

Welcome ASTCT - NMDP Access Workshop Attendees!

Thursday August 24th – Friday August 25th, 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



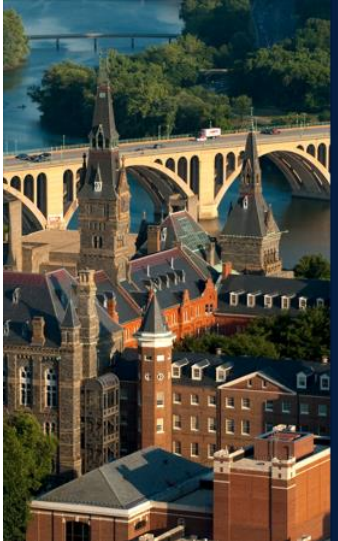
Eneida Nemecek



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

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^{1,2,*}, Brenda M. Sandmaier^{3,4}, Erica Jensen¹, Navneet S. Majhail⁵, Jessica Knutson¹, Eneida Nemecek⁶, Femina Ajayi-Hackworth¹, Stella M. Davies⁷, on behalf of the ACCESS Workshop Team^{† †}

¹ National Marrow Donor Program, Minneapolis, Minnesota

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

³ Fred Hutchinson Cancer Center, Seattle, Washington




⁴ University of Washington School of Medicine, Seattle, Washington

⁵ Sarah Cannon Transplant and Cellular Therapy Network, Nashville, Tennessee

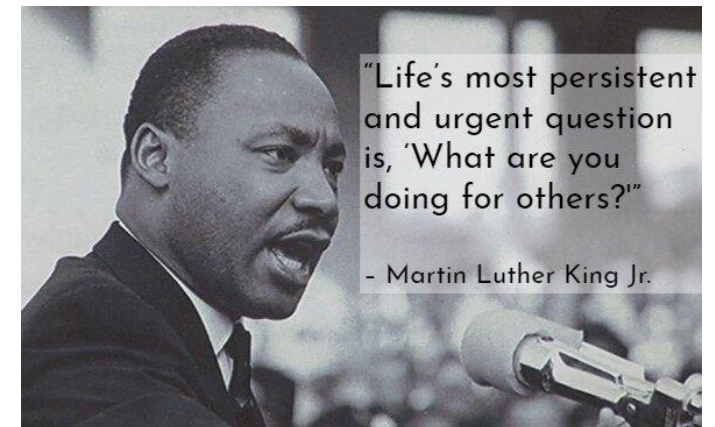
⁶ Oregon Health Sciences University, Portland, Oregon

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

The ASTCT-NMDP ACCESS Initiative

The American Society for Transplantation and Cellular Therapy (ASTCT[™]) and the **National Marrow Donor Program** (NMDP[®]) formed the ACCESS Initiative to address access and outcome disparities in the hematopoietic cell transplantation (HCT) and cell therapy (CT) ecosystem.



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

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

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

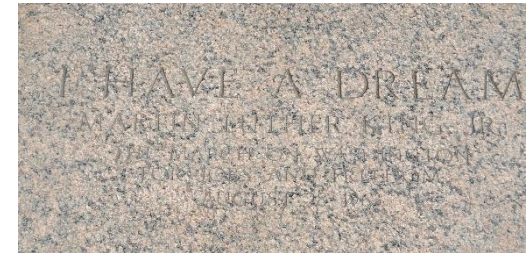
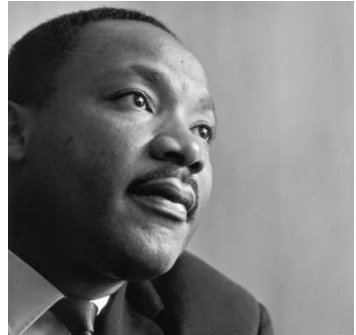
Considerations

- 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

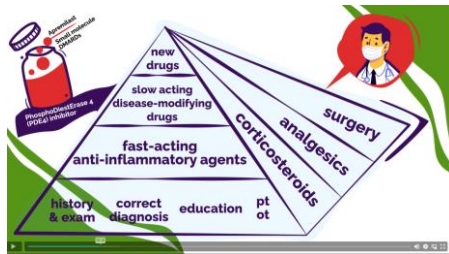


Specialty Symposia



Congress Sessions

WHAT WE DO...Online Activities



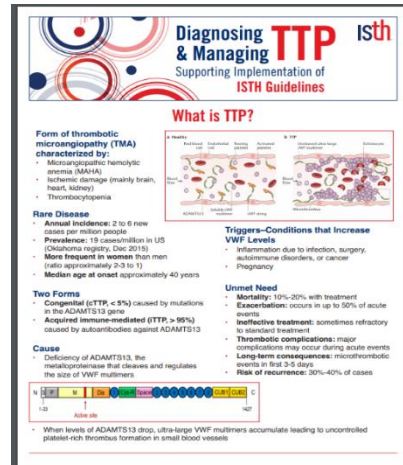
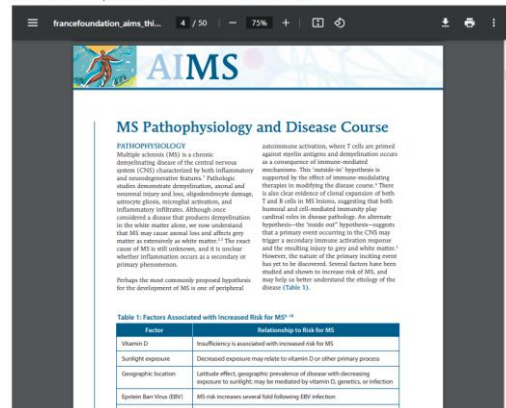
Animation Videos

rheumatic Arthritis?

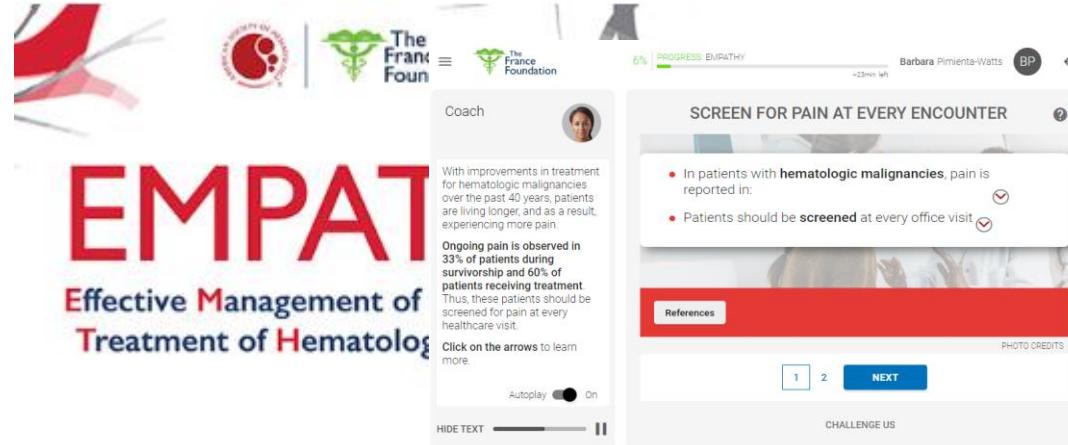


Video Modules

Advances in Multiple Sclerosis (AIMS) Primer: Third Edition



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.



American Society of Hematology
Helping hematologists conquer blood diseases worldwide



Society of
Interventional
Oncology



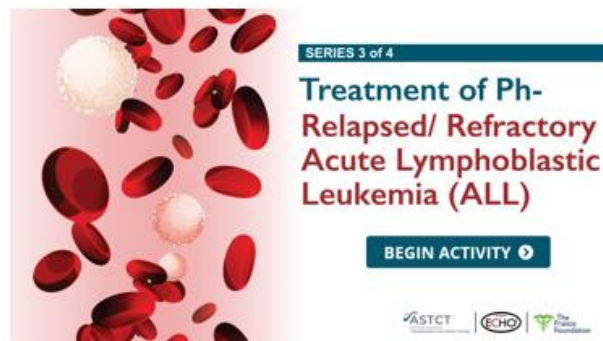
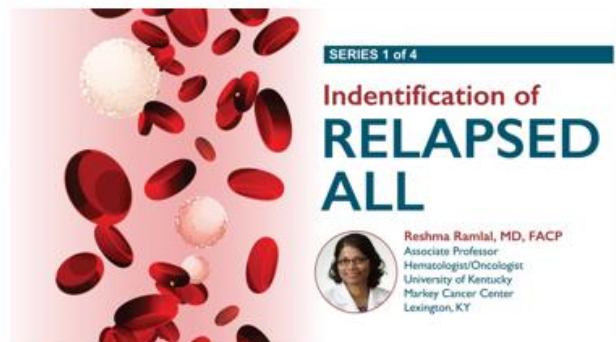
Kidney Cancer Association™
Unstoppable Together.



STRONGER TOGETHER

RECENT WORK WITH ASTCT...

Project ECHO Series and Online Modules



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

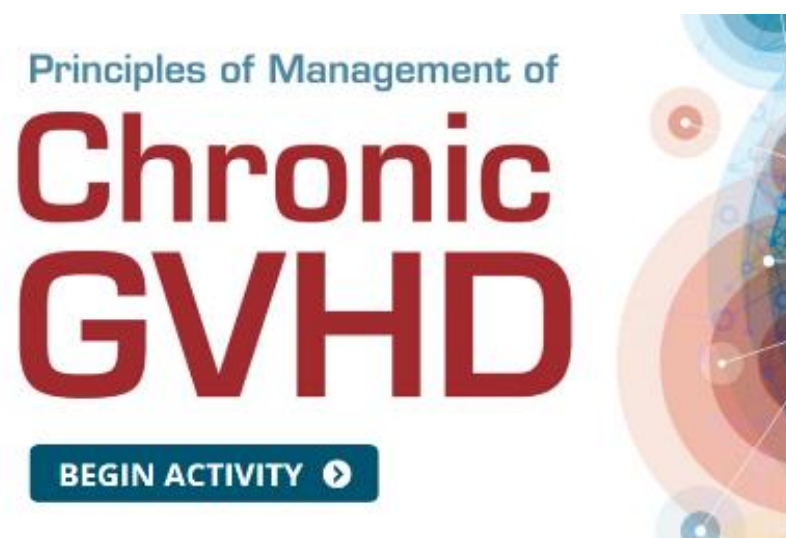
- **University of Kentucky Markey Cancer Center**
 - 09/08 | 12:00 pm EST - Identification of Relapsed ALL (Topic 1)
 - 10/13 | 12:00 pm EST - Treatment of Relapsed/Refractory Ph+ ALL (Topic 2)
 - 11/10 | 12:00 pm EST - Treatment of Relapsed/Refractory Ph- ALL (Topic 3)
 - 12/08 | 12:00 pm EST - Managing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



RECENT WORK WITH ASTCT...

