ASTCT-NMDP ACCESS Initiative

2024 Summer Workshop

Stella Davies Jeff Auletta

Washington, D.C.

July 23-24, 2024

Equal Outcomes for All

The HCT/CT Patient Journey: Is not the same for all

Place

Payer

Care-giver

Pre-HCT/CT

- Presentation
- Diagnosis
- Referral

Patient — Provider

Peri-HCT/CT

- Clinical trials
- Treatments
- Complications

Pharma — Center

Post-HCT/CT

- Transition care
- Survivorship
- End-of-life

Social Roles — Provider

Policy

HCT/CT remains out-of-reach for many

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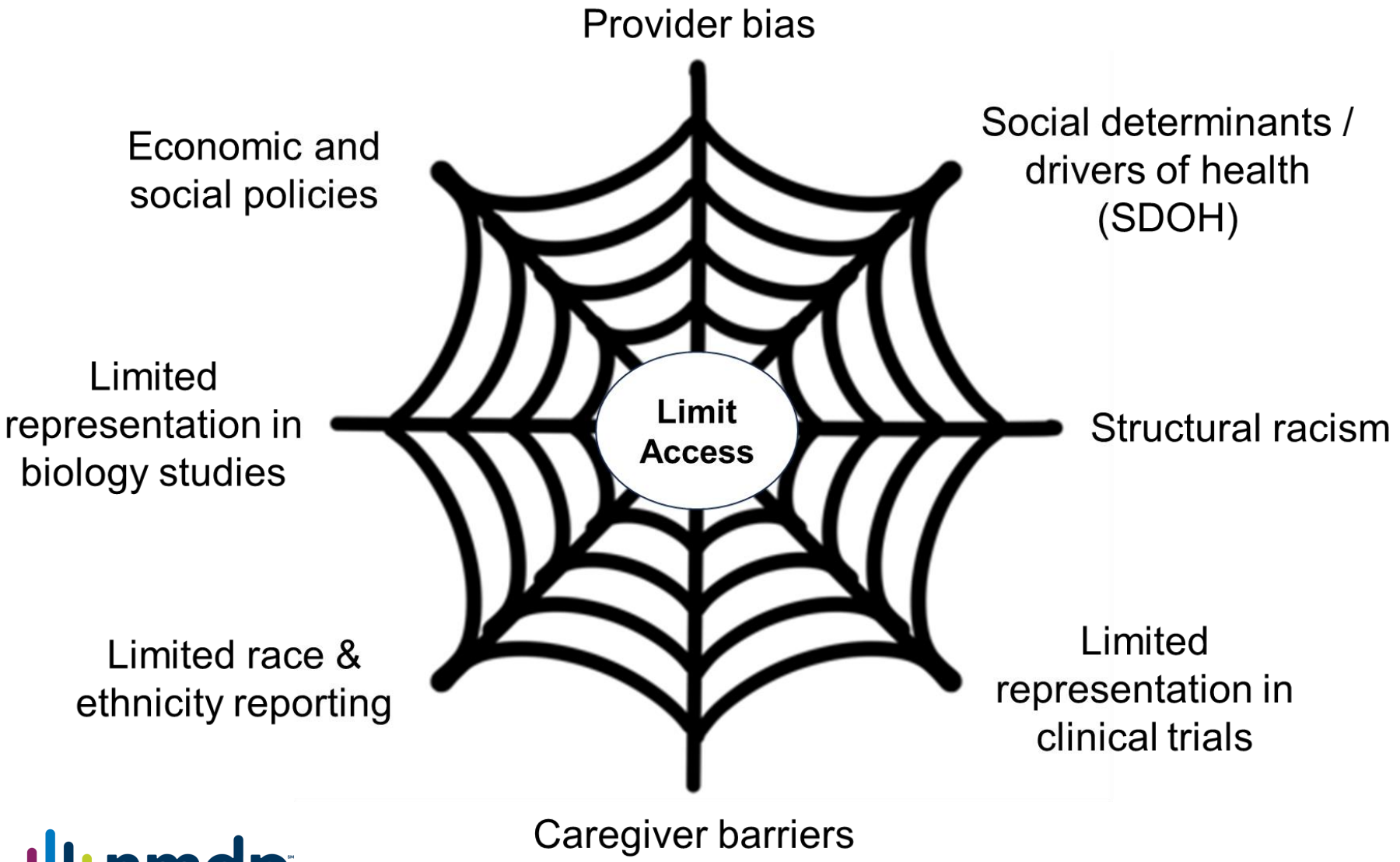
Entanglement of factors impeding access to HCT/CT



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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: Committee Leadership

NEW

	Awareness	Poverty	Racial Inequity	Junior Faculty Immersion Program
ASTCT Chairs	 Brenda Sandmaier	 Navneet Majhail	 Eneida Nemecek	 Anureka Hall
NMDP Chairs	 Erica Jensen	 Jessica Knutson	 Amber Ruffin	 Alexandra Gomez

WELCOME

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ACCESS Initiative: Vice Chairs → 2025 Chairs

ASTCT Vice Chairs

Awareness

Jennifer Holter-Chakrabarty

OU Health

Poverty

Nandita Khera

MAYO CLINIC

Racial Inequity

Rayne Royce

BCM Baylor College of Medicine

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ACCESS Initiative: 2025 ASTCT Group Chair

ASTCT Group Chair

Stella Davies

Cincinnati Children's

Eneida Nemecek

OREGON HEALTH & SCIENCE UNIVERSITY

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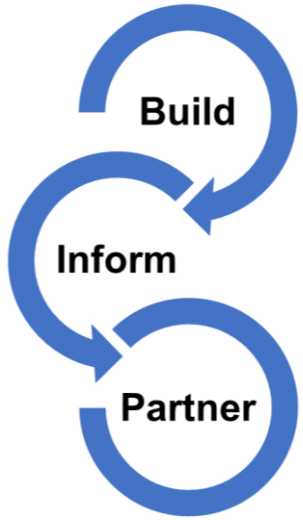


