# Meals: Per Diem Limits

Nearly all states cover meal expenses related to travel to Medicaid-covered services.

Meal reimbursement is often limited to instances when the Medicaid beneficiary **must travel a significant distance or be away from their residence overnight** to receive treatment or attend an appointment.



# Other Findings for Travel, Lodging, Meals Benefits



Nearly all states cover attendant expenses.

Expenses covered for Medicaid beneficiaries age 18 and under and as medically necessary for adult Medicaid beneficiaries.



The payment process for travel related expenses varies greatly across states;

Lack of access to prepaid travel services in some states may limit Medicaid beneficiaries' access to treatment.



Most states have some prior authorization requirements in place for travel and lodging services.



Less than half of states require authorization for all travel services.

# Scan Findings: Payment for Donor Costs

States that provide additional reimbursement for donor costs have varying payment methodologies such as cost basis, percentage of charges, charge or cost-based reimbursement subject to a cap and other methodologies.

Donor Cost Payment Methodology	Payment Methodology Description	States With Methodology
<b>Cost Basis</b>	Payment approximately equals the <b>acquisition costs that are reported by the hospital or reasonable costs</b> . Similar to Medicare reimbursement.	CA, MD, MI, OK, WV
<b>Percentage of Charges</b>	Payment is a <b>percentage of charges</b> that the provider bills for stem cell acquisition.	AR, WA, WI, WY
<b>Charge or Cost-Based Reimbursement, Subject to a Cap</b>	<b>Payment based on charges or costs</b> , but reimbursement is subject to a <b>cap</b> .	IL, LA, MS, MO, NV, OR
<b>Other Methodologies</b>	Payment methodology other than based on costs or charges.	HI, IA, OH, VA

# Conclusions and Next Steps

---

## Conclusions

- Medicaid coverage for alloHSCT is vague or misaligned with current practice
- Car-T coverage policies are better, but could be improved
- Travel, lodging, meals benefits vary widely and are most likely not serving patients well
- Payment for donor costs spans the spectrum

## For Tomorrow

- In-depth discussion about the next steps
- Think about your experience with your state Medicaid program
  - Specific examples of barriers
  - Practices or processes that cause delays in time to transplant

Scan summary slides will be shared with the ACCESS group this afternoon

# ACCESS Working Group Committee: Racial/Ethnic Inequities



ASTCT Chair:  
Eneida Nemecek

NMDP Chair:  
Rafeek Yusuf

Vice Chair:  
Rayne Rouce

## Committee Members:

Belinda Avalos  
Pavan Reddy  
Steve Devine  
Lis Welniak

Nancy DiFronzo  
Frank Holloman  
Elizabeth EJ Shpall  
Anurekha Hall

Delilah Robb  
Jennifer Sees Coles  
Meggan McCann  
Amber Ruffin  
Brianna Springer  
Jackie Foster

# Goal for Our Committee

To improve equity in access and outcomes for all transplant and cell therapy recipients regardless of their race or ethnicity



# Initiatives to Address Racial/Ethnic Inequities (Original)

**Initiative #1**

Level the knowledge

**Initiative #2**

Optimize the data

**Initiative #3**

Workforce Development

# Initiatives to Address Racial/Ethnic Inequities (Current)

**Initiative #2**

Optimize the data



**Initiative #1**

Level the knowledge

**Initiative #3**

Workforce Development



# Initiative #2: Race/Ethnicity Data Optimization

1. Pilot with selected centers from different regions of the US, public and private insurance mix, affiliated to NCI-cancer institute
2. Data gathering: # and summary demographics of potential patients in catchment areas, patients for which donor search was initiated and final disposition and reasons for drop, if applicable, patients who proceeded to BMT
3. Identify trends in data and opportunities for positive impact (collaboration with Poverty committee)
4. Develop & disseminate best practices guidelines for collection of R&E data in transplant centers

Stakeholders: Transplant center representatives, NMDP Health Services Research & CIBMTR staff, representative from Poverty committee

# Accomplishments in the last year

1. Expansion of the project to include NMDP Health Equity team
2. Initial assessment of transplant center needs & interest to engage in the project
3. Development of toolkit for centers
4. Plan to launch Health Equity in Practice pilot project with selected centers (Fall 2023)

# ASTCT-NMDP ACCESS Initiative

Racial Inequity Committee  
Initiative #2: Race/Ethnicity Data Optimization

## Health Equity in Practice

Washington D.C.