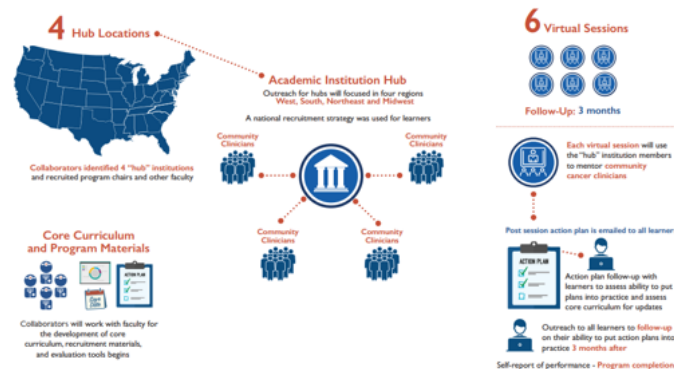
Project ECHO Series and Online Modules in Partnership with ASH



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

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

Coming Up

- Adult MDS Physician Exchanges (coming Fall 2023)

Partnerships to Increase Patient Awareness



Subcommittee Chair: Becca Miller

Subcommittee Members:

- Mary Hengen, NMDP
- Katie Schoeppner, 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

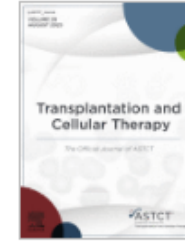
- Reducing barriers to access through Medicaid
- Understanding access barriers using Kaiser dataset
- Developing TCT advocacy *swat posse*



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-NMMDP ACCESS Initiative

Jeffery J. Auletta^{1 2} [👤](#) [✉](#), Nandita Khera³, Patrick DeMartino⁴, Amar H. Kelkar⁵,
Rafeek A. Yusuf¹, Stella M. Davies⁶, Jessica Knutson¹, Ellie Beaver¹, Alycia Maloney⁷,
Navneet S. Majhail⁸



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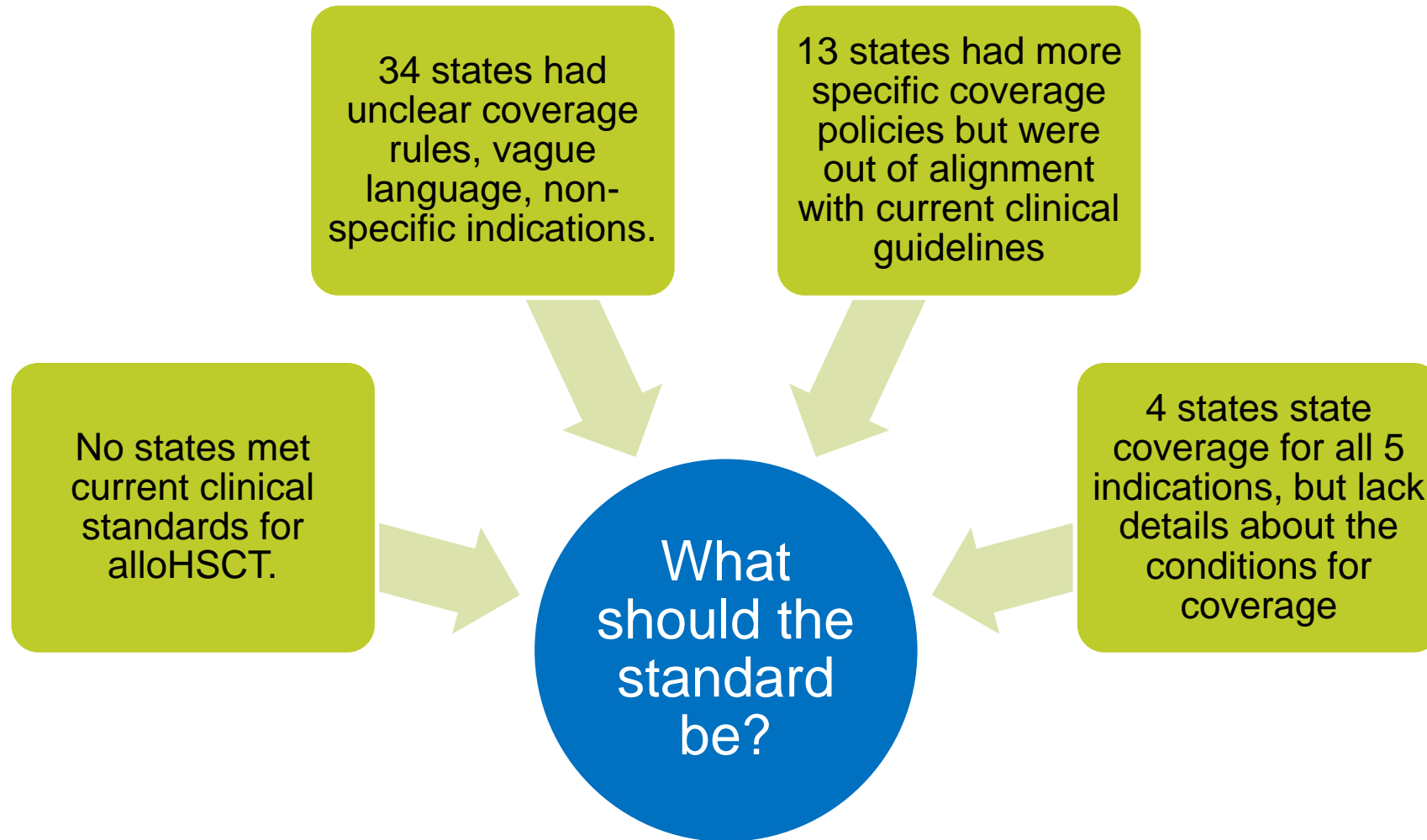
Manatt analyzed key state *Medicaid fee-for-service (FFS)* coverage and reimbursement issues related to stem cell transplants and CAR T-cell therapies

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.

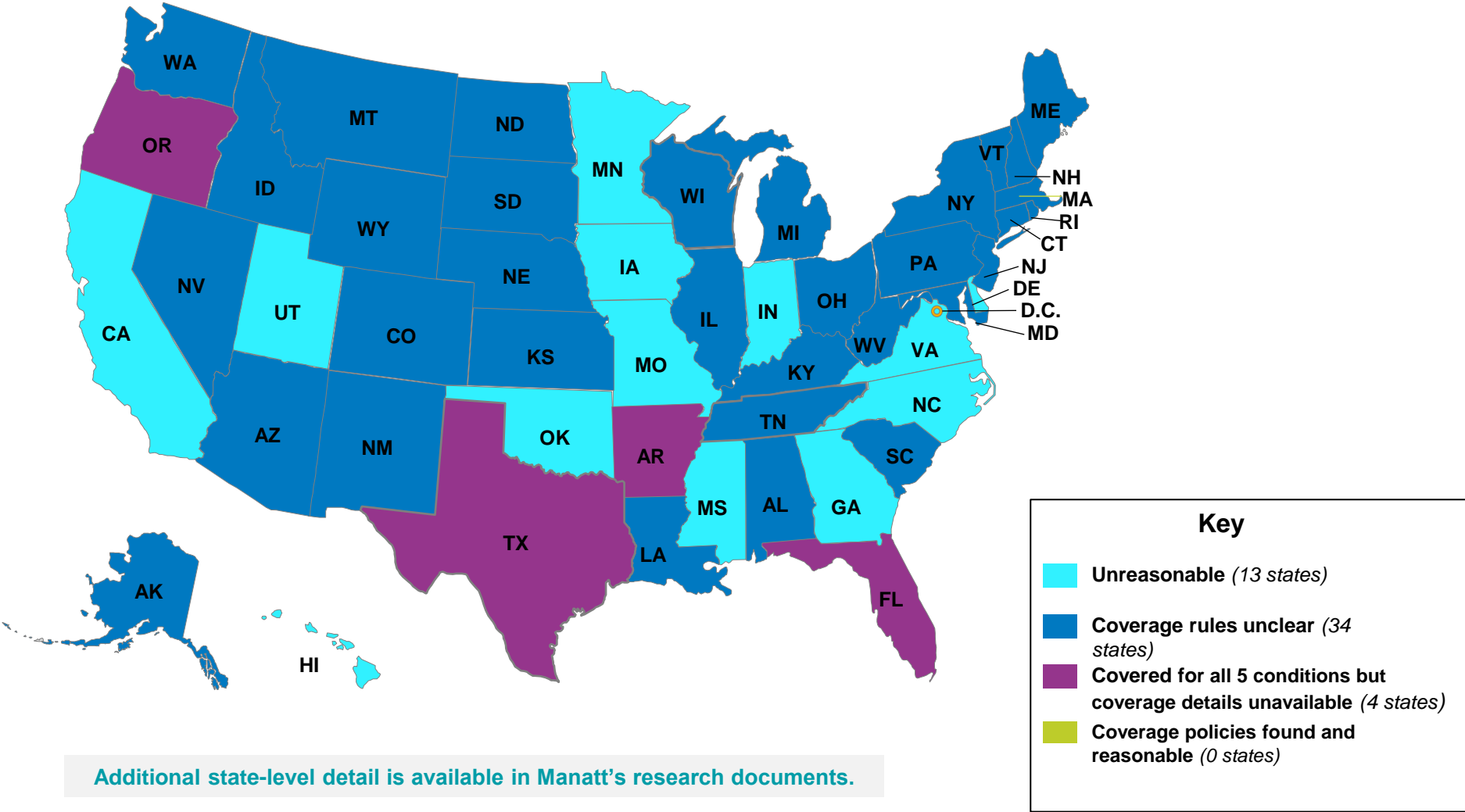
Note: Manatt's analysis focused on state policies, not those developed by or applied to Medicaid managed care organizations. CAR Ts examined consisted of Yescarta for lymphoma, Carvykti for multiple myeloma, and Kymriah for pediatric acute leukemia.

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

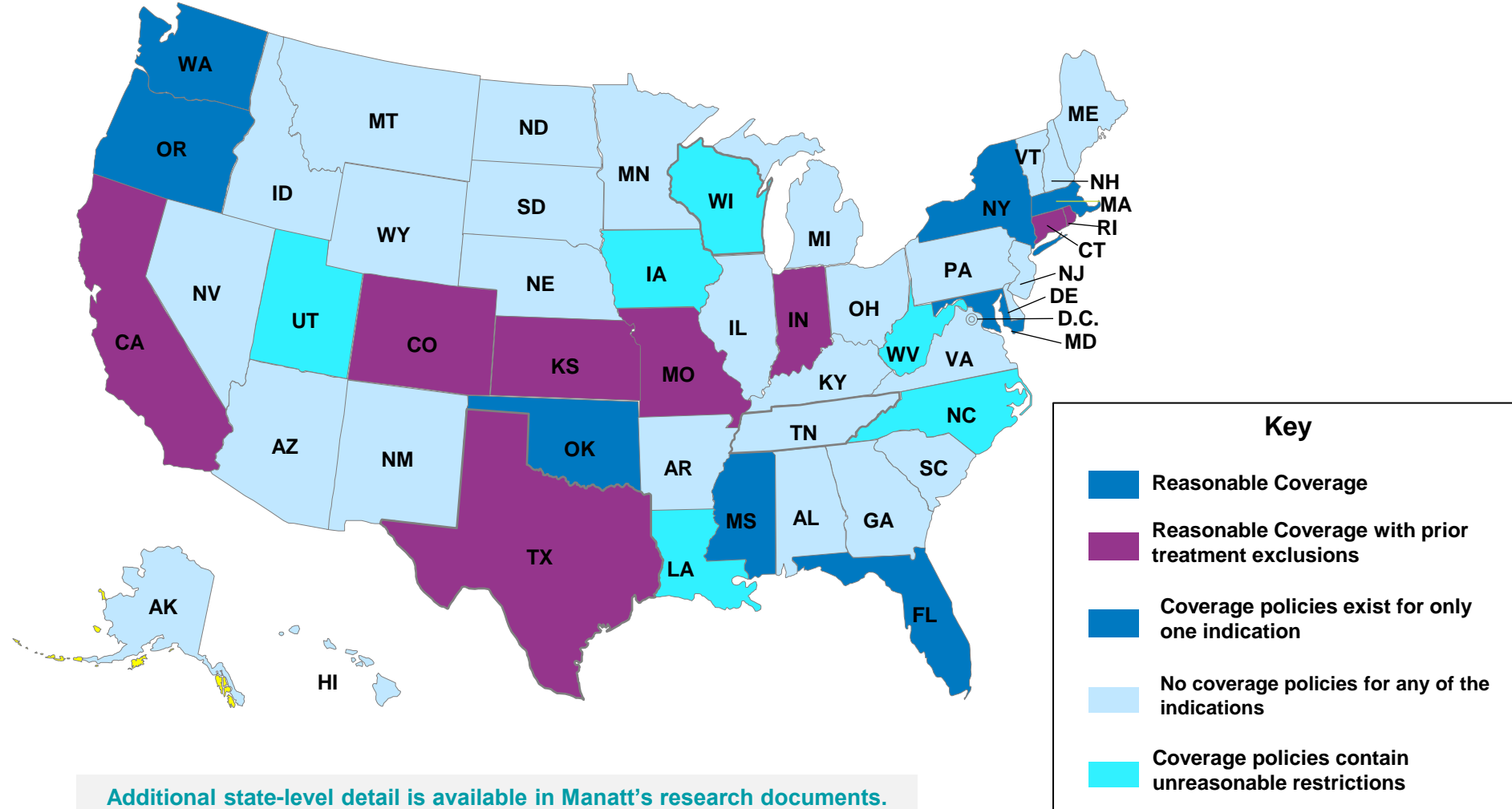
*The data analysis was based on Yescarta for lymphoma, Carvykti for multiple myeloma, and Kymriah for pediatric acute leukemia