Health Equity Pillars

- Education
- Community Engagement
- Research
- Systems Change

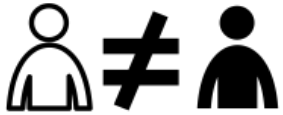
Awareness

- Physician Education
- Caregiver Reimagined

Poverty

- Medicaid Scan
- Social drivers of health (SDOH) pre-HCT/CT

Racial Inequity



- Health in Equity Toolkit

Junior Faculty and Trainee Immersion Program

- Workforce Diversity

- Physician Advocacy

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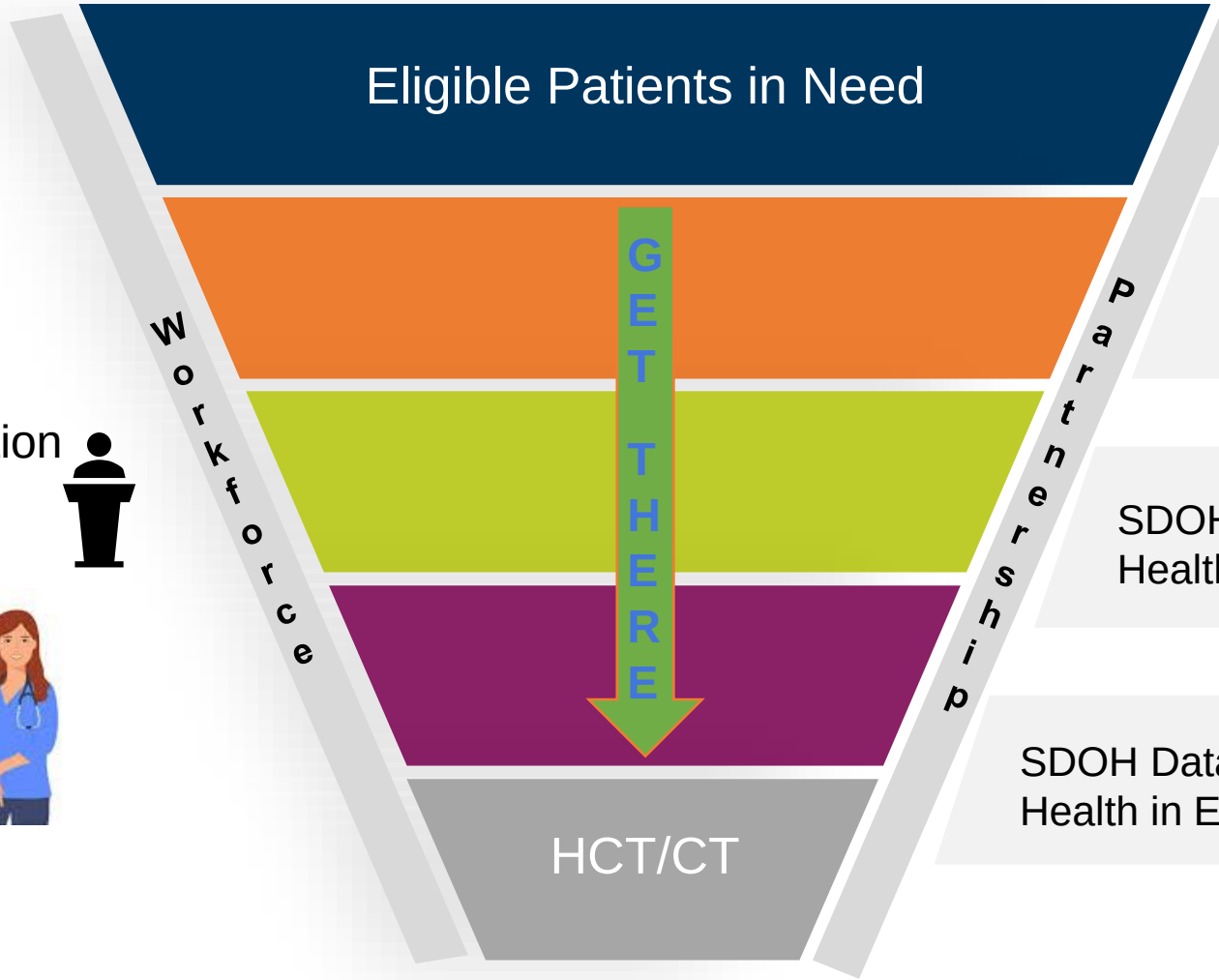
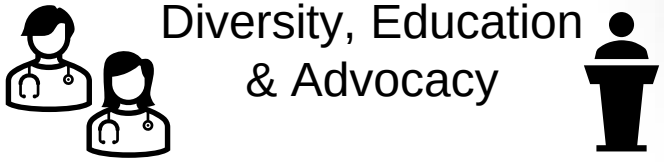
ASTCT-NMDP ACCESS Initiative Impact



Medicaid Scan
SDOH Database Pilots
Health in Equity Toolkit
Caregiver Reimagined

SDOH Database Pilots
Health in Equity Toolkit

SDOH Database Pilots
Health in Equity Toolkit



Diversity, Education & Advocacy

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- The first 3 years: Foundational
- The next 3 years: Intentional
- Project portfolio assessment
  -- What is the impact of the project?
  -- How can project impact be measured?
  -- What tactics are needed to achieve project goals?
  -- What resources are needed to achieve results?
- Thou need not continue every project…
  -- Remove underperforming/supported projects
- Be flexible to pivot as the need arises
- Encourage engagement, but expect results

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Agenda

- Agenda by themes, highlighting current efforts and (new) collaborations
- Setting the foundation for the next 3 years: Impactful projects and milestones
- Day 1:
  -- Policy, diversity & health equity
  -- Patient participation & community engagement
  -- Committee Break-outs: Review portfolio/develop projects and impact metrics
- Day 2:
  -- Data drives health equity
  -- New collaborations & projects
  -- Committee Report-outs: Forward-moving projects and impact metrics
- Advocacy Training & Hill Day

Thank you to our Non-profit Partners!

NATIONAL MINORITY QUALITY FORUM

LEUKEMIA & LYMPHOMA SOCIETY®

American Cancer Society®

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Thank you, Industry Partners!

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Thank you, all!

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New Collaborations and Projects: Access issues relevant to aging population

Sarah Wall

The Ohio State University Comprehensive Cancer Center

ACCESS Initiative Summer Workshop, Washington D.C.

Tuesday, July 23, 2024

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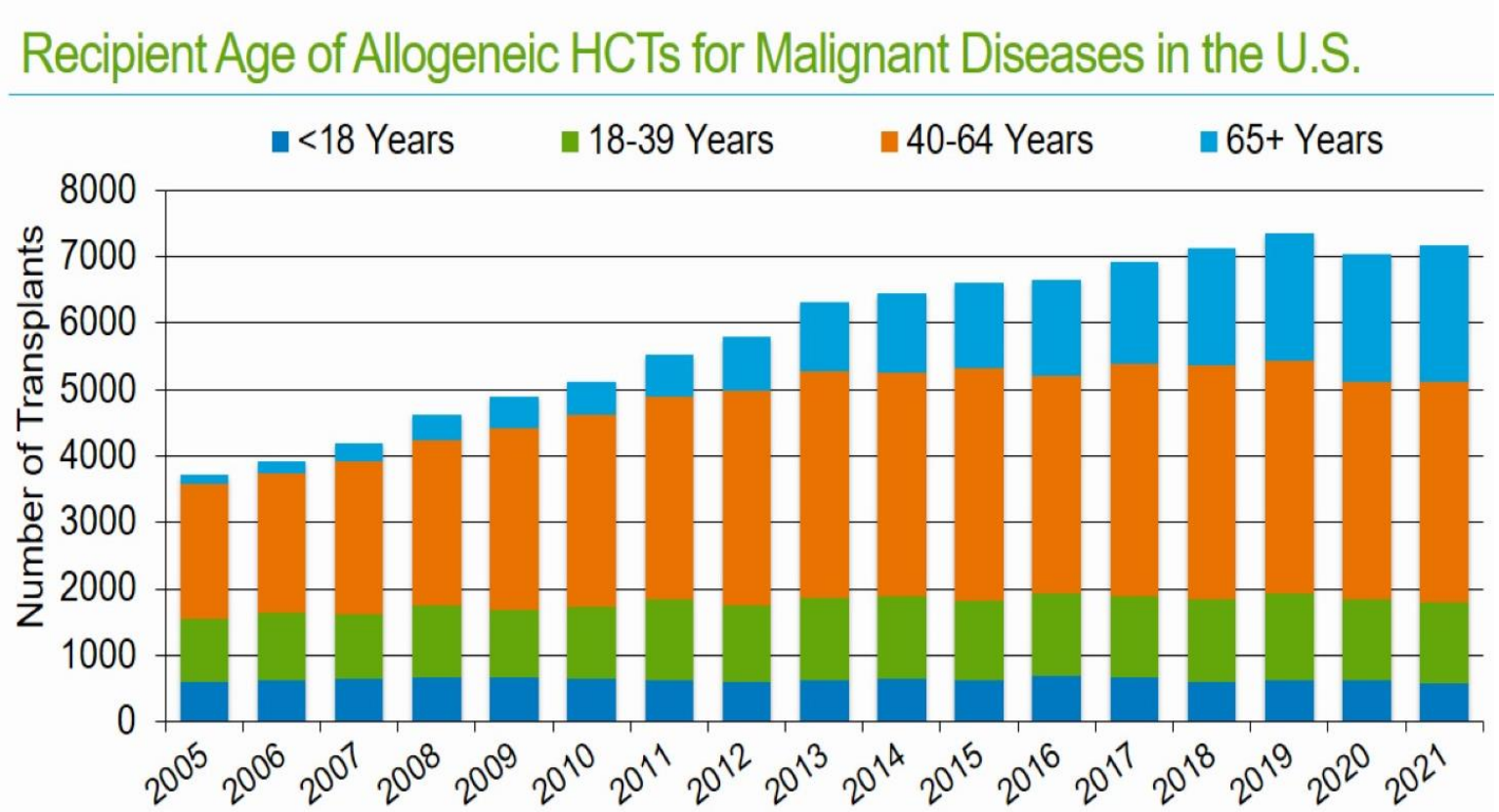
Increasing utilization of allogeneic transplant in older adults



2011 Proportions:
- 65+ years: 12%
- 40-64 years: 55%
- 18-39 years: 22%
- < 18 years: 11%

2021 Proportions:
- 65+ years: 29%
- 40-64 years: 46%
- 18-39 years: 17%
- < 18 years: 8%

Increasing representation in research reported at ASH and ASTCT meetings . . .

