ACCESS Working Group Committee: Racial/Ethnic Inequities

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Vice Chair: Rayne Rouce

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Frank Holloman
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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

Equal Outcomes for All
Initiatives to Address Racial/Ethnic Inequities (Current)

Initiative #1
Level the knowledge

Initiative #2
Optimize the data

Initiative #3
Workforce Development

Equal Outcomes for All
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.
What is your role at the transplant center? (select all that apply)

- Nurse, Transplant Coordinator, 3, 7%
- Other, 2, 5%
- Administrator/Program Manager, 7, 17%
- Transplant Coordinator, 13, 32%
- Social Worker, 13, 32%
- Physician, 3, 7%

Equal Outcomes for All
Health Equity Survey Cont.

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

- **Resources**: 14
- **Staff shortages**: 12
- **Capacity**: 10
- **Knowledge of how and where to begin**: 10
- **Limited data**: 3
- **Other**: 0
What tools and resources would be helpful to improve health equity efforts at your transplant center (select all that apply)?

- Community engagement tools: 25
- Clinical research health equity resources: 24
- Implicit bias training and cultural humility training (potentially specific to BMT): 21
- Planning and meeting tools: 18
- Quality improvement tools: 17
- Relationship building with community referring physicians: 17
- Other: 0
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)

- Unmet needs analysis and market maps: 29
- Racial and ethnic demographics for searches initiated with NMDP: 25
- Social vulnerability index of the communities your transplant center: 25
- Racial and ethnic demographic of the community population: 24
- Patient reported outcomes: 23
- Patient race and ethnic claims data: 13
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

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<th>Age Group</th>
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<th>Black / African American</th>
<th>More than one race</th>
<th>Hispanic</th>
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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

- **Jan – March**: Delilah Robb hired at NMDP/Be The Match
- **April – June**: Information gathering, Internal stake holder interviews, Literature review
- **June - July**: Toolkit Development, Implementation, Strategy development
- **August-Sept**: Health Equity Survey
- **October**: Toolkit finalized
- **November 6 - 10**: Begin HEP Pilot: Kickoff meeting with TCs
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?