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

Equal Outcomes for All

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

Presented by: Ellie Beaver

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

Administrative
Legislative
Educational
Organizational

Potential Interventions

Considerations

Impact
Feasibility
Patient Safety
Unintended Consequences
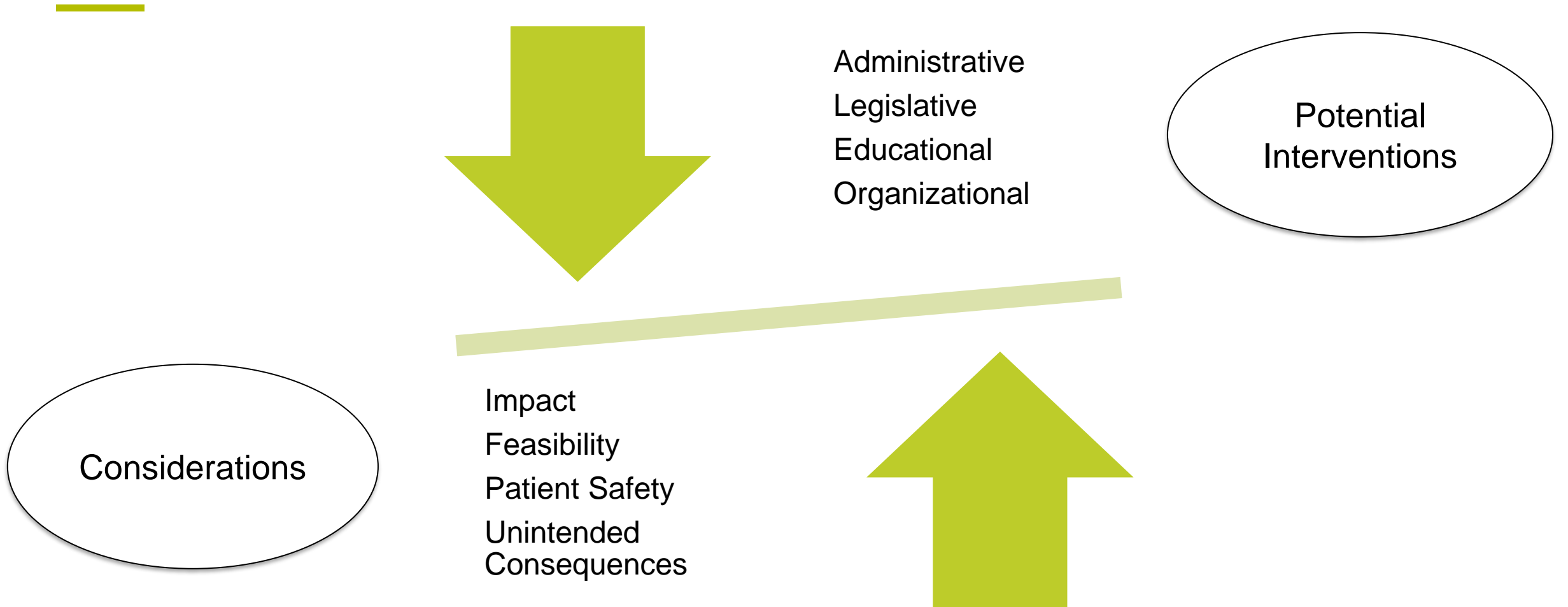
Recommended Intervention

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.**

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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

| Education | Advocacy (asking nicely) | Direction Acton (Organizing and applying pressure) |

- 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
What do we want to win: **Long Term:** All Medicaid patients to have access to life-saving cell therapy. **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 • 108,117residents willing to donate • 403 have received a patient grant	**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. **What do we need/ want:** More ASTCT members? More Advocates in OH? Be advocacy leaders	**Constituents** **Dr. Devine**, ½ of the people in the room;) NMDP headquartered **Allies** • This is Medicaid Coalition • Mayo Clinic • University of MN	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