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Impact of recipient age

109 The Composite Health Risk Assessment Model (CHARM) to Predict 1-Year Non-Relapse Mortality (NRM) Among Older Recipients of Allogeneic Transplantation: A Prospective BMT-CTN Study 1704

Andrew Artz, MD, MS[1], *Brent R. Logan, PhD*[2*], *Wael Saber, MD, MS*[3], *Nancy Geller, PhD*[4*], *Anna Bellach, Ph.D.*[4*], *Jianqun Kou, MS*[5*], *William Wood, MD, MPH*[6], *John M. McCarty, MD*[7], *Thomas G. Knight, MD*[8], *Lyndsey Runaas*[9*], *Laura Johnston*[10], *Jeremy Walston*[11*], *Ryotaro Nakamura, MD*[12], *Tammy Schuler*[13*], *Asmita Mishra, MD, MBA*[14], *Joseph Uberti, MD, PhD*[15], *Parastoo B. Dahi, MD*[16*], *Jennifer N. Saultz, DO*[17], *Shannon R McCurdy, MD*[18], *Lawrence Morris, MD*[19], *Philip Imus, MD*[20], *William J. Hogan, MD*[21], *Kalyan Nadiminti, MBBS*[22], *Vijaya Raj Bhatt, MD*[23], *Deborah Mattila, BA*[24*], *Bailey Protz*[25*], *Steven M. Devine, MD*[26], *Mary M. Horowitz, MD*[27] *and Mohamed Sorror, MD, MSc*[28]

- Prospective study of adults ≥ 60 years
  - Heme malignancy diagnosis
  - Limited geriatric assessment within 21 days of start of conditioning
- 1105 patients included in analysis and model development
  - Median age 67, 32% ≥ 70 years
  - AML (45%), MDS (30%)
  - Vulnerabilities
    - Slow walk speed 22%; IADL limitation 37%; cognitive impairment 12%
- One-year non-relapse mortality = 14.4%
- One-year overall survival = 72%

Impact of recipient age

- Model of non-relapse mortality
  - Albumin, c-reactive protein, HCT comorbidity index, weight loss independently associated with NRM in multivariable model

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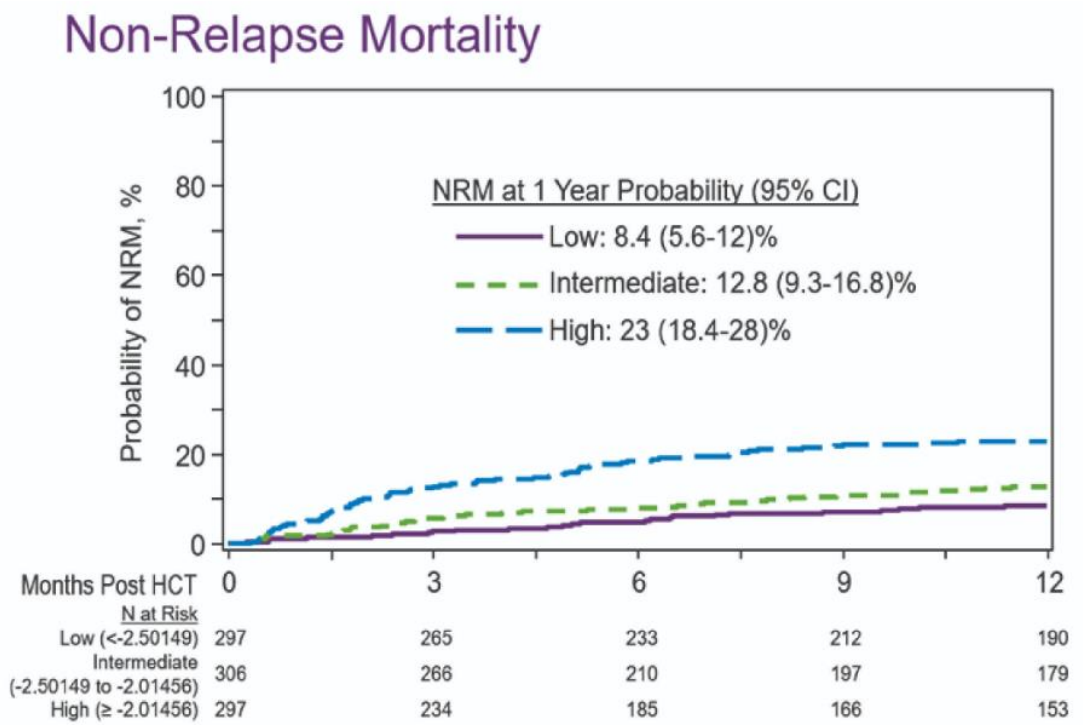
Table: Covariates selected by multivariate analysis influencing NRM within 1 year

Variable (continuous)	Subdistribution Hazard Ratio **	95% CI	*p*-value
HCT-CI	1.165	1.092 - 1.243	<0.0001
LOG (CRP)*, mg/L	1.142	1.020 – 1.278	0.0188
Albumin, g/dL	0.491	0.347 – 0.693	<0.0001
% Weight Loss, squared***	1.001	1.000 – 1.002	0.0023

*natural log. **values > 1.0 indicate a positive association with risk of NRM; ***weight gain or no weight loss is scored as a 0;
CHARM formula = 0.15310*(HCT-CI)+0.13247*(LOG(CRP))-0.71227*(ALBUMIN)+0.00119*(% Weight Loss)^2



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Impact of recipient age

261 Age-Related Differences in Utilization of Allogeneic HCT for Acute Myeloid Leukemia in California: Results of a Population-Based, Novel Linked Dataset

Christa L Meyer, MS[1], Theresa H.M. Keegan, PhD, MS[2], Ann Brunson, MS[2*], Jeffery J. Auletta, MD[1,3], Lindsay M. Morton, PhD[4*], Ted Wun, MD[2], Sara J. Schonfeld, PhD[4*], Bryan Valcarcel, MD, MPH[4], Renata Abrahao, MD, MSc, PhD[2*], Rafeek Yusuf, MD, PhD[1*] and Lori S. Muffly, MD[5]*