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.
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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

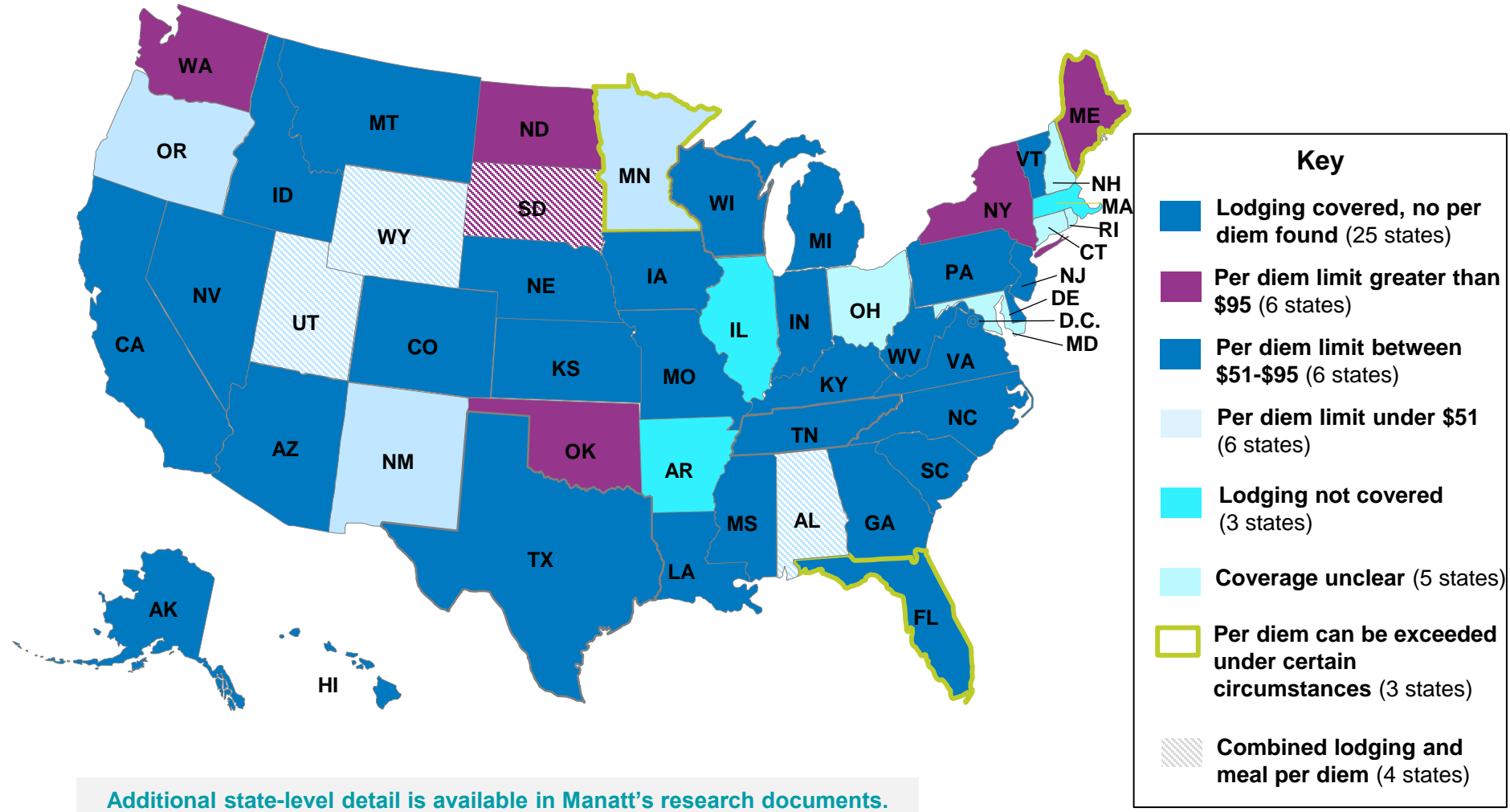
drive to the appointment or treatment.

- 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.

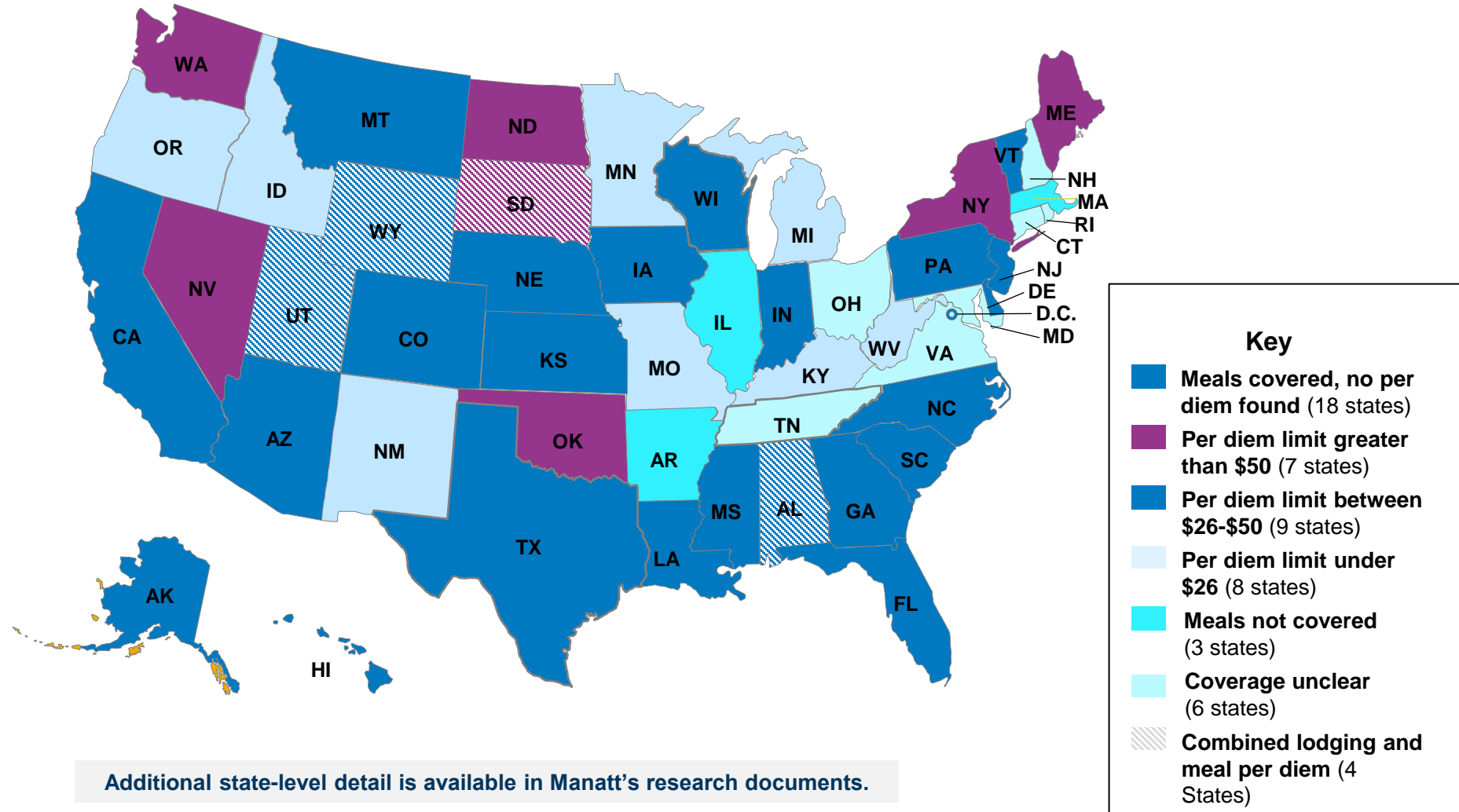
Lodging reimbursement is often limited to instances when lodging is **more economical than additional round trip transportation** to the medical facility or the **beneficiary needs to be nearby the medical facility**.



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
Cost Basis	Payment approximately equals the acquisition costs that are reported by the hospital or reasonable costs . Similar to Medicare reimbursement.	CA, MD, MI, OK, WV
Percentage of Charges	Payment is a percentage of charges that the provider bills for stem cell acquisition.	AR, WA, WI, WY
Charge or Cost-Based Reimbursement, Subject to a Cap	Payment based on charges or costs , but reimbursement is subject to a cap .	IL, LA, MS, MO, NV, OR
Other Methodologies	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 Rouse

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: 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.

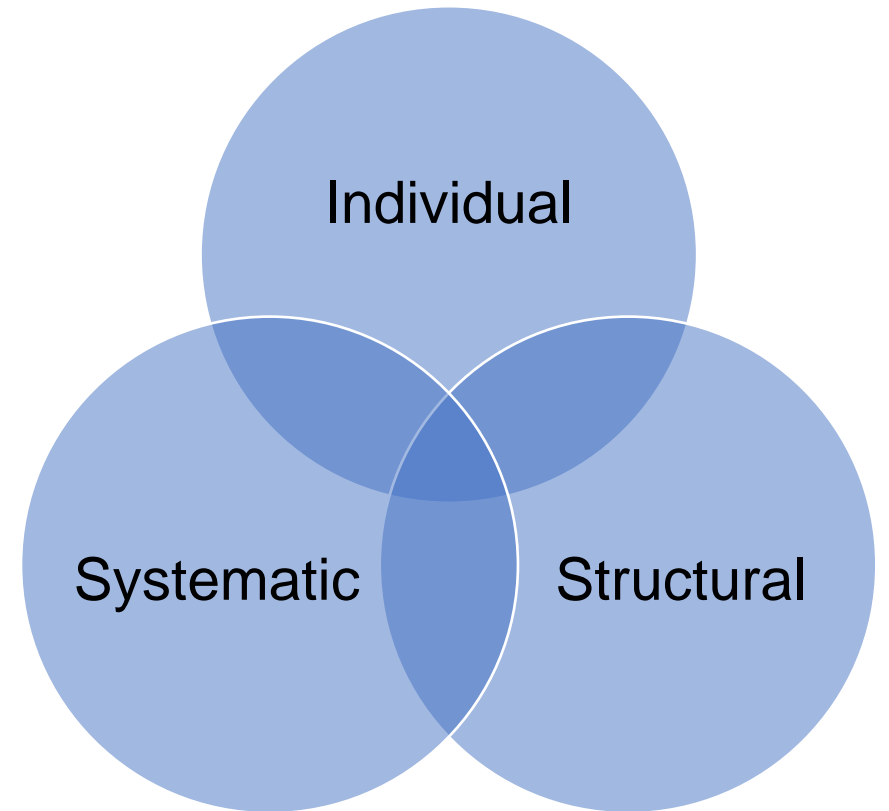
August 24 & 25, 2023

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.