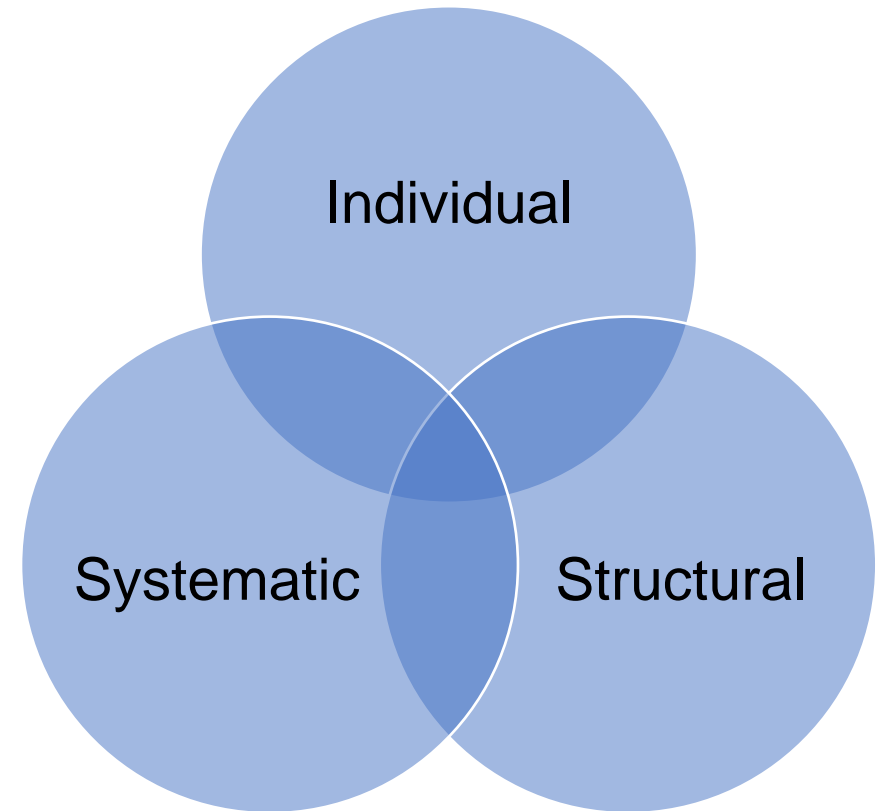
August 24 & 25, 2023

Delilah Robb, MPH

Program Manager, Data and Implementation Science

# Opportunity for Improvement

- Health outcomes and healthcare access barriers are inextricably connected.
- Barriers at the individual, structural and systematic levels have resulted in transplant access and outcomes disparities by race.
- Transplant centers (TCs) are interested and motivated to increase access to racially and ethnically diverse patients but do not always have access to data driven solutions.