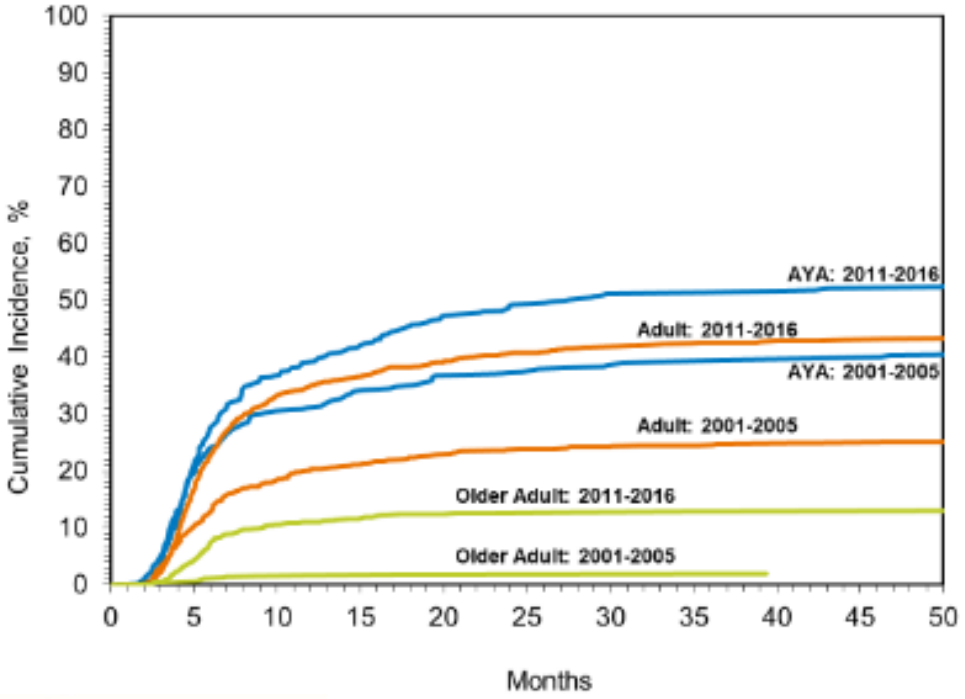
- Dataset capturing >99% of newly diagnosed AML
  - Utilizing data from California Cancer Registry and Patient Discharge Data
- 7925 total patients
  - AYA (15-39) 15%, adults (40-64) 41%, older adults (65-79) 43%
- Majority adults non-Hispanic white, AYA 41% Hispanic
- Most older adults on Medicare
- Low SES in 25% of AYA, 15% of adults
- Approx 25% in each cohort lived > 50 miles from transplant center

Impact of recipient age

261 Age-Related Differences in Utilization of Allogeneic HCT for Acute Myeloid Leukemia in California: Results of a Population-Based, Novel Linked Dataset

Christa L Meyer, MS[1], Theresa H.M. Keegan, PhD, MS[2], Ann Brunson, MS[2*], Jeffery J. Auletta, MD[1,3], Lindsay M. Morton, PhD[4*], Ted Wun, MD[2], Sara J. Schonfeld, PhD[4*], Bryan Valcarcel, MD, MPH[4], Renata Abrahao, MD, MSc, PhD[2*], Rafeek Yusuf, MD, PhD[1*] and Lori S. Muffly, MD[5]*

Figure 1. Cumulative incidence of alloHCT utilization among patients with acute myeloid leukemia in California, by diagnosis era, 2001-2005 and 2011-2016, accounting for the competing risk of death



Multivariable Analysis:

- Low SES, distance, higher co-morbidity associated with lower utilization in younger cohorts
- In Older Adults, increasing age, unmarried, and Asian ethnicity associated with lower utilization of allo

"Although utilization among older adult patients increased from 2% to 13% at 2 years post AML diagnosis, the absolute magnitude of change was lowest in this age group and remains far lower than AYA and adult patients."

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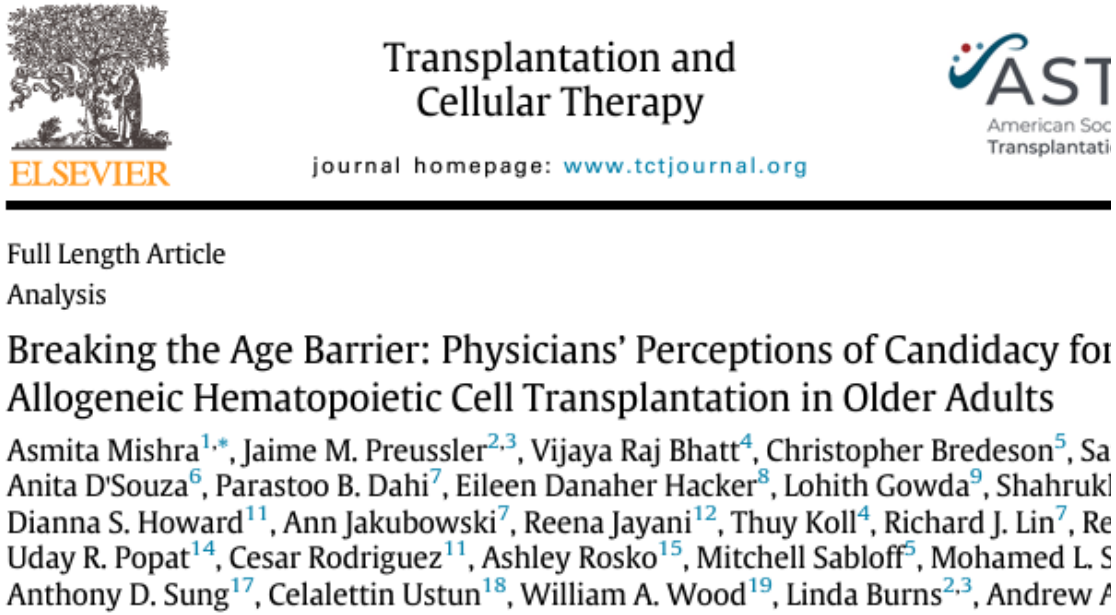
ASTCT SIG for Aging

- Early adopters of transplant for septua- and octogenarians!
- Expertise in evaluation and management of older adult transplant candidates
- SIG members at geographically diverse transplant centers
  - Informal network of physician-to-physician consultants for older adult transplant candidates
  - Provide expert consultation with geriatric assessment

Existing work from SIG for Aging

- Charter recognized in 2020
- Spotlight/Education Sessions at Tandem Meetings 2020-2023
- Invited Concurrent Session on Accelerated Aging (2023)



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Transplantation and Cellular Therapy

journal homepage: www.tctjournal.org

Full Length Article

Analysis

Breaking the Age Barrier: Physicians' Perceptions of Candidacy for Allogeneic Hematopoietic Cell Transplantation in Older Adults

Asmita Mishra[1,*], Jaime M. Preussler[2,3], Vijaya Raj Bhatt[4], Christopher Bredeson[5], Sa
Anita D'Souza[6], Parastoo B. Dahi[7], Eileen Danaher Hacker[8], Lohith Gowda[9], Shahrukh
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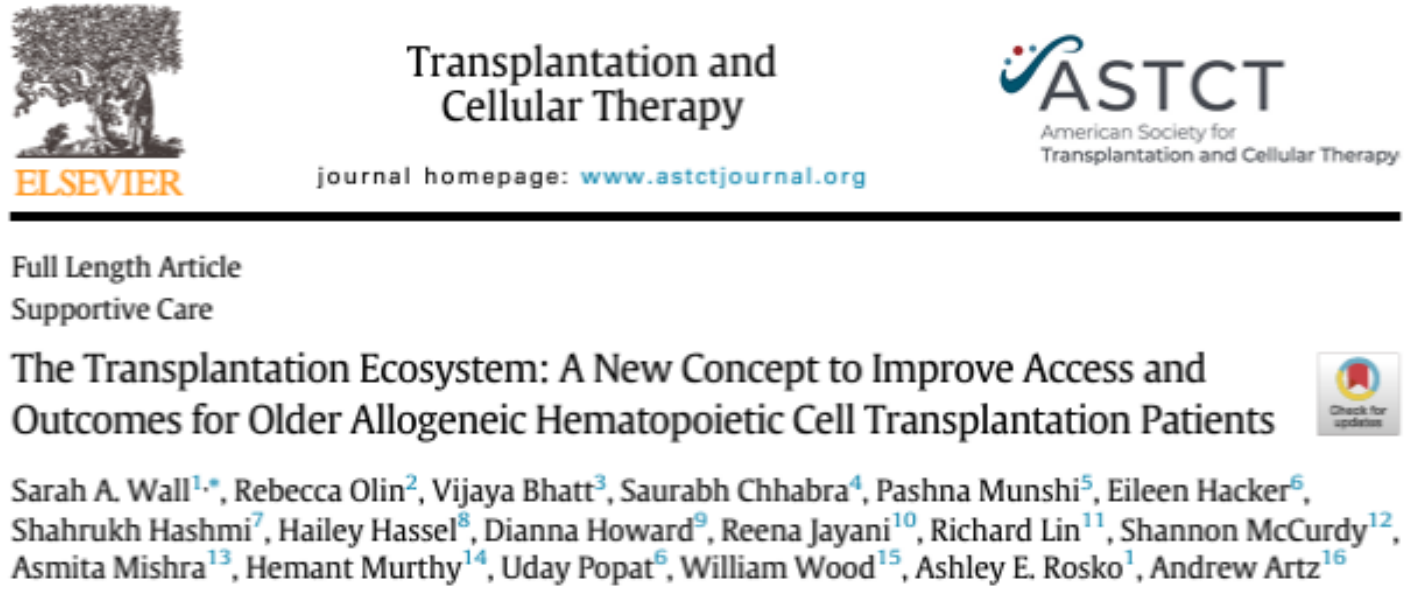
Uday R. Popat[14], Cesar Rodriguez[11], Ashley Rosko[15], Mitchell Sabloff[5], Mohamed L. S
Anthony D. Sung[17], Celalettin Ustun[18], William A. Wood[19], Linda Burns[2,3], Andrew A



