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

- Considerations
- Potential Interventions

- Administrative
- Legislative
- Educational
- Organizational

- Impact
- Feasibility
- Patient Safety
- Unintended Consequences
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- Target those states with coverage policies that are discriminatory or outdated.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 what you want.
- Be winnable.
- Understand Power (votes or money)
- Being right isn’t enough. Being right is NOT power.
## Outline campaign for Ohio

- **Long:** Increase Medicaid coverage  
- **Mid:** Establish relationship with Medicaid office  
- **Short:** Gather anecdotal evidence of problem

## Timeline

### Goals Minnesota

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<tr>
<th>Goals</th>
<th>Organizational Considerations</th>
<th>Constituents and Allies</th>
<th>Decisions Maker</th>
<th>Tactics</th>
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<td><strong>What do we want to win:</strong></td>
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| **Long Term:** All Medicaid patients to have access to life-saving cell therapy. | **What do we have:** Budget: Yes. Staff: Yes. NMDP Lobby Firm: Yes. – and Coalition Marketing: No. Social Media: No. Data: Not really. Can we raise money? Maybe. Political Power: Democratic trifecta: House, Senate and Governor. | Constituents Dr. Devine, ½ of the people in the room; NMDP headquartered | Julie Marquardt as Commissioner of Health.  
- Assembly Created a joint Medicaid Oversight Committee (JMCO)  
- Chair Edwards House Finance Committee  
- Chair Dolan, Senate Finance | MN Medicaid Facts:  
- 1.26 Million people covered  
- Medicaid is 3rd largest payer in MN  
- Total Medicaid Spending $15B |
| **Intermediate:** |                               |                        |                                      |         |
| **Short Term:** Send a letter to Commissions asking to update coverage for sickle cell disease and MDS transplant only covered under clinical trial. |                               |                        |                                      |         |

### MN State Data 2018-2022

- 1248 searching patients  
- 461 transplants  
- 300 donors  
- 108,117 residents willing to donate  
- 403 have received a patient grant
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
Kaiser Permanente Dataset Overview

KP Dataset

Proprietary & owned by KP

Data capture, collection & tracking from 12.7M members over 8 regions

Comprise;
- Blood & marrow, solid organ & mechanical circulatory support transplant data
- >900 unique attributes & data types
- Collection from EMR & surveys
ACCESS Initiative KP Dataset Working Group – Motivation

Champion
Dr. Ron Potts, KP Medical Director, Quality for National Transplant Services & member of the ACCESS Initiative Poverty Committee

Interest
Seeking collaborations to study disparities and SDOH specific to access for HCT within KP

Equal Outcomes for All
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
- Disparity
- Poverty

Equal Outcomes for All
ACCESS Initiative KP Dataset Working Group – Structure

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

- Hematology/Oncology
- Adult/Pediatric BMT
- Public health
- Nursing
- Health services research
- Quantitative (1º&2º data) research design & analysis
- Qualitative research design & analysis
- Data linkage
- Administrative claims data analysis
- Economic and cost analysis
- Survey design & administration
- Health outcomes & QoL research
- Population health status/risk assessment
- Health policy analysis
- Program planning and evaluation
- Patient-reported outcomes
- Survey research methodology
- Data management
- Healthcare management
- Grants and contracts management
- Dissemination and implementation

Equal Outcomes for All
Research Question, Proposal Generation & Selection Plan

Research question & proposal solicitation

Forming
- KP data dictionary circulated within working group (WG)
- Individual idea generation
- Proposal conceptualization

Storming
- Brainstorming sessions convened
- Research questions & proposals discussed
- Brainstorming continues using Delphi method to reach consensus

Norming
- Standardized template used to develop proposals
- Research questions/proposals repository created
- Repeat

Adjourning
- Equal Outcomes for All
Research Question, Proposal Generation & Selection Plan

- Proposal reviews & selection
  Iterative peer-review process used to select & prioritize proposals using following selection criteria:

<table>
<thead>
<tr>
<th>Category</th>
<th>KP Feasibility Review Committee conditions</th>
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<tr>
<td>Feasibility</td>
<td>- Common interest; Relevance to KP mission</td>
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<td>- No conflict with ongoing KP studies; Availability of KP faculty collaborator</td>
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<td>- Impact on KP resources; Availability of data to answer research question(s)</td>
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<td>Scientific Merit</td>
<td>- Adherence to good science via sound design, methodology</td>
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<td>- Use of sound study design &amp; methodology</td>
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<td>- Potential contribution to the field</td>
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<td>Timeliness</td>
<td>- Timeliness of study question(s)</td>
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<td>Impact</td>
<td>- Ability to move the field forward</td>
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<td>Completion Time</td>
<td>- Timely completion of project</td>
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Equal Outcomes for All
Research Question, Proposal Generation & Selection Plan

Project funding & execution

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<thead>
<tr>
<th>Funding sources</th>
<th>Federal</th>
<th>Private Foundations</th>
<th>Industry</th>
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<tr>
<td></td>
<td>• National Institute of Health (NIH)</td>
<td>• Gates Foundation</td>
<td>• AstraZeneca</td>
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<td>• National Cancer Institute (NCI)</td>
<td>• Intel Foundation</td>
<td>• Merck</td>
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<td>• Center for Disease Control &amp; Prevention (CDC)</td>
<td>• Patient-Centered Research Institute (PICORI)</td>
<td>• Novartis</td>
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<td>• Centers for Medicare &amp; Medicaid Innovation</td>
<td>• Robert Wood Johnson Foundation (RWJF)</td>
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<td>• Sanofi-Aventis</td>
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• KP Research encourages external,
  • Collaborations with KP system
  • Sponsors & funders looking to work with KP
## Proposals Synopses

<table>
<thead>
<tr>
<th>Title</th>
<th>Research Questions</th>
<th>Aims</th>
<th>Known</th>
<th>Unknown</th>
<th>Justification</th>
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| **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 & pretreatment are social factors a barrier to proceeding with transplant? | - 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? | - 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? | - 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

Join ACCESS Initiative Poverty Committee
Participate in KP Dataset Working Group
Engage in research question, proposal generation & selection plan

Equal Outcomes for All
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

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<th>Age Group</th>
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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

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**Debbie Fernandez**
*Project Manager*

dfernandez@francefoundation.com

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Equal Outcomes for All
Metrics of Success

• What are they?
  o Publications (primary and secondary: Age and CAR T-cell barriers)
  o Presentations
  o Partnerships
  o Philanthropic support / grants
  o Policy changes
  o Lives impacted

• How do we monitor our success?

• How do we promote/publicize the Initiative’s impact?
Challenges

• Partnership
  o Communication
  o Contribution / resources

• Maintaining momentum
  o Personal investment
    ▪ Enthusiasm
    ▪ Time commitment
  o Interested parties/persons
    ▪ Engagement, assignment, retention

• Evolution
  o 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

Equal Outcomes for All
Consideration #1: Define your objective

1. Incorporate patient and caregiver feedback in planning, implementation and evaluation
2. Empower patients and caregivers to create and work on initiatives aligned to ACCESS
3. Help spread key messages from the ACCESS initiative through the patient and caregiver voice
4. 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

Equal Outcomes for All
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
  o 2023 Tandem Symposium
    ▪ Intro + 3 speakers [Staci Arnold, Sumi Vasu, Warren Fingrut]
    ▪ Overview of committee pilot projects
  o 2024 Tandem Symposium
    ▪ Invited speaker(s): Topic/theme(?)
    ▪ Committee progress reports

• Patients (?)

• Industry presentation/representation
What’s Next?

• Chair Debrief Meeting
• Interim Virtual Meetings
  o Chairs
  o Committees
• Workshop white paper
  o Author group:
    ▪ Notetakers + Chairs + Interested people (meaningful contribution)
  o 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