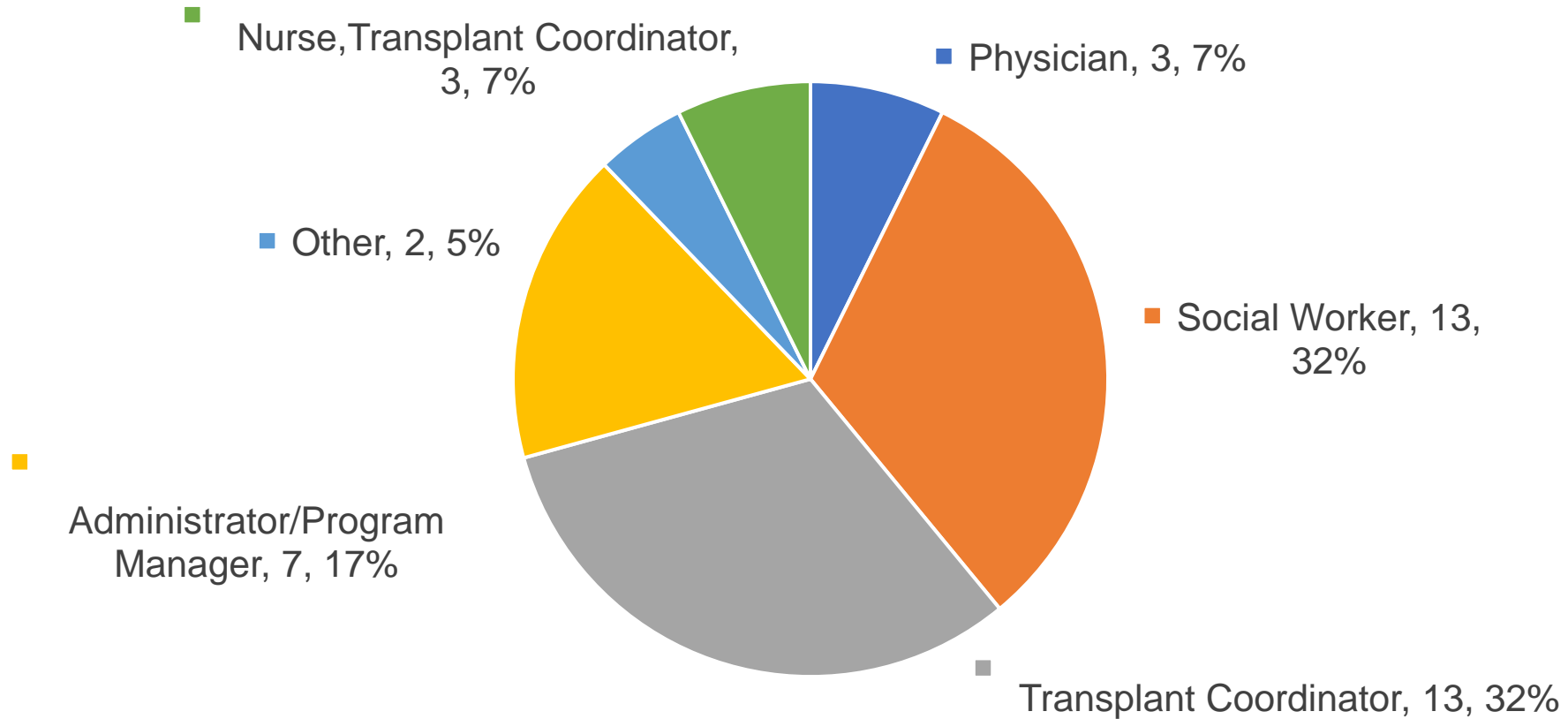


# Health Equity Survey

The survey goal is to better understand TC needs around health equity, create usable tools and resources to help improve practice leading to better patient outcomes and improved system performance.

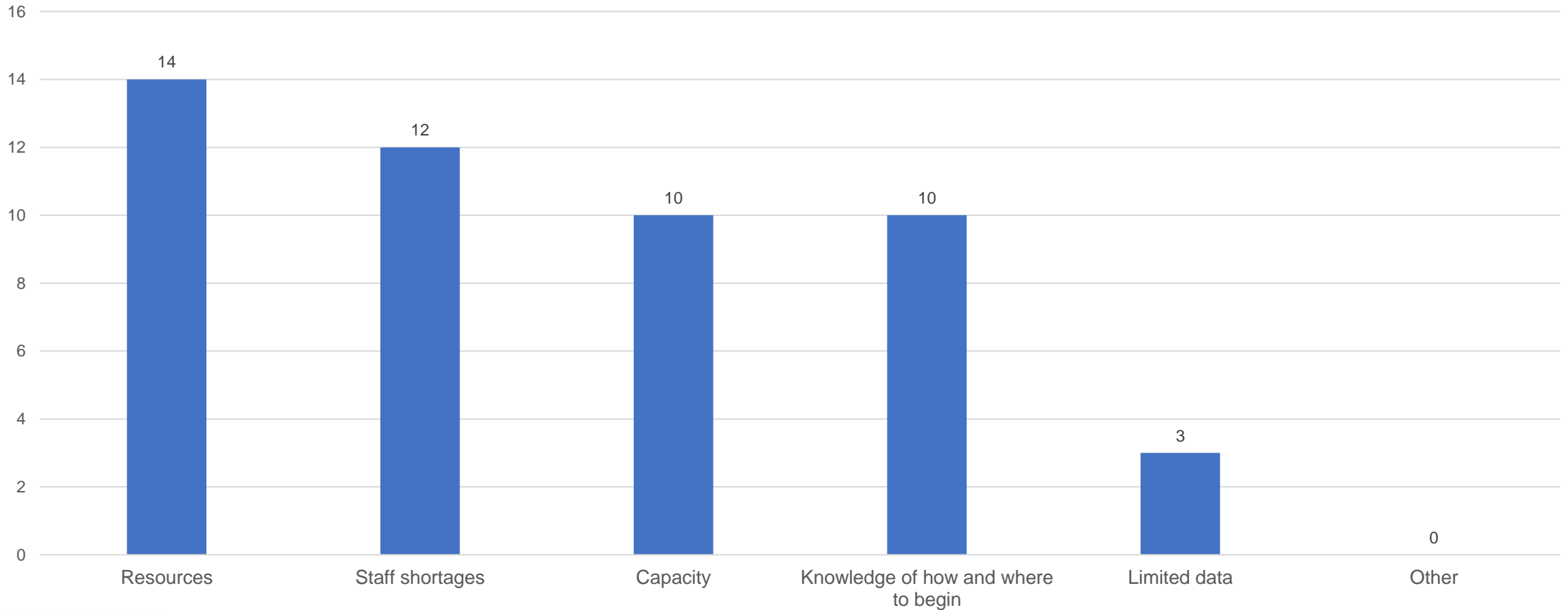
# Health Equity Survey Cont.