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Transplantation and Cellular Therapy

journal homepage: www.astctjournal.org

Full Length Article

Supportive Care

The Transplantation Ecosystem: A New Concept to Improve Access and Outcomes for Older Allogeneic Hematopoietic Cell Transplantation Patients

Sarah A. Wall[1,*], Rebecca Olin[2], Vijaya Bhatt[3], Saurabh Chhabra[4], Pashna Munshi[5], Eileen Hacker[6], Shahrukh Hashmi[7], Hailey Hassel[8], Dianna Howard[9], Reena Jayani[10], Richard Lin[11], Shannon McCurdy[12], Asmita Mishra[13], Hemant Murthy[14], Uday Popat[6], William Wood[15], Ashley E. Rosko[1], Andrew Artz[16]

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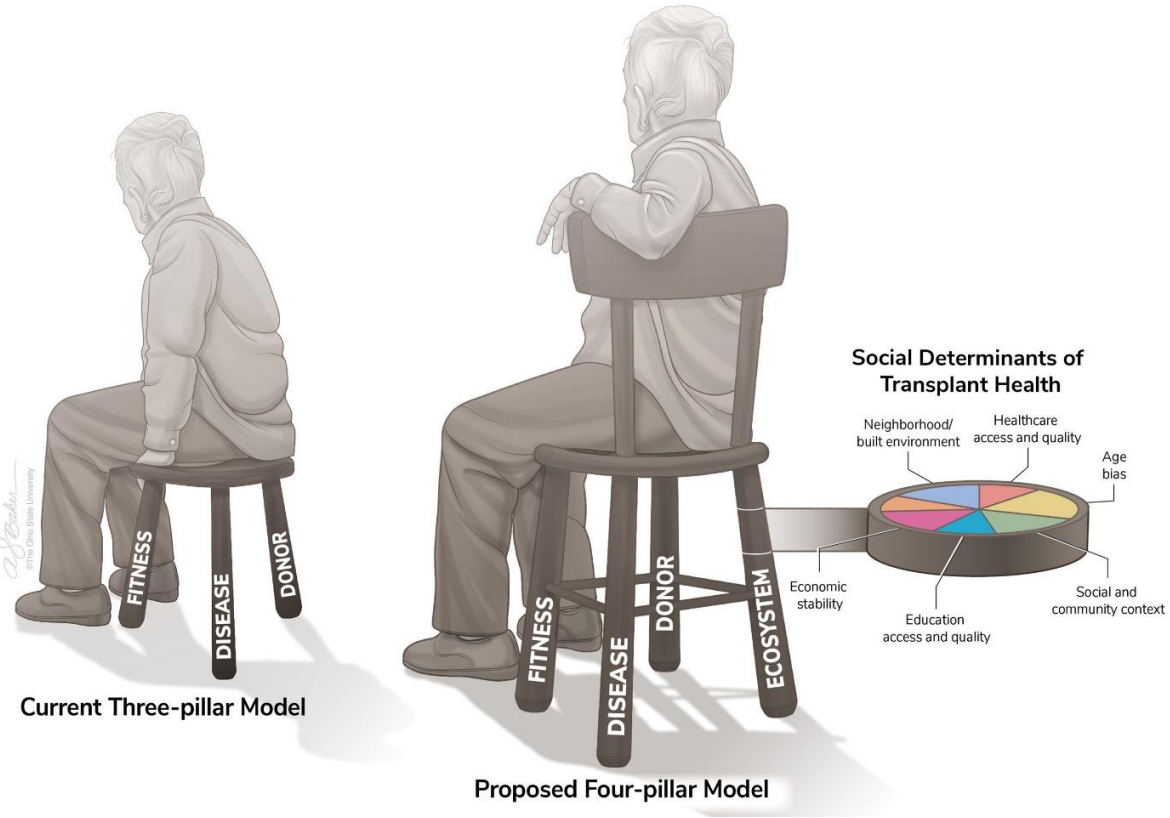
Defining the “Transplant Ecosystem”



Wall SA, Olin R, Bhatt V, et al. *Transplant Cell Ther*. 2023;S2666-6367(23)01258-7.

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Next Steps with Transplant Ecosystem Framework

Table 2. Knowledge Gaps and Research Strategies Defined by Social Determinant of Transplant Health

Social Determinant of Transplantation Health	Knowledge Gap	Research Strategies
Economic stability	How does financial toxicity hinder access to HCT? What HCT-related financial hardships are most common among older patients?	Evaluate patient economic concerns broadly at time of diagnosis in all clinical settings Survey with validated tools, such as the COST-FACIT questionnaire [81]
Education access and quality	Does education level of recipient or caregiver affect HCT outcomes? Do older patients and their caregivers receive adequate pre-HCT education generally and specific to aging-related concerns?	Involve caregivers in research efforts, particularly in older HCT recipients Prospective studies including health literacy assessments and pretest and post-test knowledge assessments
Healthcare access and quality	Does distance from the transplant center affect referrals or access to HCT among older patients? Do older HCT recipients utilize different resources than younger patients to access HCT (eg, transportation, area agencies on aging)?	Utilize SEER, CMS, or state registry data to identify patients with HCT-eligible diagnoses Engage with social work to identify what resources are available and being utilized and where gaps in supportive services may exist
Neighborhood/built environment	How often do older HCT recipients receive aging-friendly care as in the 4M model? How many transplant centers have care pathways to prevent delirium? Does SVI of a neighborhood effect transplant outcomes?	Utilize established criteria for aging-friendly care from the Hartford Foundation to evaluate (1) whether transplant centers have this designation and (2) whether the 4Ms are being applied Observational cohort studies of older HCT recipients to track the incidence of geriatric conditions like delirium and falls post-HCT Compare outcomes between aging-friendly transplant centers and standard of care
Social and community context	Who are the most common caregivers for older HCT recipients? How often do older HCT recipients utilize private-pay home care, skilled home care, or skilled nursing care compared to younger peers?	Involve caregivers in research efforts, particularly in older HCT recipients Observational cohort studies of older HCT recipients to track discharge disposition and resource utilization
Age bias	How often are older patients not referred for HCT consult based on age?	Pragmatic trial of virtual transplant visits with older patients in community healthcare settings

COST-FACIT indicates Comprehensive Score for Financial Toxicity; Functional Assessment of Chronic Illness Therapy; CMS, Centers for Medicare and Medicaid Services; SEER, Surveillance, Epidemiology, and End Results Program; SVI, Social Vulnerability Index.