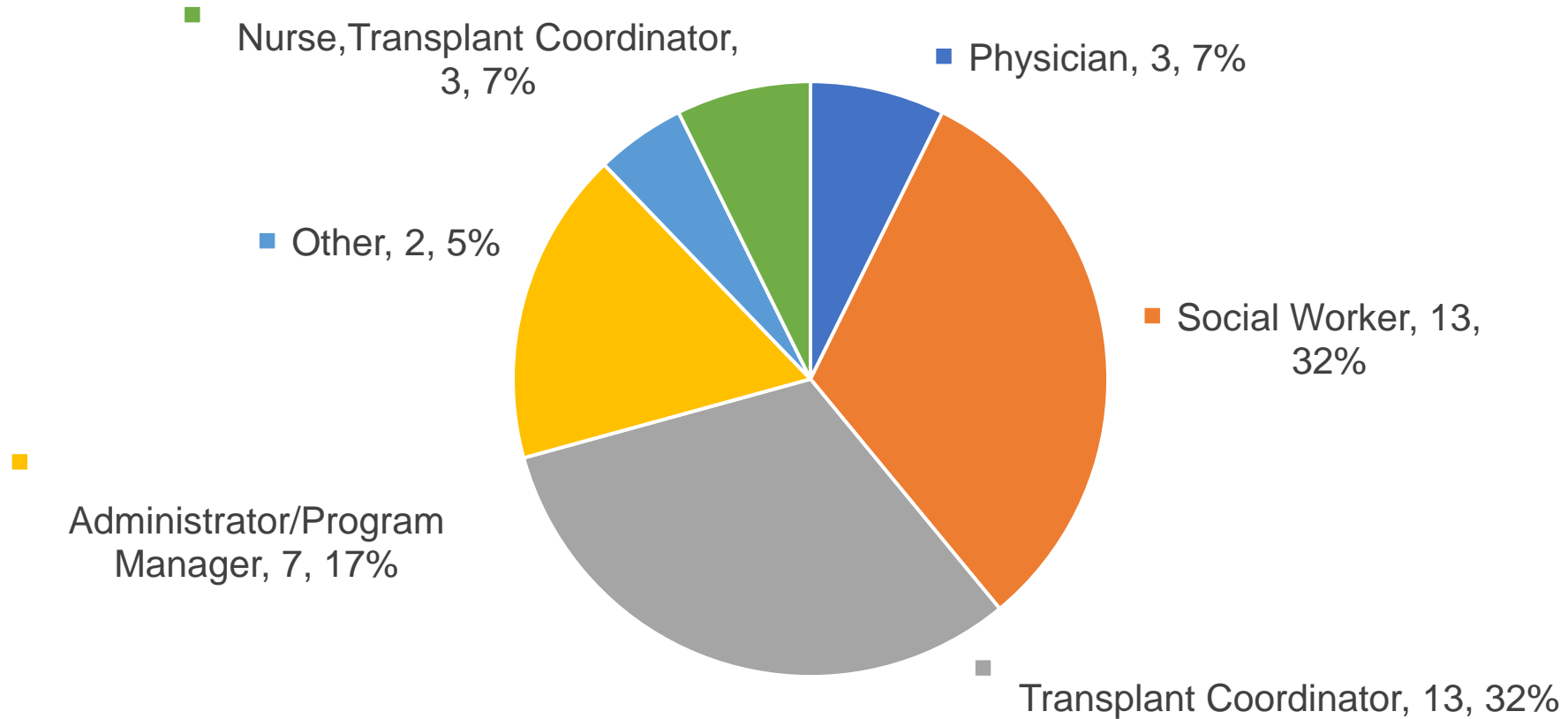


Health Equity Survey

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.

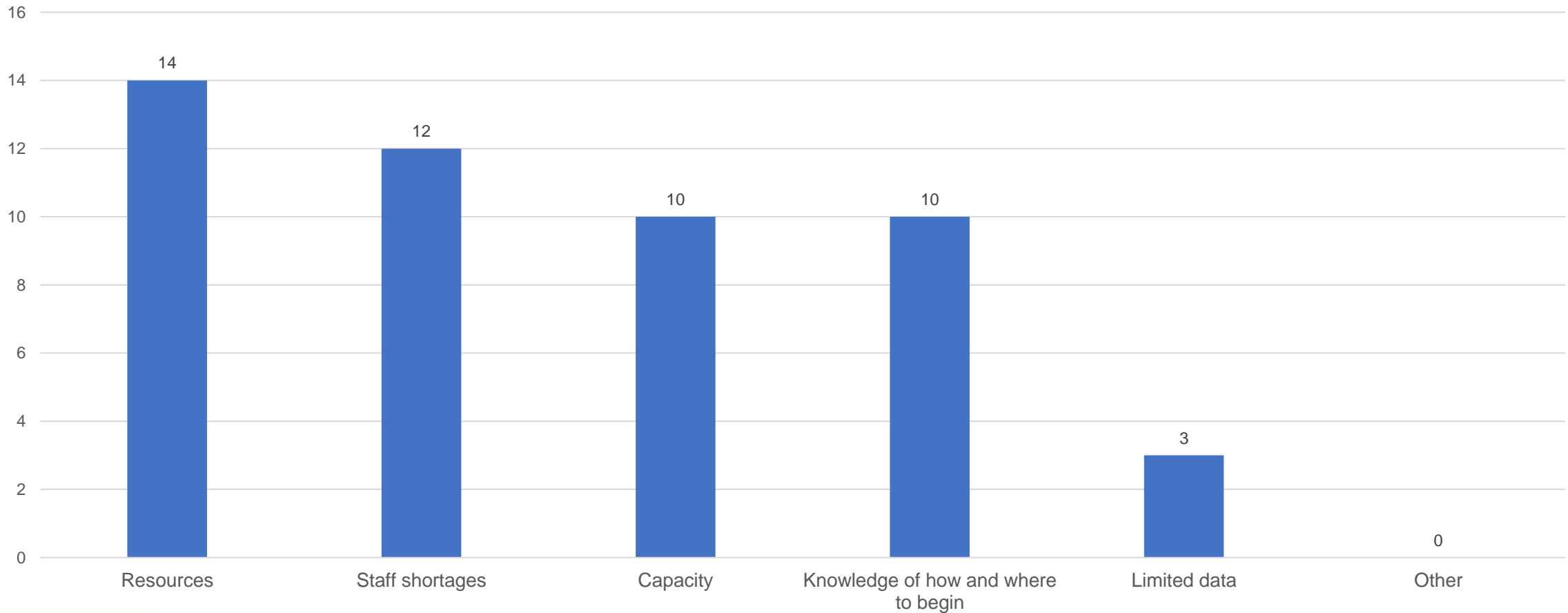
Health Equity Survey Cont.

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



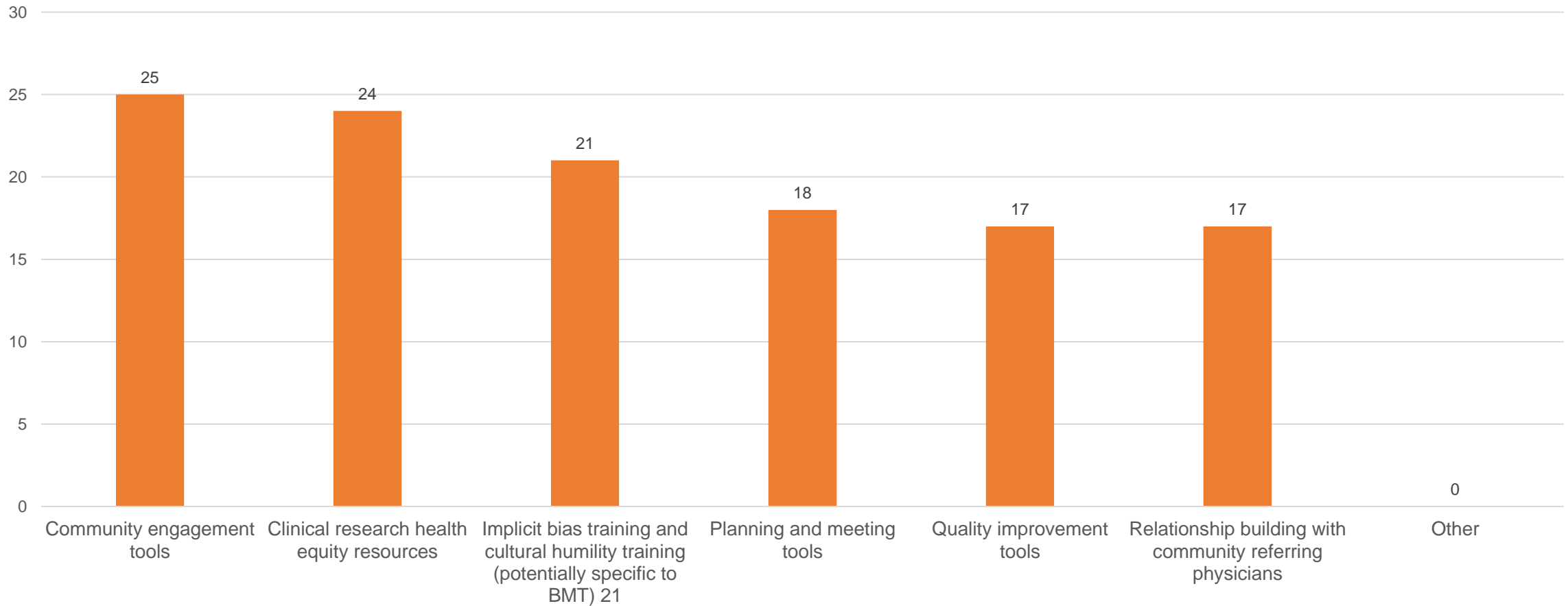
Health Equity Survey Cont.