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

Agenda

- KP system overview

- KP dataset overview

- ACCESS Initiative KP working group structure

- Research question, proposal generation & selection plan

- Proposals synopses

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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
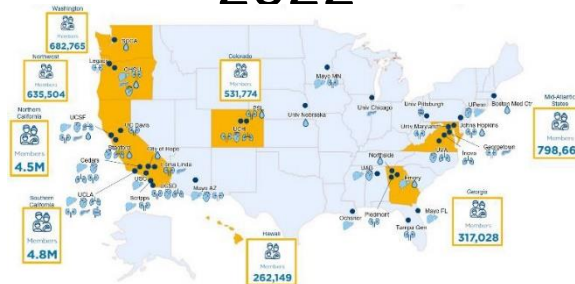
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Kaiser Permanente Dataset Overview

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

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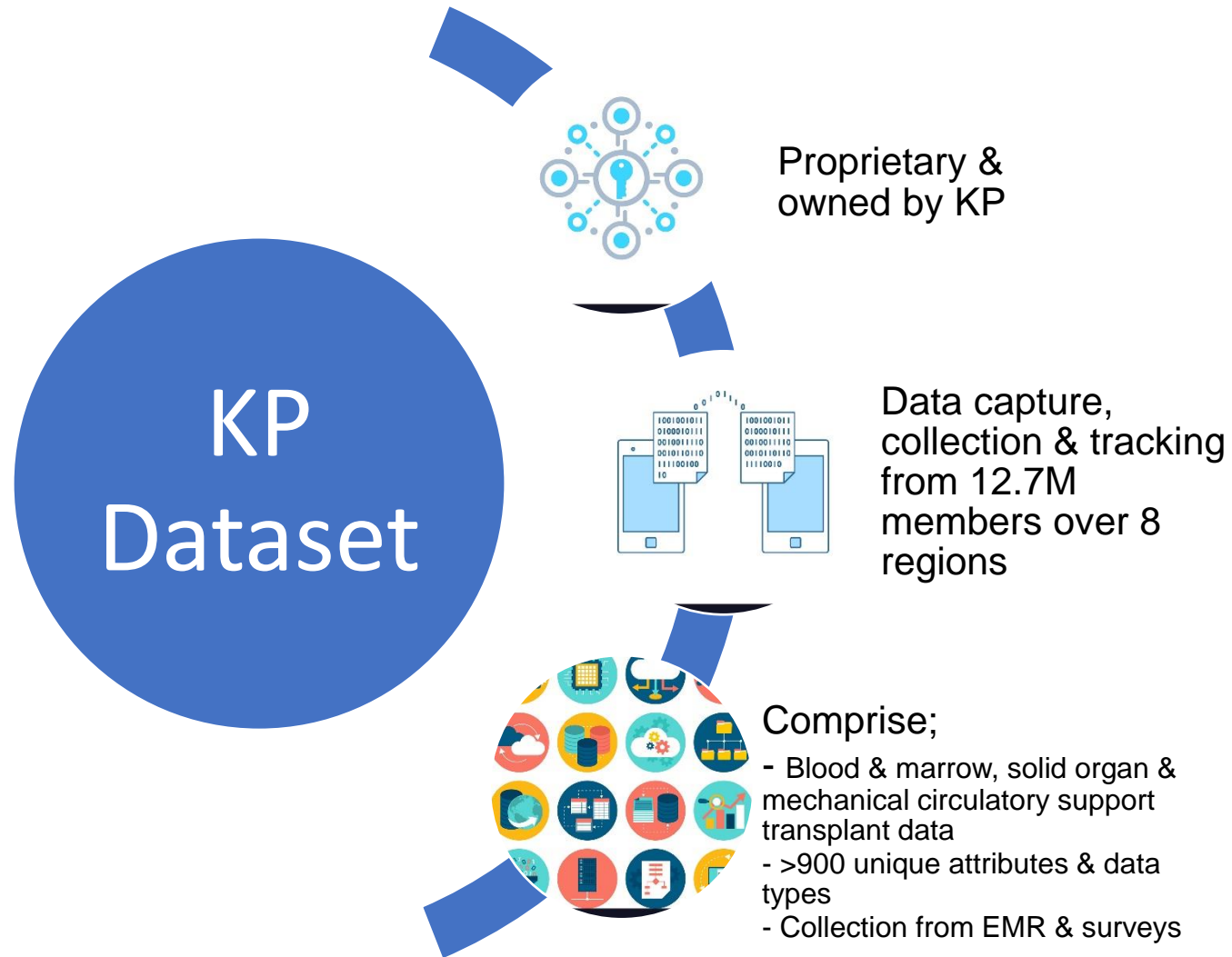
ACCESS Initiative KP Dataset Working Group – Motivation