SCAN ME

Link to Ecosystem Paper

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Increasing access to transplant ***consult*** for older adults

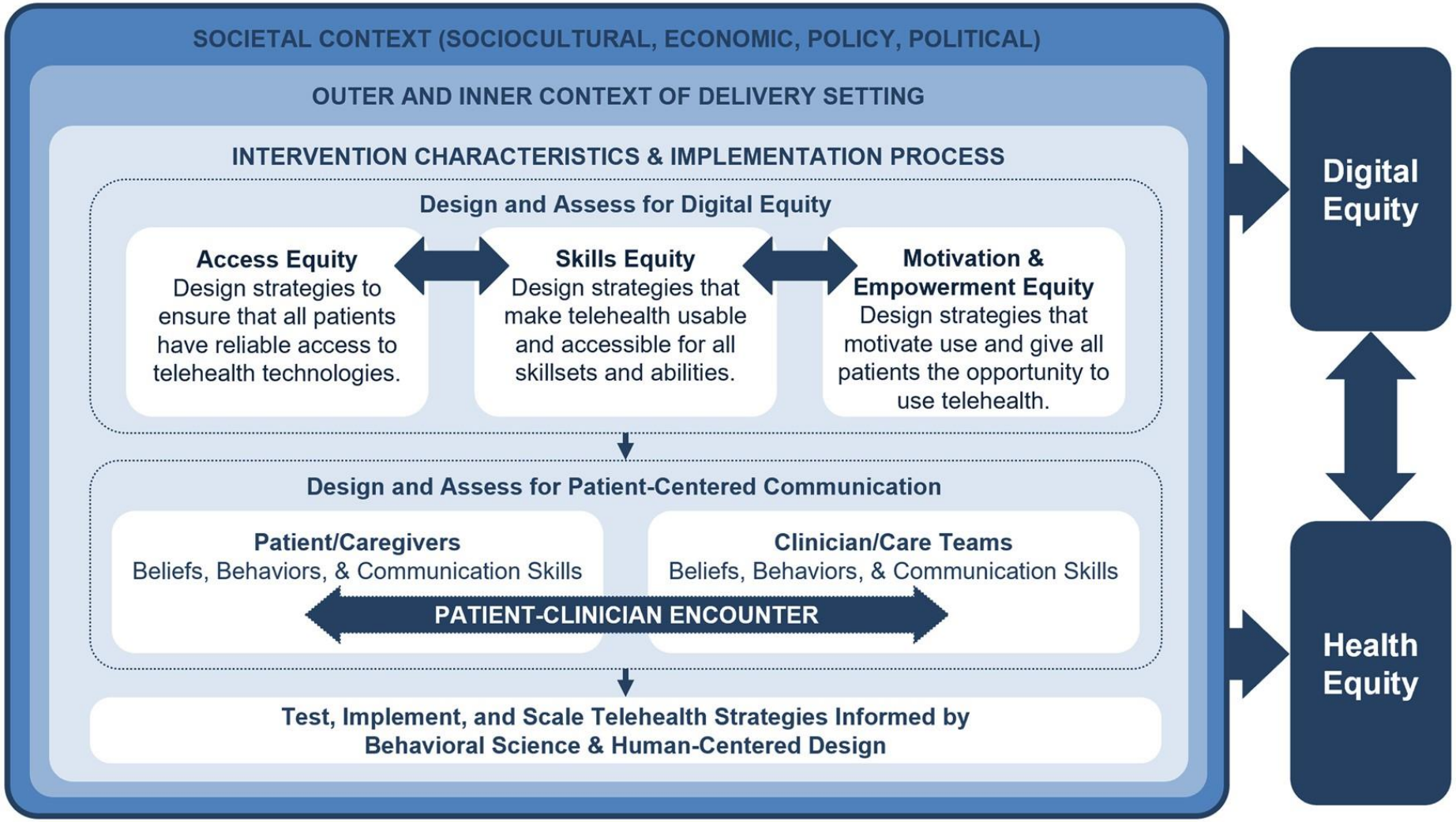
- Barriers
  - Lack of referral (age bias)
  - Distance from center (healthcare access and quality)
  - Financial – cost of travel, time off work (economic stability)
- Key Stakeholders
  - Patients
  - Caregivers
  - Primary oncologists
  - Transplant centers
- Can barriers be overcome by use of telehealth consultation and does this meet the needs of stakeholders?

Telehealth utilization by patients

- 2022 Health Information National Trends Survey
  - 57% of US adults offered telehealth, 80% used it
  - Primary barriers privacy concern and tech difficulty (15-20%)
  - Less likely to offer telehealth to older adults (>50), rural-micropolitan areas, and Midwestern and Westerners compared to Northeast
  - More likely to offer if college-educated, and broadband available
  - No difference in utilization based on any studied factors

Senft Everson N, Jensen RE, Vanderpool RC. Telemed J E Health. 2024 Jun 27.

Framework for Integrating Telehealth Equitably



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Rendle KA et al. J Natl Cancer Inst Monogr. 2024 Jun 26;2024(64):92-99.

Applications of FITE Model

- Cancer-specific Telehealth Research Centers of Excellence (TRACE)
  - MATCHES Research Center
    - Making Telehealth Delivery of Cancer Care at Home Effective and Safe
    - Memorial Sloan Kettering Cancer Center
  - STELLAR Research Center
    - Scalable Telehealth Cancer Care
    - Northwestern University
  - THRIVE Research Center
    - Telehealth Research and Innovation for Veterans with Cancer
    - NYU & Duke with Veterans Health Administration
  - Penn TRACE
    - University of Pennsylvania Telehealth Research Center of Excellence

Applications of FITE Model

- Themes from the 4 TRACE centers
  - Provision of internet-enabled devices
  - Use of interpreters or translated digital information
  - Patient-care navigation/Access to “warm technical support”

SIG-supported FITE model for older adult transplant candidates

- Consultative visit to assess transplant candidacy
- Inclusion of geriatric assessment →
  - Incorporate remote measure of physical function
  - CHARM labs (albumin, CRP)
- Access, Skills, and Empowerment
  - Supply devices as needed
  - “Warm technical support”
  - Self-referral option

Table 1. Structure of Virtual and In-person CARE Clinic

Domain	Responsible Provider & Time	Virtual CARE Clinic	In-person CARE Clinic
Co-morbidities	Physician 10 minutes + 5 minutes summary at visit conclusion	-CARG Chemotoxicity Calculator -Common geriatric syndromes (bowel or bladder symptoms, insomnia, decubitis ulcers) -Likert scale depression and anxiety -Alcohol and substance use	Same as virtual CARE clinic PLUS -Audiometry (performed by audiologist)
Cognition	Nurse 5 minutes	BOMC	MOCA
Pharmacy	Pharmacist 10 minutes	Medication reconciliation, education, and recommendations	Medication reconciliation, education, and recommendations
Nutrition	Dietician 10 minutes	-MNA (with recent BMI if possible)	-MNA -Diet recall -AND/ASPEN Malnutrition
Physical Function	Physical Therapist 10 minutes*	-Falls history -SF-36 PFS -Follow-up with PT as needed	-TUG, SPPB, 5x sit to stand -Falls history -SF-36 PFS
Social Support	Nurse case manager 10 minutes*	-Needs assessment (home safety, financial toxicity, caregiver support) -Advanced directives review -IADL/ADL -COVID-19 impact on access to food, medications, healthcare	-Needs assessment -Advanced directives review -IADL/ADL

*** Providers may jointly interview patient due to time constraints**

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Physician-to-Physician telemedical consultation

- Qualitative study of gynecologists, gynecologic oncologists, and medical oncologists

Major Themes.