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



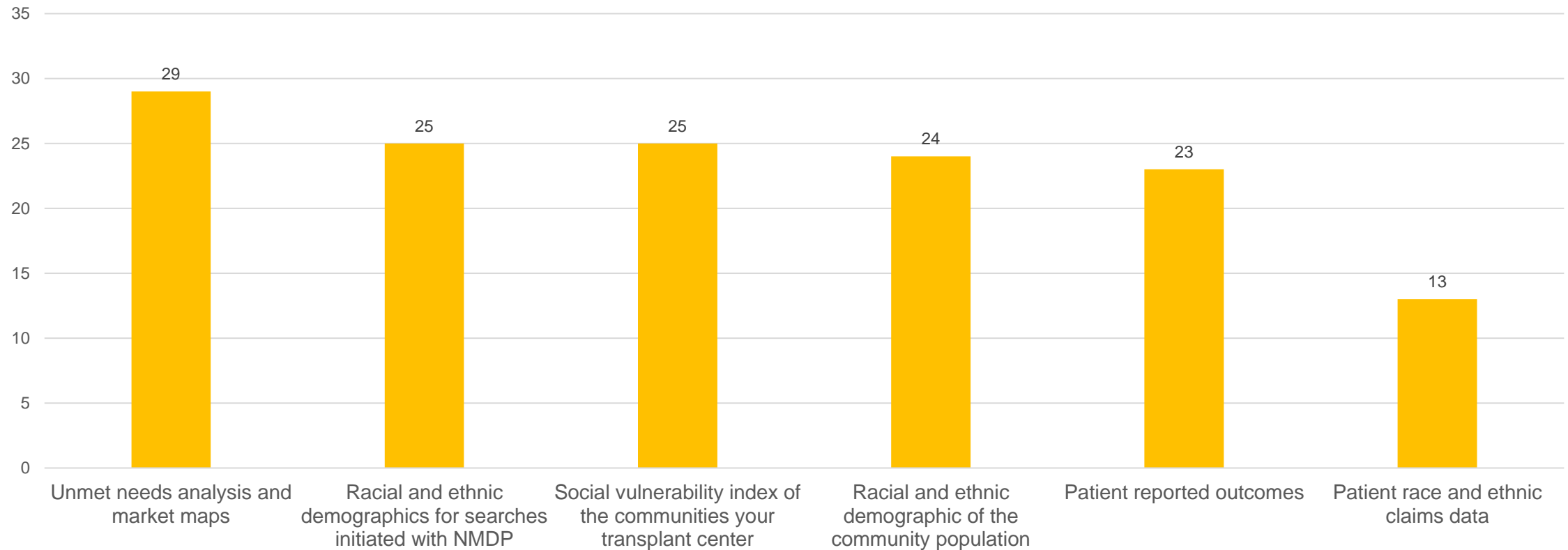
Health Equity Survey Cont.

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



Health Equity Survey Cont.

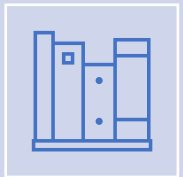
What type of data would be helpful to better understand and improve health equity at your transplant center? (Select all the apply)



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 advance 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?
- Does 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

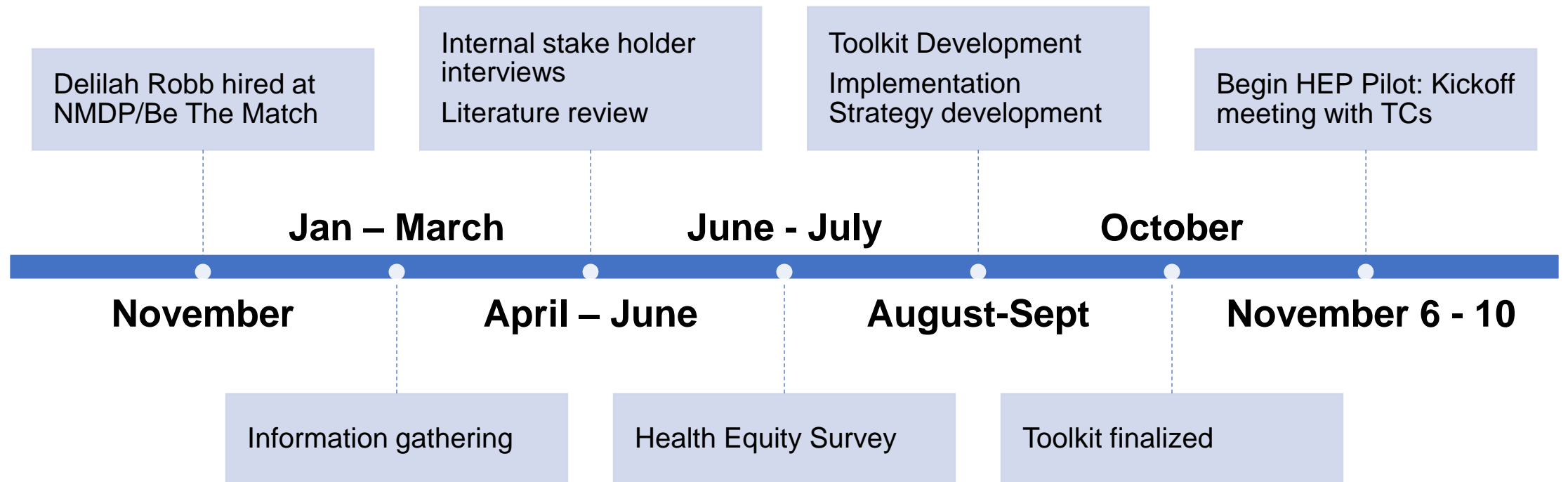
Check-in with TCs

- Provide support, as needed

Evaluation

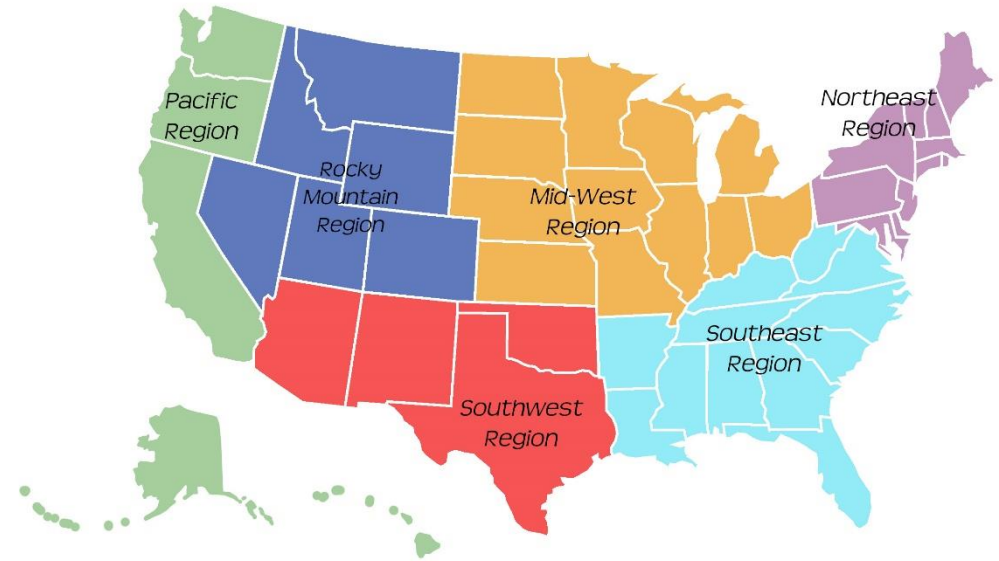
- Pre-post pilot survey

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

Welcome ASTCT - NMDP Access Workshop Attendees!

Thursday August 24th – Friday August 25th, 2023

ASTCT Washington D.C. Headquarters

Agenda

Friday, August 24, 2023

8:00 – 8:30 AM	Coffee and Breakfast/Welcome
8:30 – 9:30 AM	Pilot Project Deep Dive: Medicaid Scan
9:30 –10:00 AM	Pilot Project Deep Dive: Kaiser Permanente Database
10:00 –10:15 AM	Break
10:15 –10:45 AM	Pilot Project Deep Dive: Health Equity in Practice
10:45 –11:45 AM	Group Discussion: One Year Later – Metrics of Success and Future Directions
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

Pilot Project Deep Dive: Medicaid Scan 8:30-9:30 AM

Presented by: Ellie Beaver



Medicaid Coverage for Cell Therapy Patients: Day 2

Ellie Beaver, Sr. Manager, Health Policy

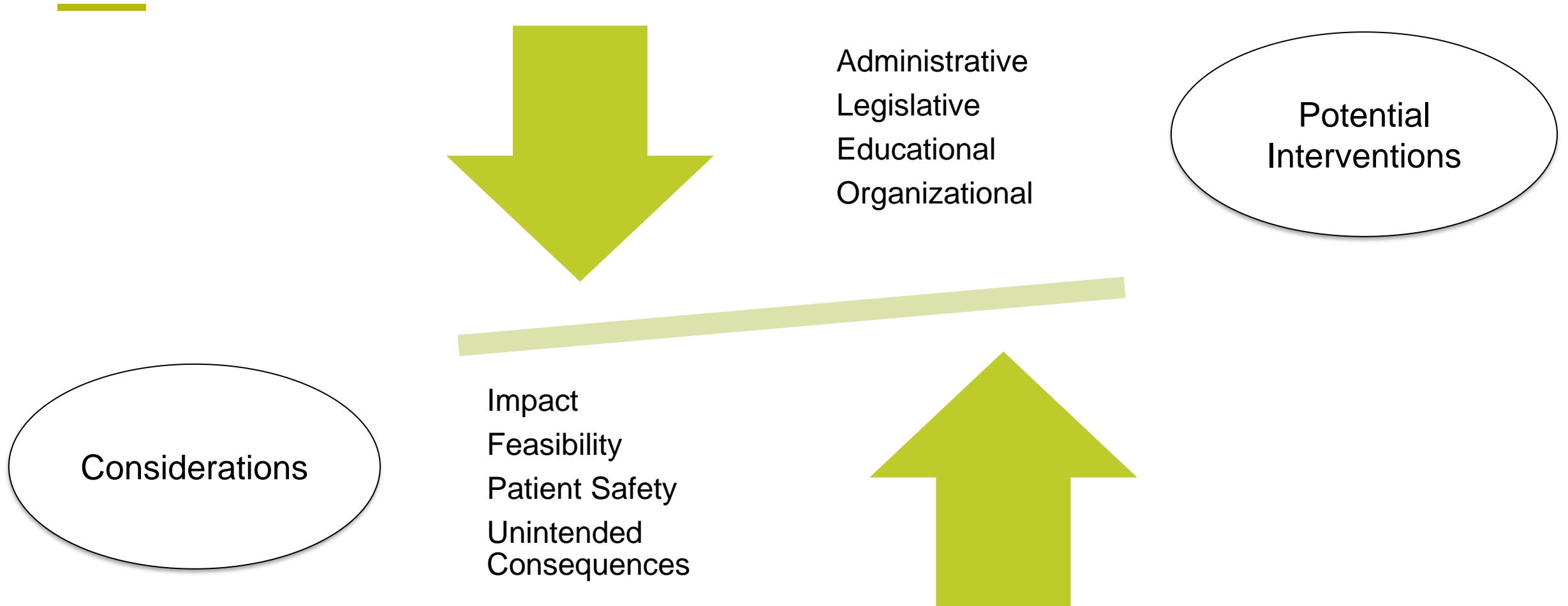
Jessica Knutson, Director, GAPP

Emma Keiski, Policy Analyst

Analysis

- The NMDP Government Relations and Public Policy team analyzed the results to determine potential administrative, legislative, educational, and organizational interventions
- Considerations
 - Impact
 - Feasibility
 - Patient Safety
 - Unintended consequences
- Begin by aligning Medicaid policies with current clinical guidelines
- Focus on states with existing specific written policies on coverage
 - Assume these states have given thought and research to how they should cover HCT

Analysis



Recommended Intervention

Begin by aligning Medicaid policies with current clinical guidelines; focus on states with existing specific written policies on coverage.