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
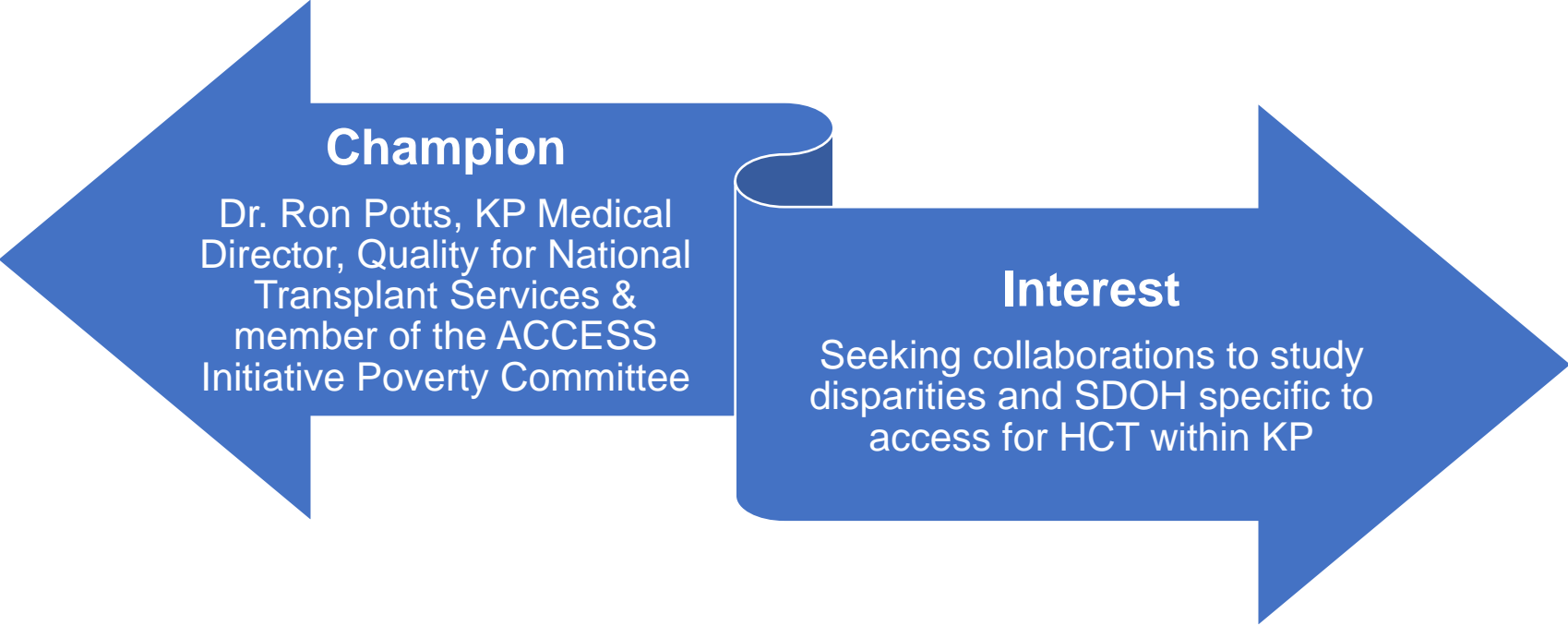
ACCESS Initiative KP Dataset Working Group – Objective