What is your role at the transplant center? (select all that apply)



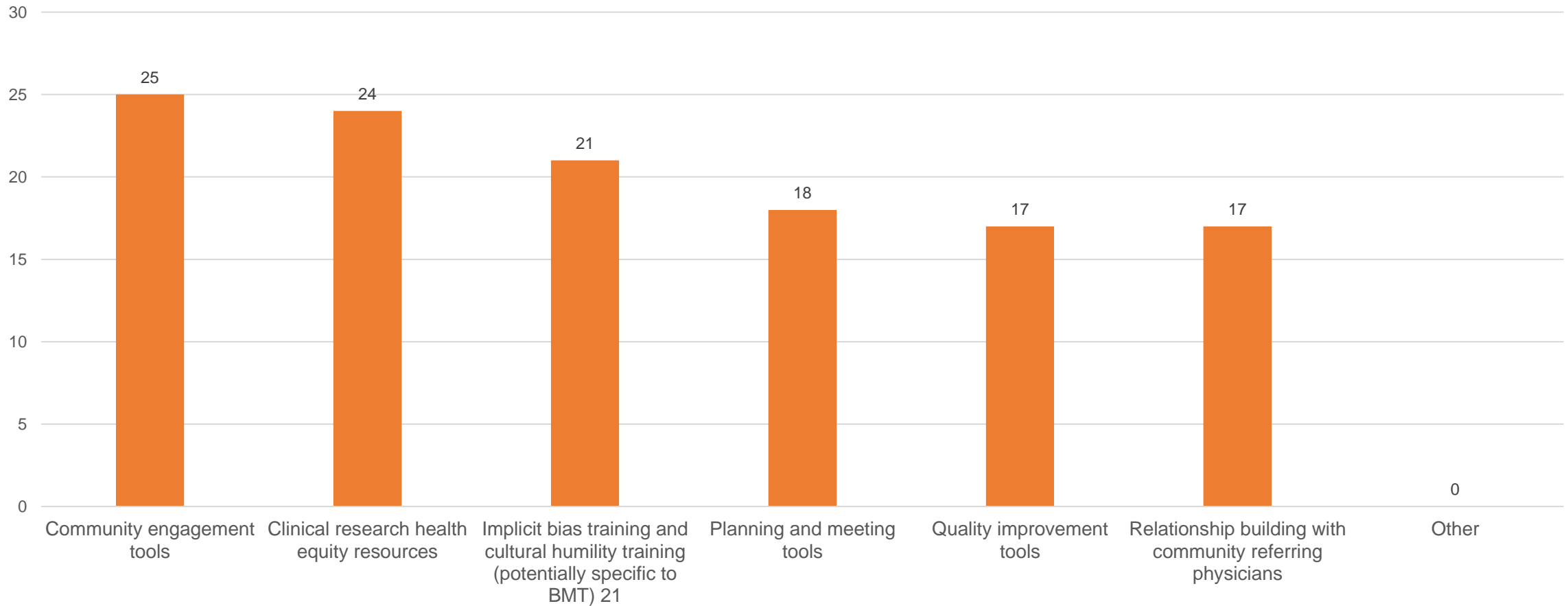
# Health Equity Survey Cont.

What challenges or barriers does your transplant center have with implementing health equity improvement projects (select all that apply)?



# Health Equity Survey Cont.

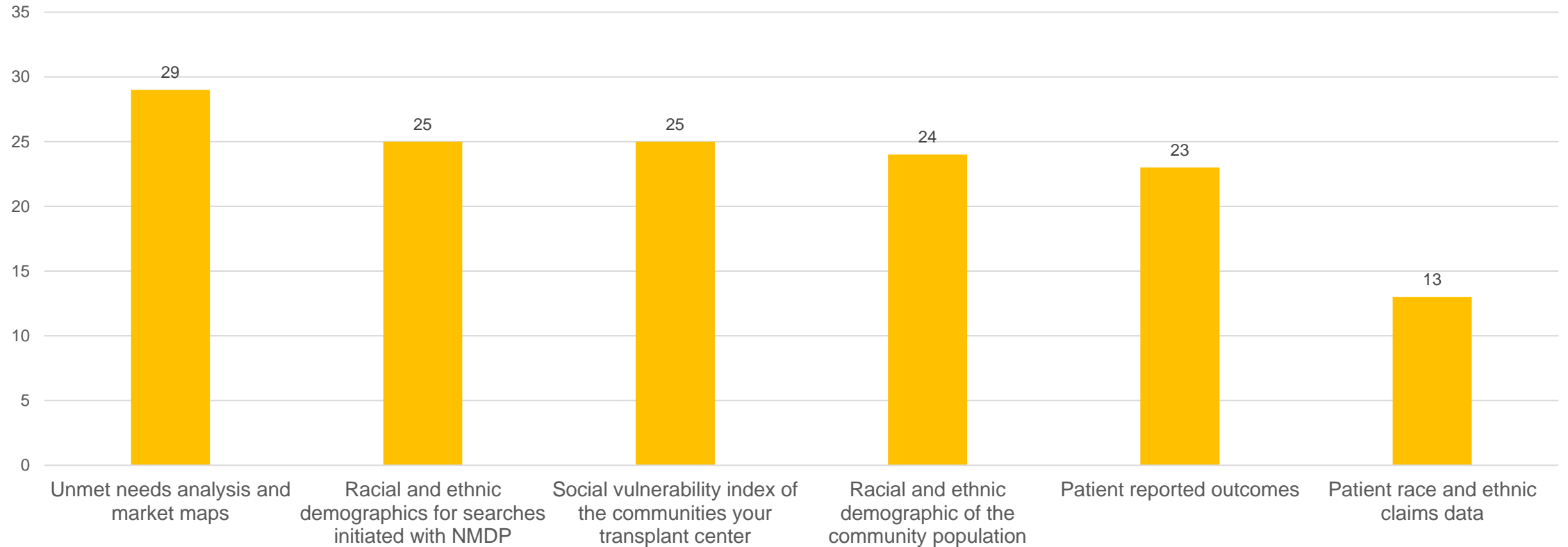
What tools and resources would be helpful to improve health equity efforts at your transplant center (select all that apply)?