Why? The following states have at least given some thought to their coverage policies for alloHSCT and codified them

HCT Coverage Interventions

Ask State Medicaid programs to update their HCT coverage by referencing national standards in their coverage policies.

- Benefits: aligns coverage policies with current practice.
- Risks: Could limit what states are currently covering if their existing process allows for more expansive coverage than the guidelines.

Educate the Medicaid program directors on the current guidelines.

- Target those states with coverage policies that are discriminatory or outdated.
- Allowing for HIV, mental illness, addiction, or high BMI can be first step in changing coverage.

Request policy cover ALL diseases or conditions requiring transplant.

- Target states that cover malignant disease only.

Outline a campaign timeline.

- Overall and state specific.







States with the Most Potential

- **North Carolina:** recently expanded Medicaid and was found to have unreasonable stem cell transplant coverage policies in the study.
- **California:** found to have unreasonable stem cell transplant coverage policies in the study; high Medicaid enrollment and would most likely be amenable to updating their policy to current guidelines.
- **Texas:** found to provide coverage for all 5 conditions of the study; coverage conditions unclear. Opportunity to update their coverage policy to be in line with current practice.
- **Minnesota:** sickle cell disease and MDS transplant only covered under clinical trial. MN doesn't currently cover donor acquisition costs.

States with the Most Potential

- **Indiana:** has multiple restrictions on coverage that are out of alignment with current clinical recommendations.
- **Utah:** does not cover alloHSCT for lymphoma, MDS, SCT.
- **Virginia:** does not cover alloHSCT for MDS, SCT.
- **Georgia:** does not cover alloHSCT for SCT.
- **Illinois:** coverage unclear for ALL and AML.
- **Target states (TBD) with more regulatory flexibility to change policy.**

Potential Interventions

-  Hold a policy webinar for NMDP/ASTCT members.
-  Create a Medicaid Action Team.
-  Develop model language for Medicaid coverage policy
-  Interview TCs in each target state to understand current Medicaid barriers for alloHSCT patients
-  Conduct Outreach to state Medicaid Director (or deputies if there is an existing relationship)
-  Determine state Medicaid schedule for updating Medicaid policy

Advocacy basics



- Have a clear decision maker= who can give you want you want.
- Be winnable.
- Understand Power (votes or money)
- Being right isn't enough. Being right is NOT power.

Goals Minnesota	Organizational Considerations	Constituents and Allies	Decisions Maker	Tactics
<p>What do we want to win:</p> <p>Long Term: All Medicaid patients to have access to life-saving cell therapy.</p> <p>Intermediate:</p> <p>.</p> <p>Short Term: Send a letter to Commissions asking to update coverage for sickle cell disease and MDS transplant only covered under clinical trial.</p> <p>MN State Data 2018-2022</p> <ul style="list-style-type: none"> • 1248 searching patients • 461 transplants • 300 donors • 108,117 residents willing to donate • 403 have received a patient grant 	<p>What do we have:</p> <p>Budget:? Yes.</p> <p>Staff: Yes. NMDP</p> <p>Lobby Firm? Yes. – and Coalition</p> <p>Marketing? No.</p> <p>Social Media? No.</p> <p>Data? Not really.</p> <p>Can we raise money? Maybe.</p> <p>Political Power: Democratic trifecta: House, Senate and Governor.</p> <p>What do we need/ want:</p> <p>More ASTCT members?</p> <p>More Advocates in OH?</p> <p>Be advocacy leaders</p>	<p>Constituents</p> <p>Dr. Devine, ½ of the people in the room;) NMDP headquartered</p> <p>Allies</p> <ul style="list-style-type: none"> • This is Medicaid Coalition • Mayo Clinic • University of MN 	<p>Julie Marquardt as Commissioner of Health.</p> <ul style="list-style-type: none"> • Assembly Created a joint Medicaid Oversight Committee (JMCO) • Chair Edwards House Finance Committee • Chair Dolan, Senate Finance 	<p>MN Medicaid Facts:</p> <ul style="list-style-type: none"> • 1.26 Million people covered • Medicaid is 3rd largest payer in MN • Total Medicaid Spending \$15B

CAR-T coverage interventions

Travel and Lodging Intervention

- Changes to reimbursement policy would affect all Medicaid recipients in a state, not just transplant patients, and so Policy Interventions:
 - Add attendant coverage for states without it.
 - Increase per diem rates in states with the lowest current rates.
 - Change payment method to an up-front payment (cash, direct deposit, prepaid debit card) to reduce the burden on patients and caregivers.
 - Remove requirement in some states to seek out medical housing first before being able to receive reimbursement for other housing.
 - Request states (that don't already cover it) cover meals and lodging if they already cover travel only.
- Publish NMDP/ASTCT national standards specifically for food/lodging/travel coverage.

Donor Cost Reimbursement Policy

- Model policy would mirror CMS's policy for reimbursement for search and cell acquisition costs.
 - Pass through payment for those costs separate from the hospitalization costs/DRG payment
 - No limit on the number of donors that can be typed, tested and worked up for donation
- Pick a few states to target to cover donor costs.

Accelerating Kids' Access to Care Act (AKACA)

Overview

- The Accelerating Kids Access to Care Act (AKACA) is an additional opportunity to influence Medicaid policy outside of the scope and results of the Medicaid Scan.
- AKACA reduces regulatory burdens to allow children with complex medical needs greater access to out-of-state providers who can best meet their needs.
- Requires state Medicaid programs to establish a process through which qualifying out-of-state providers may enroll as participating providers without undergoing additional screening requirements in the patient's home state.
- Why is this important for children seeking cell therapy?
 - They may live in one of the 15 states without a pediatric transplant program.
 - Innovative therapies such as clinical trials may not be available in their home state.
 - Have a rare disease and there are few specialists across the country that know how to treat their disease.

How can the ACCESS group engage?

-
- Add QR code
- 1) Link
 - 2) Stories / examples



Pilot Project Deep Dive: Kaiser Permanente Database 9:30-10:00 AM







Presented by: Rafeek Yusuf

Agenda

- KP system overview
- KP dataset overview
- ACCESS Initiative KP working group structure
- Research question, proposal generation & selection plan
- Proposals synopses

Kaiser Permanente System Overview

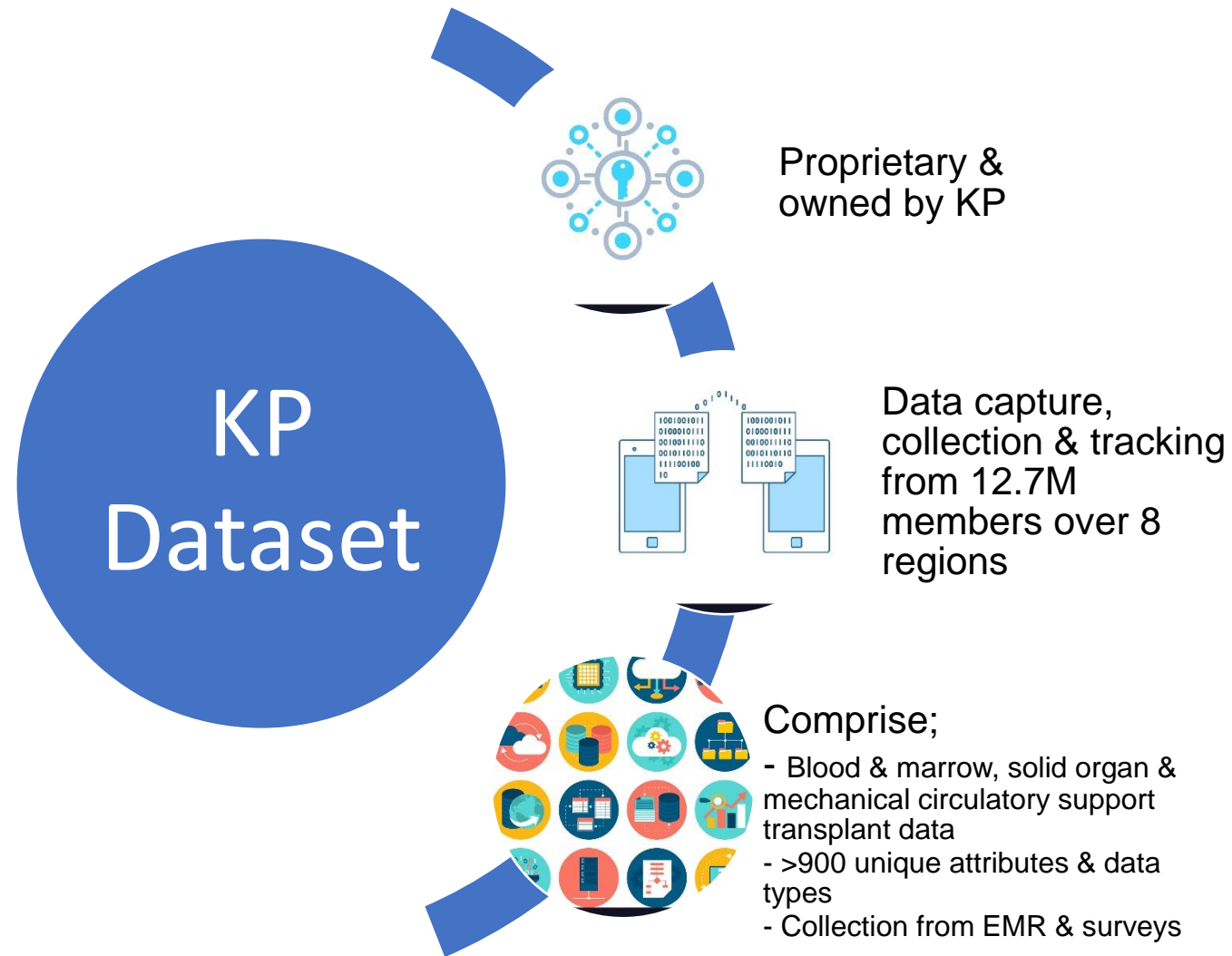
- Founded 1945 
- Headquarters in Oakland California
- Not-for-profit health plan
- Largest U.S. integrated healthcare system 
- Comprises;
 - Kaiser Foundation Health Plan
 - Kaiser Foundation Hospitals & subsidiaries
 - Permanente Medical Groups
- 8 regions covered;
 - Colorado, Hawaii, Mid-Atlantic, Northwest, Southeast, Washington, Northern & Southern California

- 12.7M members served 
- 39 hospitals 
- 622 medical offices 
- 236,956 employees;
 - 23,982 physicians 
 - 68,218 nurses 
 - 144,756 technical, administrative, clerical & non-physician caregivers 
- 95.4B annual operating revenue in 2022