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

Access

Disparity
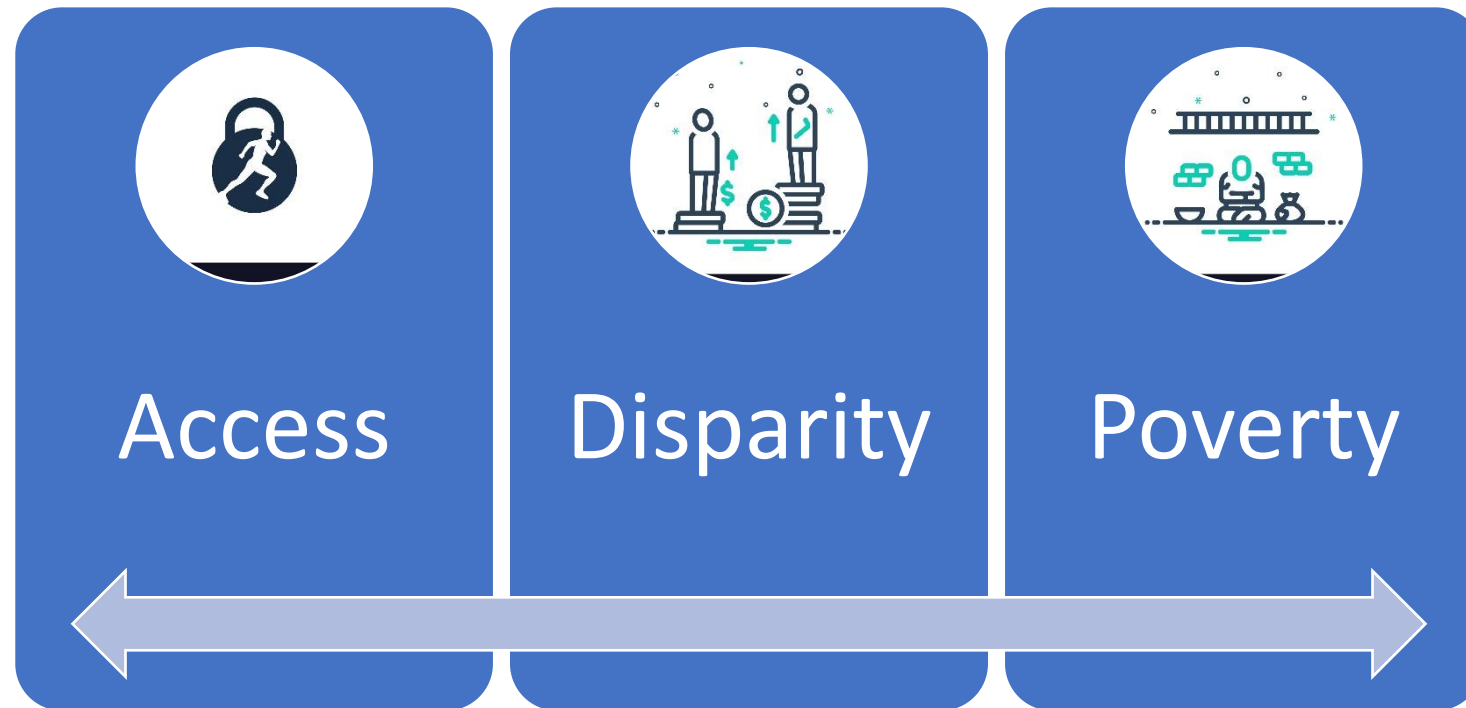
Poverty

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		

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Research Question, Proposal Generation & Selection Plan

Research question & proposal solicitation

Forming

- KP data dictionary circulated within working group (WG)