- Clinicians believe that formalized telemedicine consultation could build relationships between gynecologists and specialists.
- Clinicians believe formalized telemedicine consultation could improve patient access to specialized care.
- Clinicians are overwhelmed by existing communication channels (EHR, phone, fax, pagers, text) and are concerned about burnout, increased work volume, interruptions to workflow, and effectiveness of communication.
- Clinicians find it difficult to share patient information with other clinicians not on the same EHR system.
- Specialists are frustrated by the lack of information sharing during informal consultations.
- Clinicians want more information about accountability and compensation in using a formalized consultation platform.

Wagi C et al. Gynecol Oncol Rep. 2024 Mar 13;52:101363.

SIG-supported physician-to-physician telemedical consult for transplant candidates

- Development in the context of (funded) research
  - Potentially by-pass financial constraints and accountability concerns (for now)
  - Use of study-specific documents to address information-sharing and EHR concerns
- Provides groundwork to support policy change
  - Get paid and/or recognized for the work we already do
  - Drive need for EHR systems that can communicate with each other

Opportunities and Next Steps

- Potential Collaborators
  - ASTCT SIG for Aging
  - NMDP & ASTCT ACCESS Initiative
  - TRACE Working Group
  - Community Oncology Alliance
  - Digital health companies
- Identification of funding mechanisms
- Protocol development

ASTCT-NMDP ACCESS Initiative

Reimagining Caregiving Together: Engagement to Address Caregiver Requirement Barriers

Anna DeSalvo[1,2], Ben Tweeten[1], Jaime Preussler[1,2]

[1]NMDP, [2]CIBMTR

ASTCT-NMDP ACCESS Initiative Meeting, Washington DC

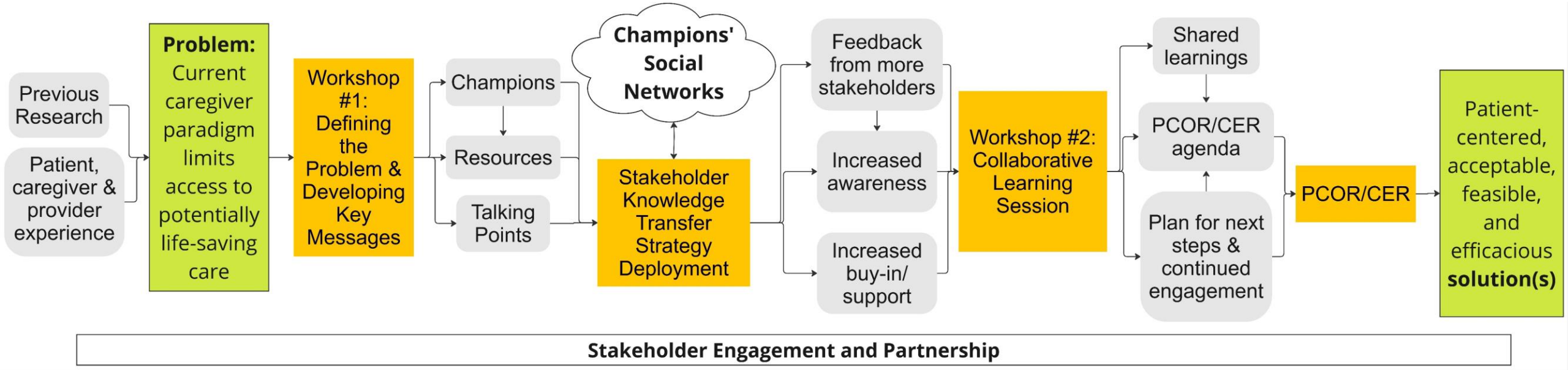
July 23, 2024

Equal Outcomes for All

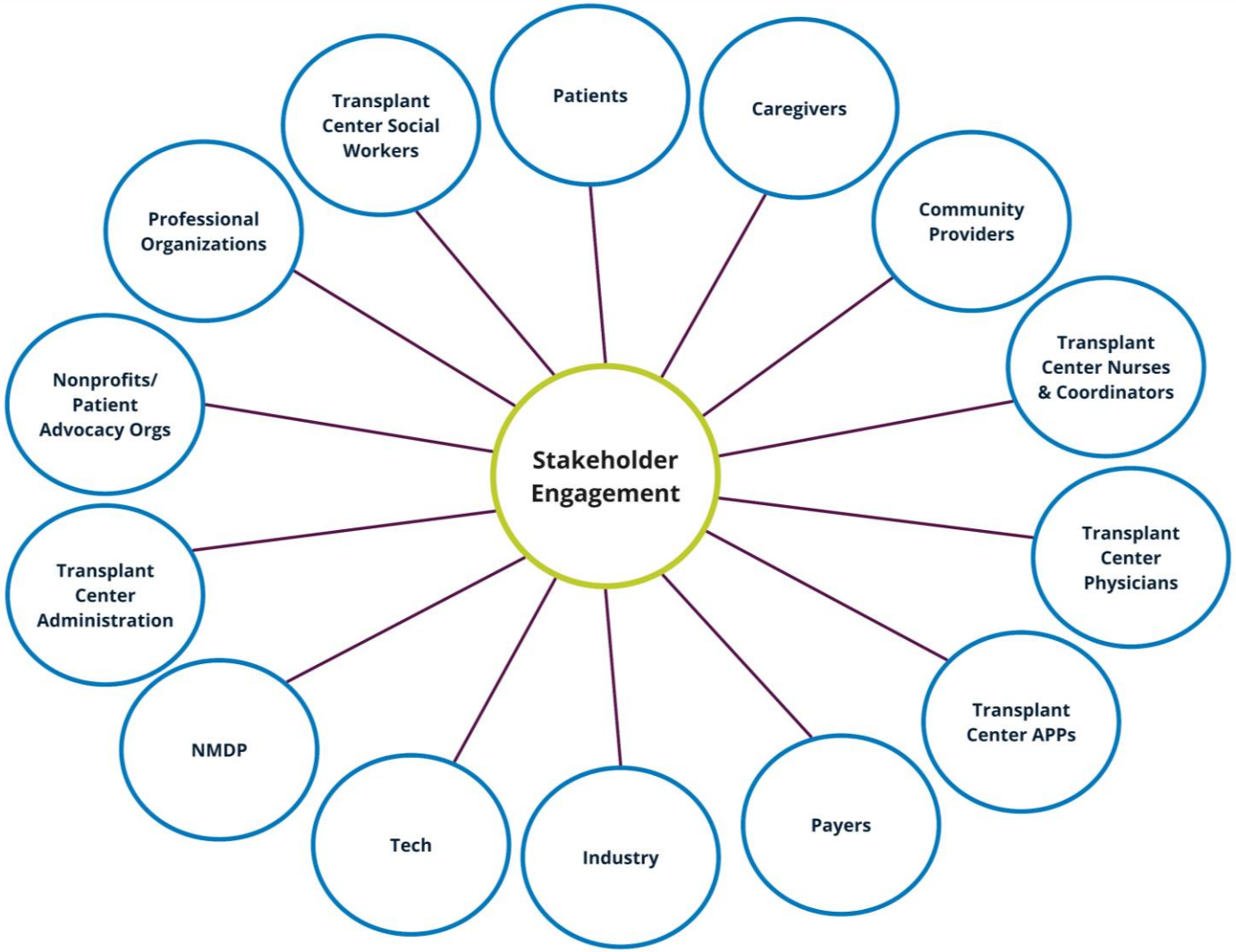
Background

- Requirements can vary across transplant centers[1-7]
- There are no written guidelines recommending against hematopoietic cell transplantation for patients with poor social support[8]
  - Paucity of evidence examining social support with HCT survival[9]
- Access barrier
  - Married patients were more likely to receive an alloHCT in a study of patients with AML in Virginia[10]
  - 69% of clinicians noted that they would not proceed with alloHCT if a patient did not have a caregiver[11]