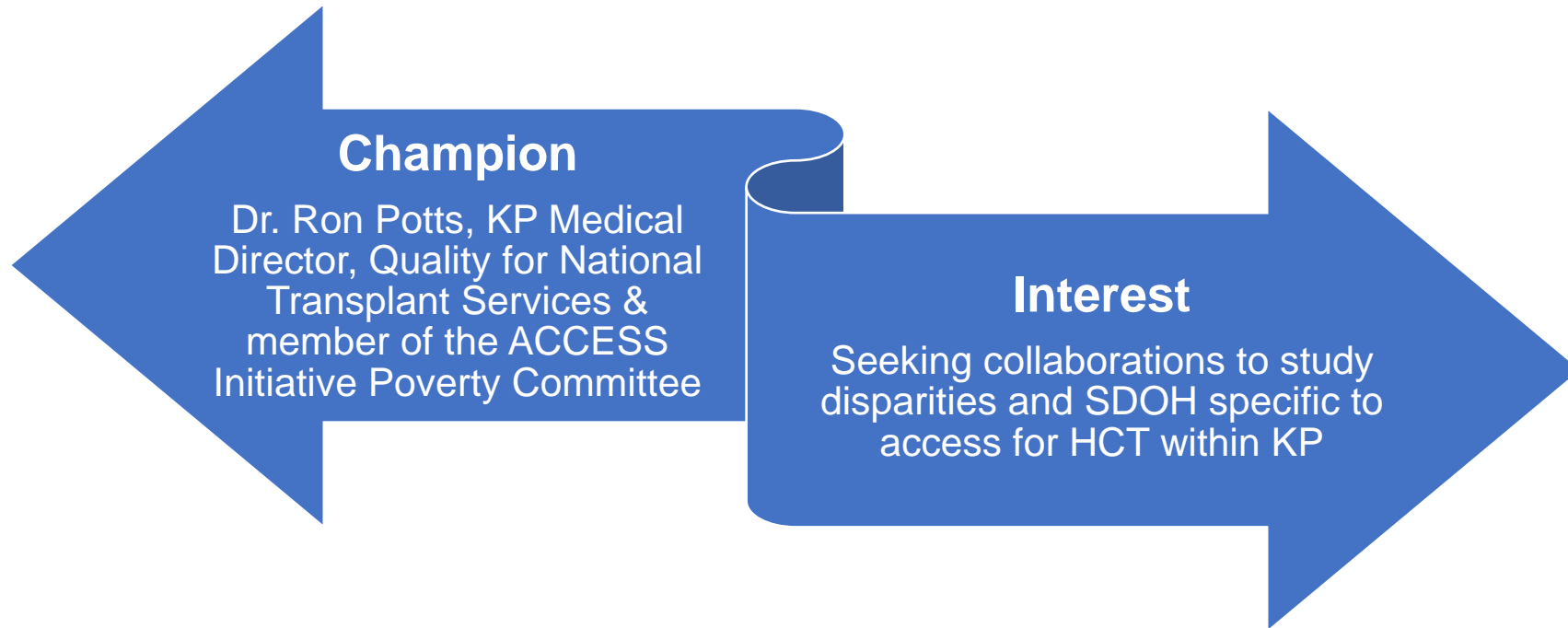


Equal Outcomes for All

Kaiser Permanente Dataset Overview

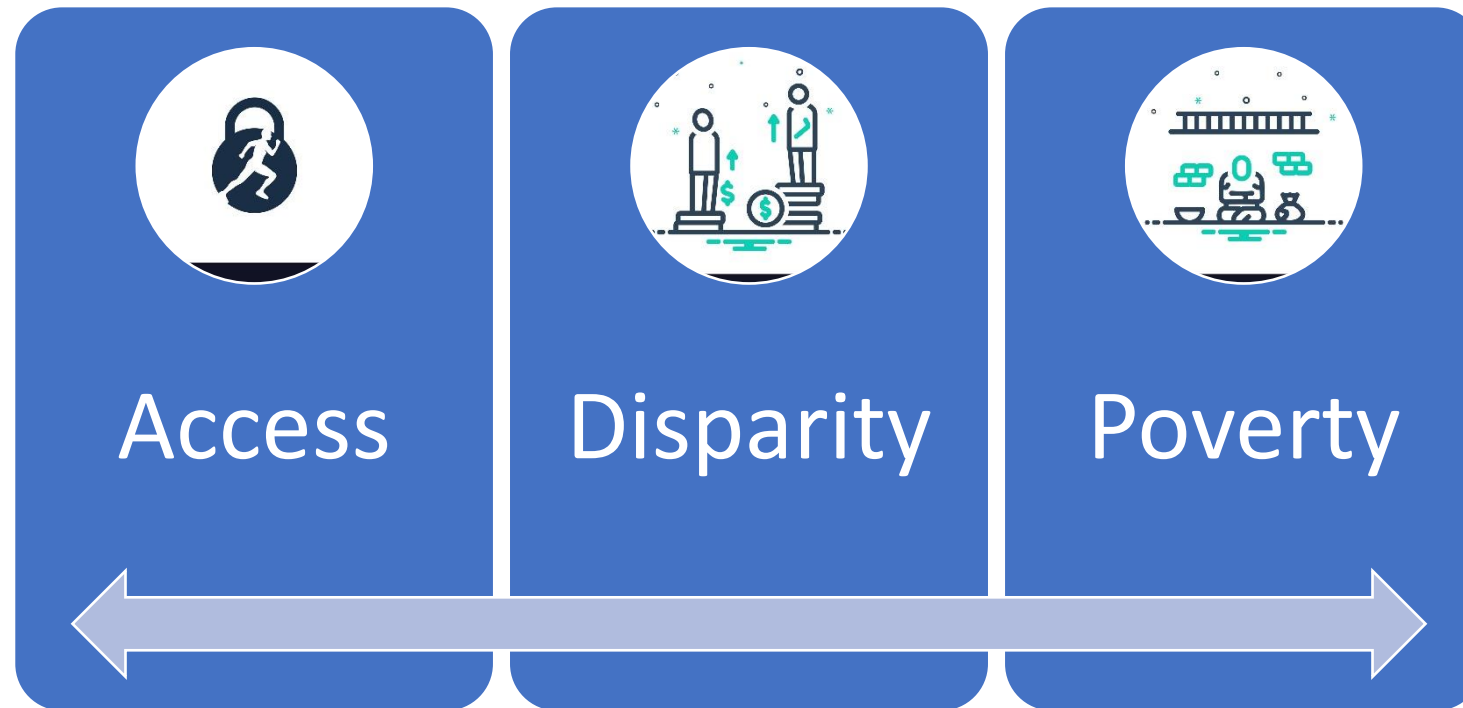


ACCESS Initiative KP Dataset Working Group – Motivation



ACCESS Initiative KP Dataset Working Group – Objective

- To consider questions & related issues around TCT via secondary analysis of KP dataset resulting in projects addressing,



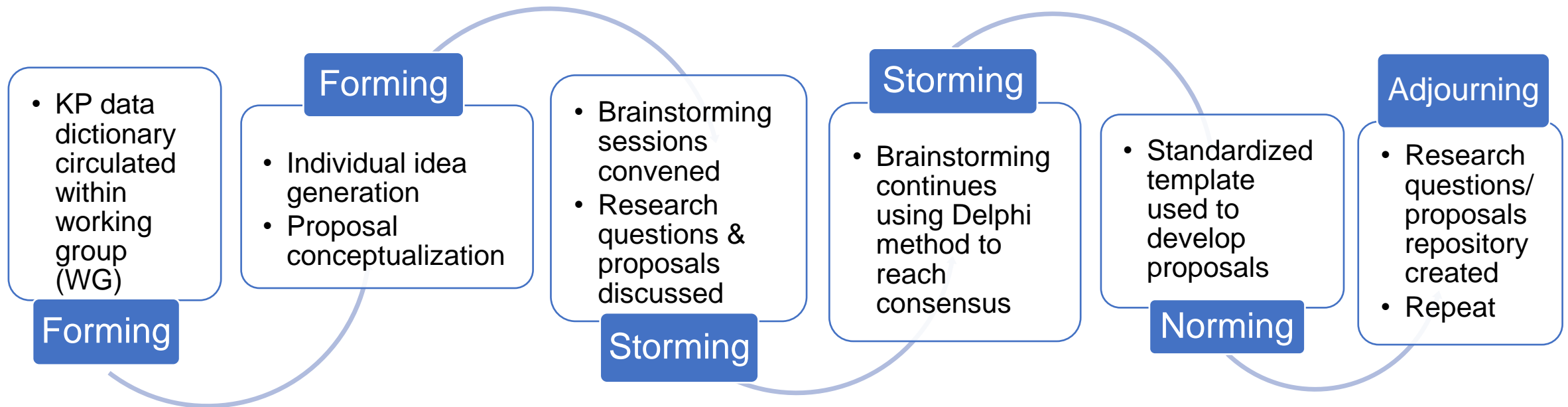
ACCESS Initiative KP Dataset Working Group – Structure

10 individuals from poverty and racial & ethnic inequities committees indicated interest in collaborating with background & expertise in,



Research Question, Proposal Generation & Selection Plan

Research question & proposal solicitation



Research Question, Proposal Generation & Selection Plan

- Proposal reviews & selection

Iterative peer-review process used to select & prioritize proposals using following selection criteria;

Feasibility

KP Feasibility Review Committee conditions

- Common interest; Relevance to KP mission
- No conflict with ongoing KP studies; Availability of KP faculty collaborator
- Impact on KP resources; Availability of data to answer research question(s)

Scientific Merit

- Adherence to good science via sound design, methodology
- Use of sound study design & methodology
- Potential contribution to the field

Timeliness

- Timeliness of study question(s)

Impact

- Ability to move the field forward

Completion Time

- Timely completion of project

Research Question, Proposal Generation & Selection Plan

Project funding & execution

Funding sources

- KP Research encourages external,
 - Collaborations with KP system
 - Sponsors & funders looking to work with KP

Federal

- National Institute of Health (NIH)
- National Cancer Institute (NCI)
- Center for Disease Control & Prevention (CDC)
- Centers for Medicare & Medicaid Innovation

Private Foundations

- Gates Foundation
- Intel Foundation
- Patient-Centered Research Institute (PICORI)
- Robert Wood Johnson Foundation (RWJF)