Forming

- Individual idea generation
- Proposal conceptualization

Forming

- Brainstorming sessions convened
- Research questions & proposals discussed

Storming

Storming

- Brainstorming continues using Delphi method to reach consensus

Storming

- Standardized template used to develop proposals

Norming

Adjourning

- Research questions/ proposals repository created
- Repeat

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)
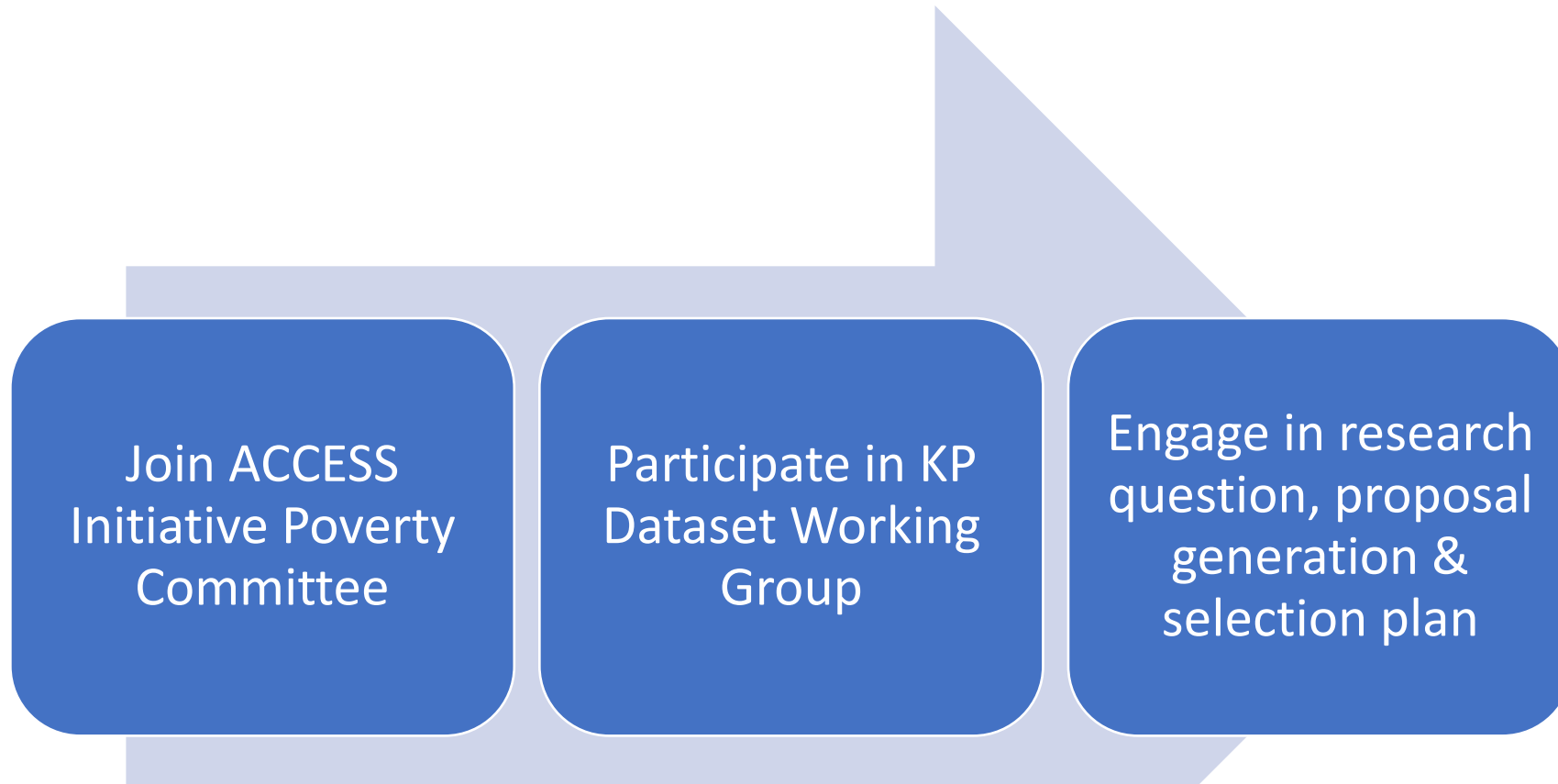- Robert Wood Johnson Foundation (RWJF)

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?	- 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?	…	…	…	…

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How To Participate

Questions

Thank You!

Break
10:00- 10:15 AM

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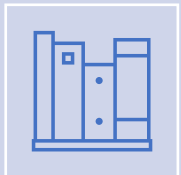
Address and reduce barriers to transplant by providing a TC-directed quality improvement toolkit empowering centers to identify and strengthen health equity programming and services they provide.

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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

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Toolkit Outline

Introduction

Assessment

Data

Community Engagement

Quality Improvement

Education and Training Resources

Evaluation Tools

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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

SCAN ME

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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