# Health Equity Survey Cont.

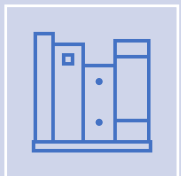
What type of data would be helpful to better understand and improve health equity at your transplant center? (Select all that apply)



# Solution



Provide data focused on racial equity and best practices for collecting racial and ethnic data to better inform TCs direction on implementing solutions.



Address and reduce barriers to transplant by providing a TC-directed quality improvement toolkit empowering centers to identify and strengthen health equity programming and services they provide.

# Aims



Increase TC access to data and resources to reduce capacity to drive health equity projects.



Increase TC knowledge of their patient demographics, community population and barriers to transplant.



Support TC in building relationships with community, community providers and NMDP.

# Outcomes

- Increase the number of racially and ethnically diverse patients transplanted.
- Improve health outcomes for racially and ethnically diverse patients.
- Increase health equity metrics at the TC that are mandated by governing entities:
  - National Cancer Institute
  - Clinical Trials Enrollment
  - CMS
- TC complete one health equity improvement project in toolkit

# Toolkit

# Audience

TCs who are interested in health equity and ready and able to engage in systems change projects

- Physicians and advanced practice providers
- Social workers
- Nurse coordinators
- Data managers
- Administrators



# Toolkit Outline



Introduction



Assessment



Data



Community Engagement



Quality Improvement



Education and Training Resources

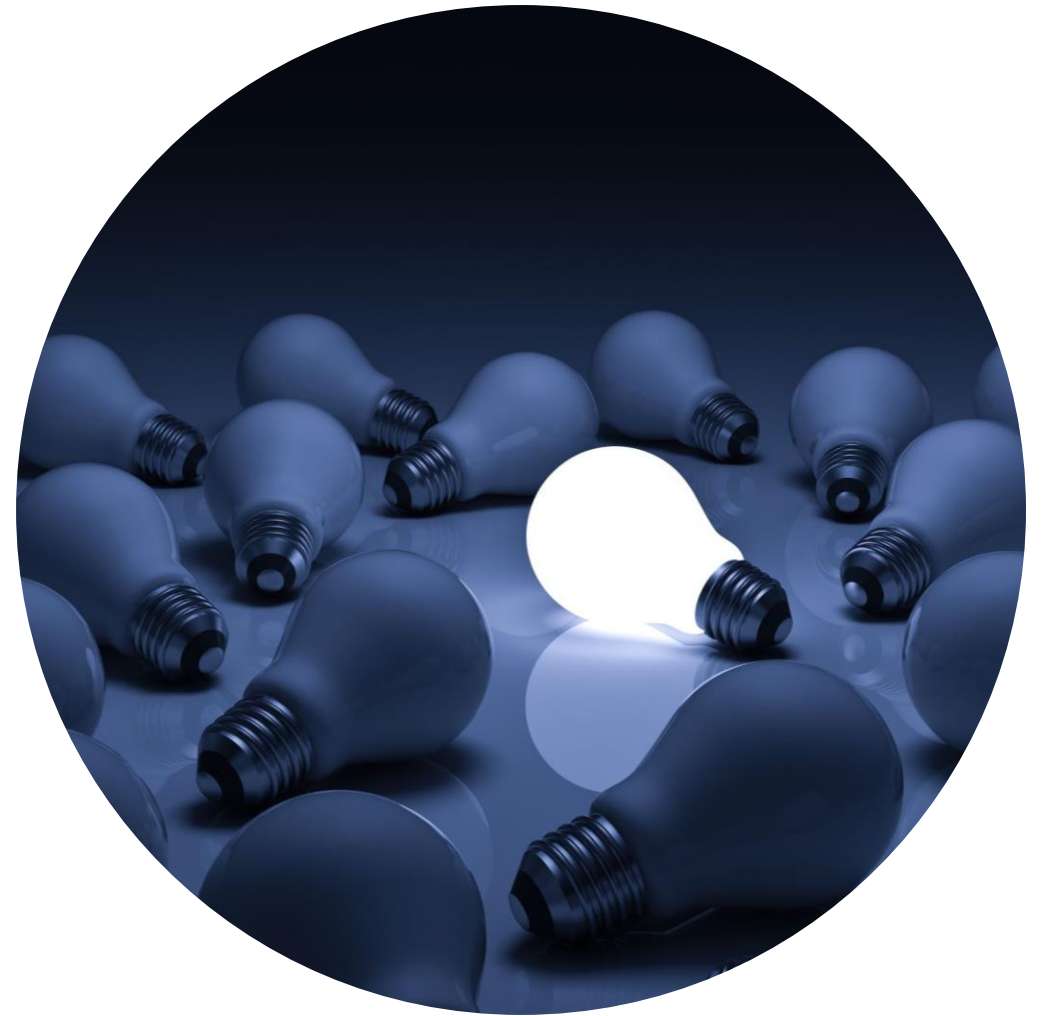


Evaluation Tools

# Assessment

Self-guided evaluation using internal (TC) and external (NMDP/Be The Match) data to identify:

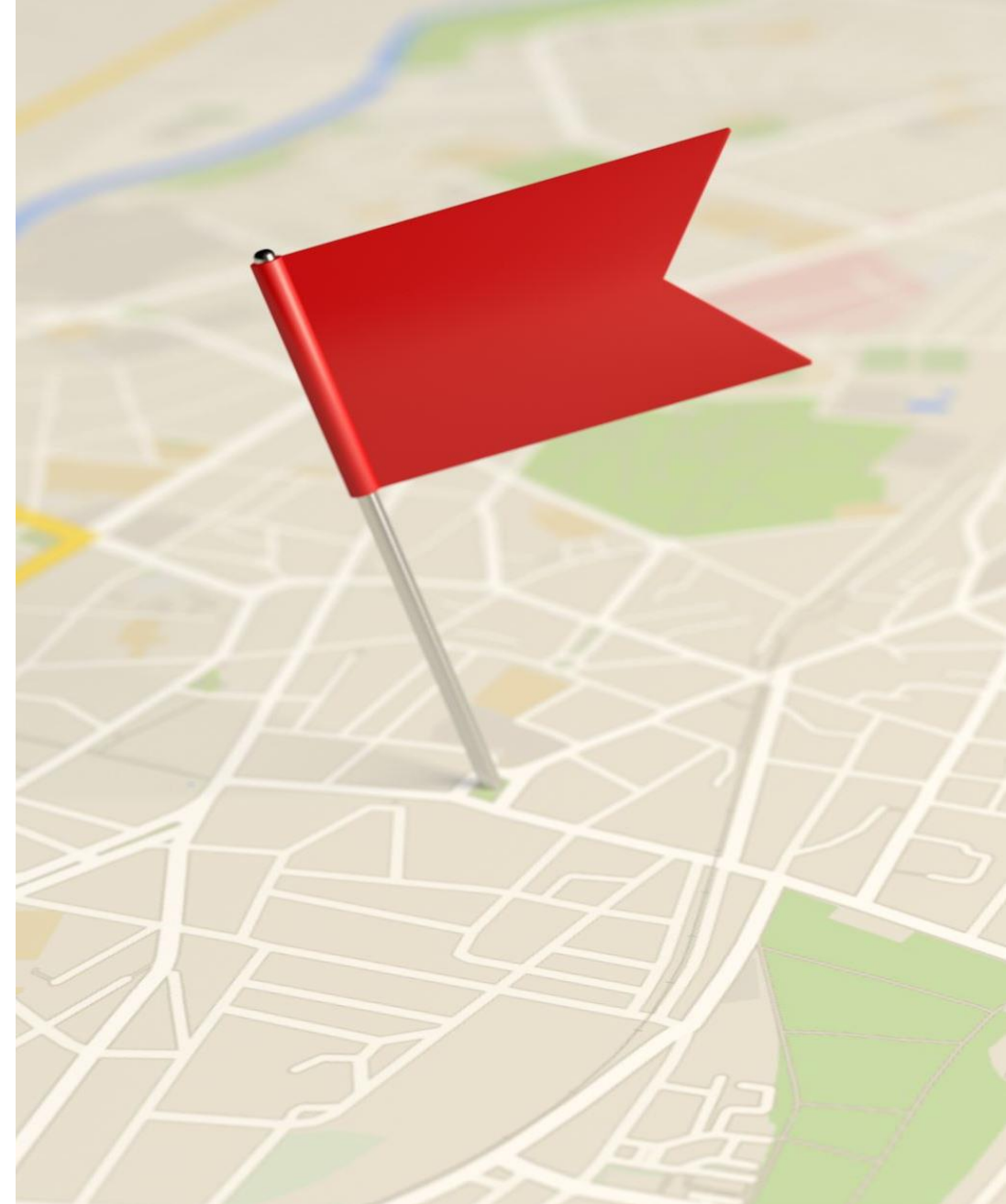
- Health equity areas to strengthen/enhance
- Individual, structural and systematic barriers
- Resources needed to increase transplant access to racially and ethnically diverse populations





# Data

- Preliminary search
- Formal search
- Transplants
- Market Analysis
- Age
- Gender
- Race/Ethnicity
- Disease