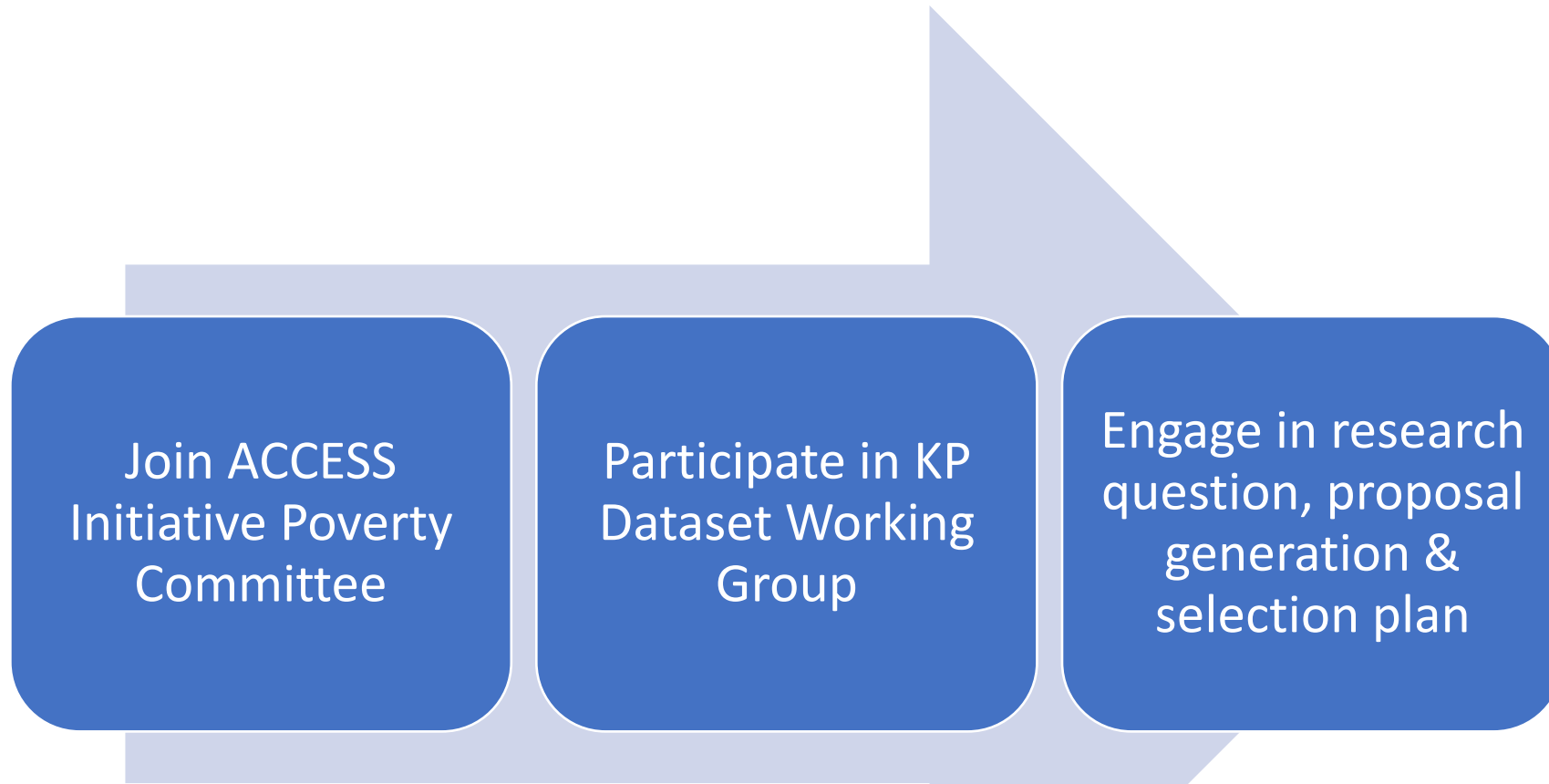
Industry

- AstraZeneca
- Merck
- Novartis
- Pfizer
- Sanofi-Aventis

Proposals Synopses

Title	Research Questions	Aims	Known	Unknown	Justification
Social Determinants of Health (SDOH) and Access to Hematopoietic Cell Transplantation for Patients from the Kaiser Permanente System	1. How do SDOH influence referral/ non-referral & receipt/ non-receipt of alloHCT for AML & autoHCT for PCN in KP system? 2. At which step(s) of referral & pre-transplant are social factors a barrier to proceeding with transplant?	<ul style="list-style-type: none"> - Examine disease, social factors & treating physician factors related with referral by primary oncologists to consider HCT for adults with AML & PCN - Compare sociodemographic characteristics of referred vs. not referred vs. referred & not seen vs. referred & seen for adults with AML & PCN - Examine sociodemographic & disease characteristics of adult consults for vs. recipients of HCT 	Impact of inequities in healthcare access & utilization on HCT outcomes	Knowledge of SDOH-dependent HCT referral process vulnerabilities & accurate measures of access barrier rates are lacking	KP dataset provides integrated, comprehensive & geographically diverse data to understand & objectively measure such barriers
Access to BMT amongst beneficiaries with sickle cell disease: Exploration of socioeconomic factors	1. What proportion of individuals with SCD & severe SCD are referred for BMT consult, HLA typing & URD search? 2. Is likelihood of BMT referral associated with residential socioeconomic measure or distance to transplant centers?	<ul style="list-style-type: none"> - Describe BMT referral patterns for KP enrollees with SCD - Describe proportion of individuals with a severe phenotype - Explore if SES surrogate & distance to transplant center are associated with likelihood of BMT referral or receipt
Role of housing and neighborhoods as a structural determinant of health across the cancer care continuum	1. What is the role of structural determinants such as housing & neighborhoods in HCT approval & time-to-transplant for patients with hematologic disorders?	<ul style="list-style-type: none"> - Investigate differences in HCT approval between securely & insecurely housed adult patients - Examine differences in duration from consultation to transplant in securely & insecurely housed adult HCT recipients - Explore time-to-transplant differences between HCT recipients residing in high vs. low socially deprived neighborhoods
Caregiver related research	1. What caregiver roles, relationships & requirements impact outcomes post-HCT?

How To Participate



Questions

Thank You!

Break
10:00- 10:15 AM

Pilot Project Deep Dive: Health Equity in Practice 10:15-10:45 AM

Presented by: Delilah Robb

ASTCT-NMDP ACCESS Initiative

Racial Inequity Committee

Initiative #2: Race/Ethnicity Data Optimization

Health Equity in Practice

DAY 2

Washington D.C.

August 25, 2023

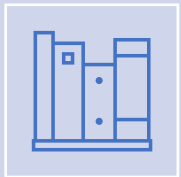
Delilah Robb, MPH

Program Manager, Data and Implementation Science

Health Equity in Practice



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 TCs' 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 Outline



Introduction



Assessment



Data



Community Engagement



Quality Improvement



Education and Training Resources



Evaluation Tools

We want to hear from you!

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

<http://bitly.ws/RyXm>



Call to Action

1. Take the survey using the QR code
2. Volunteer your TC to be on the project rollout list
3. Take this work back to your TC and socialize/gain buy-in
4. Volunteer to champion this work, even if it's not at your TC

Discussion

- What other NMDP/CIBMTR or population data would be helpful to drive health equity data driven solutions at your TC?
- What tools, training, and/or resources should be included in toolkit?

Contact Information: Delilah Robb, MPH, drobb@nmdp.org

Data

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



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)	# %	# %	# %	# %	# %	# %	# %

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

10:45-11:45 AM

Presented by: Jeff Auletta and Stella Davies

ASTCT NMDP ACCESS Initiative

One year later

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

Year I (Jul 2022 - Aug 2023) Highlights

- **ACCESS Initiative started!**

- Charter established
- ACCESS Initiative & Medicaid scan manuscripts published
- Participation: NHLBI, HRSA, Optum, Kaiser Permanente [Humana]
- Prospectus, Website

- **Meetings**

- Inaugural Workshop in DC, 2023 Tandem Meetings
- 2022 AcCELLerate Forum

- **Venue presentations**

- 2023 ASTCT Corporate Council
- 2023 HRSA Advisory Council on Blood Stem Cell Transplantation
- Biobehavioral SIG presentation at 2024 Tandem

- **Industry partnerships**

- Kite a Gilead Company, Takeda Pharmaceuticals



Debbie Fernandez *Project Manager*
dfernandez@francefoundation.com

Metrics of Success

- What are they?
 - Publications (primary and secondary: Age and CAR T-cell barriers)
 - Presentations
 - Partnerships
 - Philanthropic support / grants
 - Policy changes
 - Lives impacted
- How do we monitor our success?
- How do we promote/publicize the Initiative's impact?

Challenges

- Partnership
 - Communication
 - Contribution / resources
- Maintaining momentum
 - Personal investment
 - Enthusiasm
 - Time commitment
 - Interested parties/persons
 - Engagement, assignment, retainment
- Evolution
 - Projects and personnel



Working Lunch

11:45 AM - 1:15 PM

11:45 – 12:30 PM Patient Member considerations

Presented by: Emily Ward and Jackie Foster

12:30-1:15 PM Tandem Meeting Planning

Presented by: Jeff Auletta and Stella Davies

ASTCT-NMDP ACCESS Initiative

Engaging Patients and Caregivers

Washington D.C.

August 25, 2023

Introductions and Purpose

Jackie Foster, MPH, RN, OCN

Senior Manager, Patient Services

- CIBMTR Consumer Advisory Committee
- Be The Match Voice of Community

Emily Ward, MPA

Health Policy Analyst

- Government Affairs and Public Policy
- Barriers to Transplant Advisory Group

Top Learnings from Patient and Caregiver Groups

1

Clear purpose for participation should be communicated and understood

2

Expectations of logistics, time commitment should be clearly communicated before joining group

3

Patients and caregivers must feel comfortable and empowered to speak up

4

Consider gaps in clinical knowledge or internal work

5

Proactively evaluate effectiveness and satisfaction

Consideration #1: Define your objective



Incorporate patient and caregiver feedback in planning, implementation and evaluation

Empower patients and caregivers to create and work on initiatives aligned to ACCESS

Help spread key messages from the ACCESS initiative through the patient and caregiver voice

Provide rich and unfiltered patient and caregiver perspectives for the 3 working groups to inform their thinking

Consideration #2: Align the Structure to the Objective

Incorporate their feedback in planning, implementation and evaluation

- Formal membership in existing ACCESS workgroup
- Separate Patient/Caregiver Workgroup
- Gather feedback from patients and caregivers on specific aspects of ACCESS initiative as needed

Empower them to create and implement initiatives aligned to ACCESS

- Separate Patient/Caregiver workgroup

Help spread key messages from the ACCESS initiative through their voices

- Formal membership in existing ACCESS workgroups
- Separate Patient/Caregiver workgroup
- Patient/caregiver speaker's bureau

Provide their rich and unfiltered perspectives for the workgroups

- Interviews or focus groups with patients and caregivers
- Gather feedback from patients and caregivers on specific aspects of ACCESS initiative as needed

Consideration #3: Diversify the Voices



What experiences and backgrounds are needed to achieve the goal?

- Racial/ethnic diversity
- Range of ages, diagnoses, geography, language
- Mix of patients, caregivers, parent caregivers
- Experience with poverty, discrimination?
- Experience working in committees?
- Experience public speaking?

What will they need to be successful?

- Training on committees, public speaking, tech?
- Stipends, travel assistance?
- Primary contact for questions, concerns, support?

Consideration #4: Orientation / Training Needs

How will training be provided?

What will be covered?

- Overall project aims
- Their role in the project
- Technical help with IT systems
- Specific skills, like public speaking
- Ongoing support to build confidence in their role and voice
- Feedback for all members on how to make this a welcoming environment for patient and caregivers



Consideration #5: Evaluation Plan



- **How will you know if their engagement is successful?**
- **What will/can you measure?**
 - Achievement of goals?
 - Patient and caregiver engagement and/or satisfaction?
 - Quantity/quality of feedback?
- **What could you change/modify if the engagement plan isn't successful?**

Questions for Discussion

What is our objective for patient/caregiver engagement?

What are some of the pros/cons to different potential structures?

What is the right time to do this?

What patient/caregiver experiences and perspectives do we want?

ASTCT NMDP ACCESS Initiative

2024 Tandem Planning

Washington D.C.

August 24 & 25, 2023

2024 Tandem Meetings: ACCESS Symposium

- 90-minutes (date pending)
- Format
 - 2023 Tandem Symposium
 - Intro + 3 speakers [Staci Arnold, Sumi Vasu, Warren Fingrut]
 - Overview of committee pilot projects
 - 2024 Tandem Symposium
 - Invited speaker(s): Topic/theme(?)
 - Committee progress reports
- Patients (?)
- Industry presentation/representation

What's Next?

- Chair Debrief Meeting
- Interim Virtual Meetings
 - Chairs
 - Committees
- Workshop white paper
 - Author group:
 - Notetakers + Chairs + Interested people (meaningful contribution)
 - Attendees:
 - Will be recognized
- See you at the 2024 Tandem Meetings ACCESS Symposium!

“We cannot walk alone. And as we walk, we must make the pledge that we shall march ahead. We cannot turn back.”



Wrap-Up

1:15- 1:30 PM

Feedback

Please fill out this brief survey to provide your thoughts about the Workshop



**Workshop Ends
1:30 PM**