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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
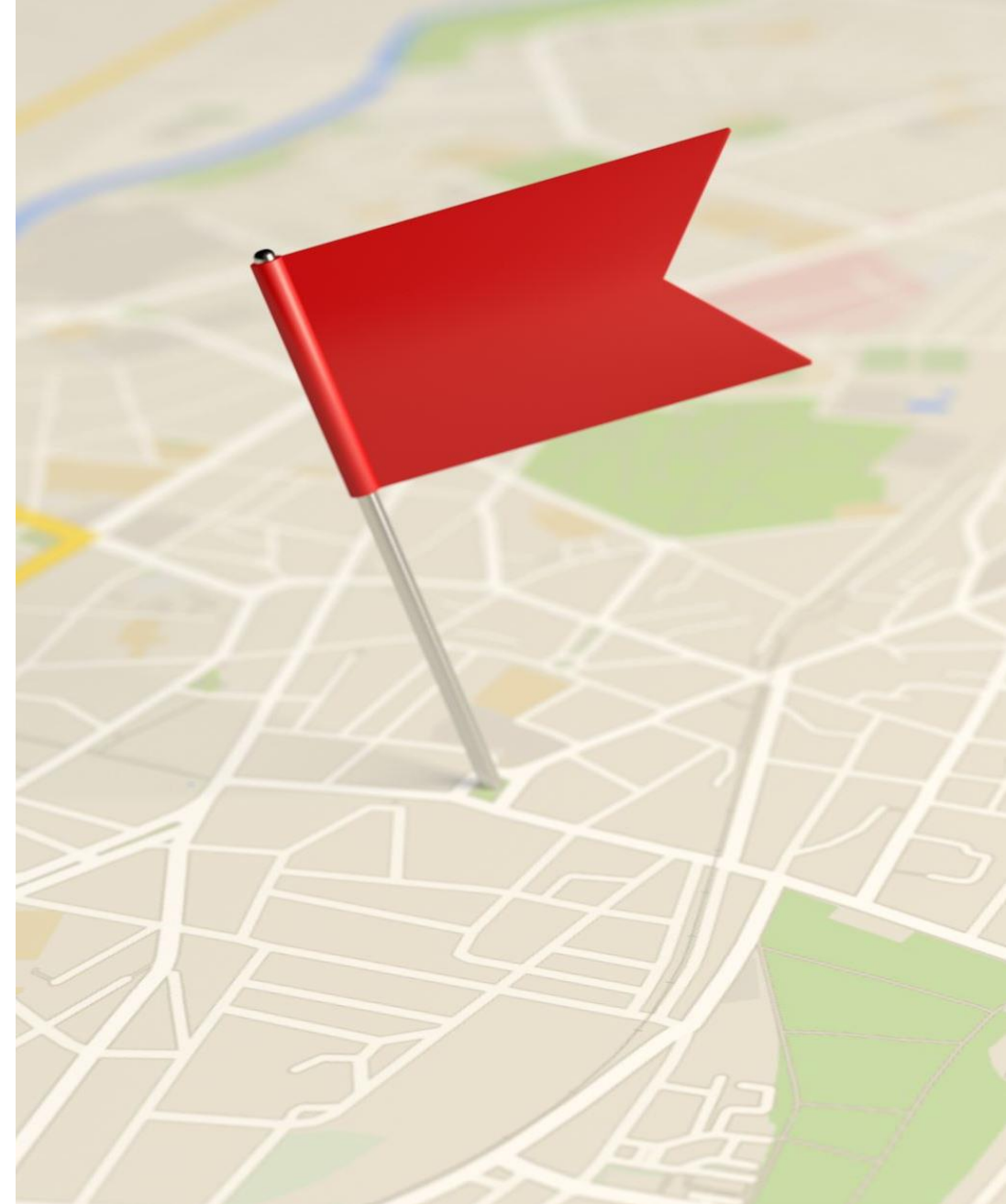
Market 5-Year Summary 2017-2021

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

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ASTCT NMDP ACCESS Initiative

One year later

Washington D.C.

August 24 & 25, 2023

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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

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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

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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

Always help someone. You might be the only one that does.

Spirit Science

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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

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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

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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

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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

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Consideration #2: Align the Structure to the Objective

Incorporate their feedback in planning, implementation and evaluation	**Empower them to create and implement initiatives aligned to ACCESS**	**Help spread key messages from the ACCESS initiative through their voices**	**Provide their rich and unfiltered perspectives for the workgroups**
• Formal membership in existing ACCESS workgroup • Separate Patient/Caregiver Workgroup • Gather feedback from patients and caregivers on specific aspects of ACCESS initiative as needed	• Separate Patient/Caregiver workgroup	• Formal membership in existing ACCESS workgroups • Separate Patient/Caregiver workgroup • Patient/caregiver speaker's bureau	• Interviews or focus groups with patients and caregivers • Gather feedback from patients and caregivers on specific aspects of ACCESS initiative as needed

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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?

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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

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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?

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ASTCT NMDP ACCESS Initiative
2024 Tandem Planning

Washington D.C.

August 24 & 25, 2023

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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