# Market Analysis

## Population and transplant data

- Analyze transplant need, met need and unmet need by patient demographics to identify disparities in accessing transplant

## Community data

- Adding layers such as income, population diversity, social vulnerability index to help identify focus areas

# Market 5-Year Summary 2017-2021

Age Group	White	Black / African American	More than one race	Hispanic	Asian	Native American – Alaska Native	Native Hawaiian, and Other Pacific Islander
Population (# and % of total pop)	# %	# %	# %	# %	# %	# %	# %
Transplant Need (# and % of total need)	# %	# %	# %	# %	# %	# %	# %
Patients Transplanted	# %	# %	# %	# %	# %	# %	# %
Unmet Need	# %	# %	# %	# %	# %	# %	# %

# Market 5-Year Summary 2017-2021

Age Group	White	Black / African American	More than one race	Hispanic	Asian	Native American – Alaska Native	Native Hawaiian, and Other Pacific Islander
Transplant Need (# and % of total need)	# %	# %	# %	# %	# %	# %	# %
Prelim searches (# and % of total need)	# %	# %	# %	# %	# %	# %	# %
Formal Search	# %	# %	# %	# %	# %	# %	# %
Transplants	# %	# %	# %	# %	# %	# %	# %
Transplants at Center (# and % of total HCT)	# %	# %	# %	# %	# %	# %	# %

# Toolkit Utilization Example #1

## Assessment Question

What racially and ethnically diverse population has the largest unmet need?  
(This information can be found in the data provided by NMDP)

*To focus on access, go to Community Engagement on pg. X of the Health Equity in Practice Toolkit*

# Toolkit Utilization Example #1 Cont.

## Toolkit Section: Community Engagement

- What programs or initiatives exist at your TC to reach racially and ethnically diverse patients and/or communities?
- What community outreach partnerships do you have?
- Do your TCs partner with community health workers? Cultural brokers? Interpreters?

**Toolkit to include resources to improve/strengthen outreach to community providers and patients.**

**Toolkit will guide TCs in developing strategies to improve/strengthen reach to racially and ethnically diverse communities.**

- How can you improve/strengthen your community outreach efforts?
- How can you improve/strengthen your community provider relationships?

# Toolkit Utilization Example #2

## Assessment Questions

What percentage of patients have their race and ethnicity documented in their chart? \_\_\_\_\_

Are you interested in improving/strengthening race and ethnicity data collection processes at your TC?

- a. Yes
- b. No, not at this time

*To focus on data collection, see the Quality Improvement Tools and Resources on pg. X of the Health Equity in Practice Toolkit*

# Toolkit Utilization Example #2 Cont.

## Toolkit Section: Quality Improvement Tools and Resources

- When is race and ethnicity information collected from patients?
- Who collects race and ethnicity information from patients?
- When and who enters patient race and ethnicity into the electronic medical record?
- How is patient race and ethnicity entered into MatchSource?

**Toolkit to provide best practice resources to improve/strengthen collection of patient race and ethnicity.**

**Toolkit will guide TCs in developing strategies to improve/strengthen racial and ethnic data collection processes.**

- How can you improve the process of collecting race and ethnicity information from patients?
- What can you do to make patients feel more comfortable disclosing their race and ethnicity information?



# Timeline

- Phase 1
  - Create toolkit
  - Deliver toolkit to five TCs starting November 6th
  - Evaluate toolkit
- Post-Phase 1
  - Modify toolkit, as needed, based on evaluation findings
- Phase 2
  - Deliver toolkit 2.0 to five additional TC by end of FY24
- Future Plans for Sustainability
  - Make HEP toolkit available to TC to establish interest

# Scope

## Kickoff Meeting

- Nov. 6-10, 2023

## Toolkit

- Assessment
- Data
- Tools and resources

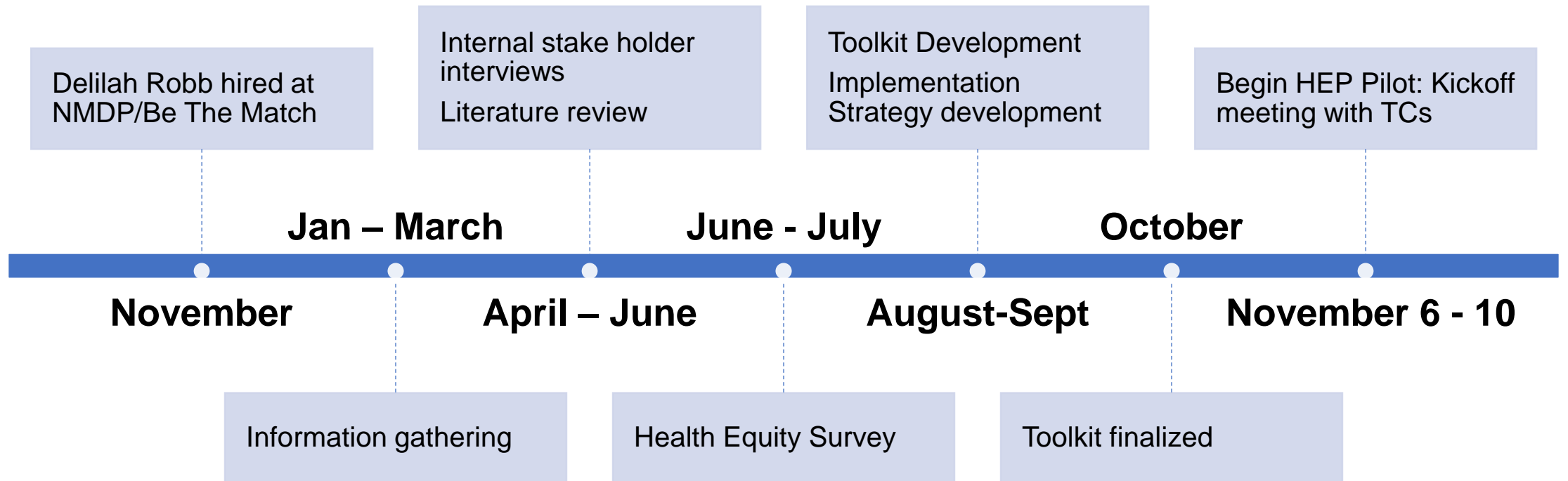
## Check-in with TCs

- Provide support, as needed

## Evaluation

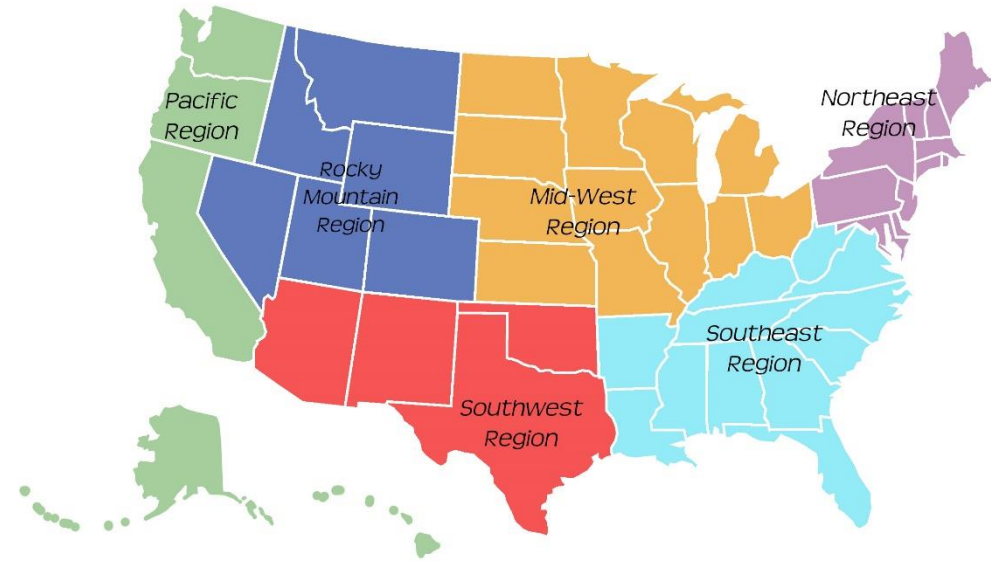
- Pre-post pilot survey

# Key Milestones



# Pilot TC Criteria

- NCI – Cancer Center (more accurate denominator data)
- Region
- Size
- Patient demographics
- Community demographics
- CIBMTR data quality
- Greatest need



# We want to hear from you!

Complete this short health equity survey to share what data, tools, and resources would TCs reach their health equity goals and if you're interested in participating in the Health Equity in Practice Pilot.

<http://bitly.ws/RyXm>



Thank you!  
Questions/Discussion?

# Preview Day 2

- Call to Action
- Group Discussion Questions

Slides of initiatives #1 and #3 for reference



# Initiative #1: Level the Knowledge

1. Review existing NMDP/ASTCT patient educational resources across transplant continuum for cultural sensitivity
2. Community Engagement Studios: Moderated sessions to obtain input from representatives from specific groups (Black, Latino, Asian, HPI, Indigenous) about transplant educational resources
3. Create a new index of modified patient educational resources, with date of review

Stakeholders: community representatives, transplant center members, NMDP Patient Services staff, representative from Awareness committee

# Initiative #3: Workforce Development

1. Collaborate with ASTCT (URM SIG, DEI committee) to support their ongoing projects to create a pipeline program for underrepresented trainees,
  - Start with physician workforce
  - If successful, continue to build similar programs for APPs, nursing, pharmacy, social workers, etc.

Stakeholders: Transplant center representatives, NMDP & ASTCT staff, Representatives from ASTCT URM SIG & DEI committee



# Dinner 7:00PM

**Chef Geoff's West End  
2201 M. Street NW  
Washington, DC 20037**