Engagement strategy to address caregiver requirement barriers



Workshop 1 Agenda



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Workshop 1 Agenda (Day 1)

Time	Topic / Agenda
8am	Breakfast
9:15 30 mins	**Welcome, purpose, agenda overview** • What to expect • Introductions
9:45 45-60 mins	**Part 1: Background on caregiver requirement** • Highlights from prep work
10:45	Break
11am 60 mins	**Part 2: Patient & caregiver perspective** • Panel to share lived experiences • Opportunity for questions
Noon 60 mins	**Group lunch** • Socializing, relationship building

Situational Assessment (sample)

PAST		PRESENT		FUTURE	
Accomplishments	Setbacks	Strengths	Weaknesses	Risks	Opportunities

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Workshop 1 Agenda (Day 1)

Time	Topic / Agenda
1:00 70 mins	**Vision for the future** • Identify elements of a vision for safe post-transplant care • Question: What do we want to see in place in the future (e.g. 3-5 years) as a result of our actions?
2:10	Break
2:20 70 mins	**Clarifying current reality** • Identify blockers and barriers to realizing our vision • Question: What is blocking us from moving toward our vision?
3:30 30 mins	**Wrap-up & debrief** • What stands out, what surprised you, where do feel optimism, what feels challenging? • What might be the impact of this work / these ideas and our conversations today?

Workshop 1 Agenda (Day 2)

Time	Topic / Agenda
8am	Breakfast, hotel check-out
9:15 30 mins	**Opening discussion to review blockers and barriers** • What do you notice about the blockers/barriers? • What do we need to keep in mind? • How should we prioritize them? Which would have the biggest impact?
9:45 50 mins	**Next steps – telling the story of the vision of the future for safe post-transplant care** • Part 1: Our vision for next steps • Part 2: Large group discussions • Part 3: Small group activity

Workshop 1 Agenda (Day 2)

Time	Topic / Agenda
10:35 20 mins	**Break + Gallery Walk to review flipcharts** • Add Post-it notes to capture additional ideas and note where / with whom attendees are willing to engage or have relationships
10:55 40 mins	**Communications & Action Planning** • Large group discussion • What can we do next? • Worksheet to collect notes / ideas from participants
11:35 10 mins	**Large group: Appreciations** • What did you learn from this workshop? What's one new perspective or idea you are leaving with? • What perspectives did you appreciate hearing during this workshop?
11:45	**Survey + Lunch**
Afternoon	**Departures**

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Questions and Feedback

Join at

slido.com

#4292 468

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ASTCT-NMDP ACCESS Initiative

Junior Faculty Immersion Program & Workforce Diversity Project

Anu Hall, MD, MS

Seattle Children's Hospital, University of Washington

2024 Summer Workshop

July 23, 2024

Equal Outcomes for All

Sustainable improvements require early education and involvement of trainees/junior faculty

+

Diverse healthcare workforce can improve patient access and care

+

Early exposure to cellular therapy → increased interest in pursuing a career in cellular therapy

Junior Faculty Immersion Program

- Goals:
  - Provide career development and mentorship opportunities for trainees and junior faculty
  - Promote diversity within BMT/CT
  - Equip members with education and tools necessary to engage in health services research and advocacy efforts

- How do we achieve this?
  - Mentorship from committee chairs
  - Project development
  - Regular meetings to include didactics (advocacy, workforce diversity, etc) and project updates from members

Junior Faculty Immersion Program- Co-Chairs

Anu Hall

Assistant Professor

Seattle Children's Hospital/University of Washington

Alexandra Gomez

Assistant Professor

Weill Cornell Medicine/New York Presbyterian Hospital

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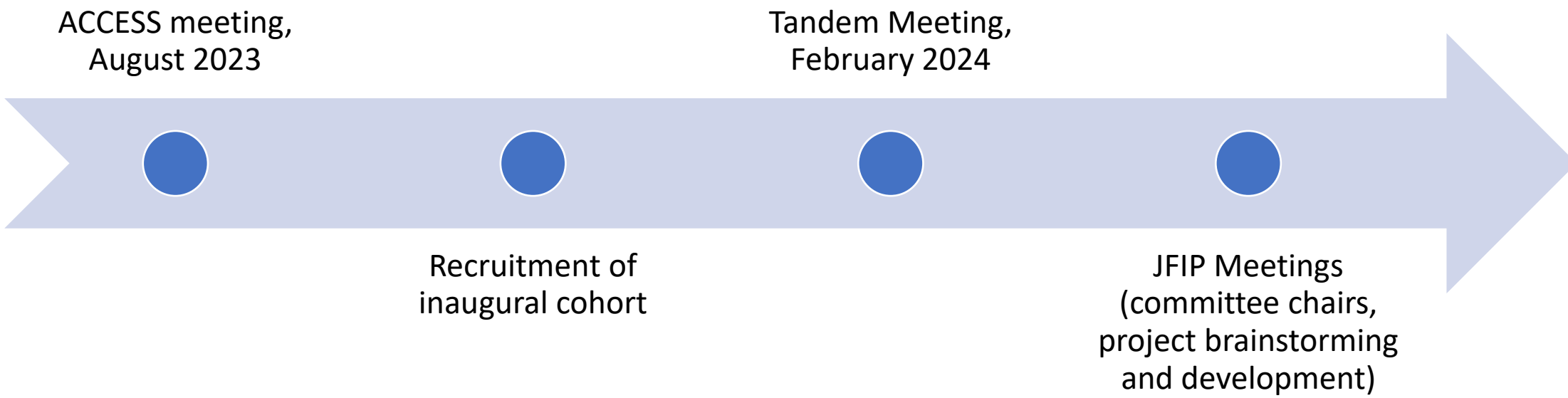
Junior Faculty Immersion Program

- Six members
  - Awareness
  - Poverty
  - Racial and Ethnic Inequities

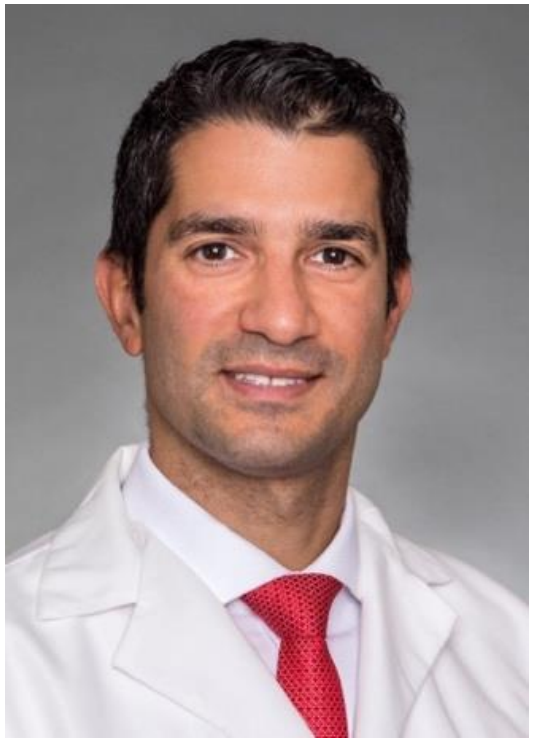
- Medical students, residents, fellows, advanced HCT/CT fellows, or junior faculty within 2 years of starting their instructor or assistant professor position

- Appointed for two years (2024-2026)
- Mentors: co-chairs of each committee

JFIP Timeline



JFIP- Awareness



Nima Ghalehsari

BMT Fellow

Stanford University

Manu Pandey

Assistant Professor

Univ of Oklahoma
Health Sciences Center

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JFIP- Poverty

Rahul Shah

Heme/Onc Fellow
(1st year!)

MD Anderson

Manuel Espinoza-Gutarra

Assistant Professor

University of Alabama at Birmingham

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JFIP- Racial and Ethnic Inequities

Kristie Ramos

Pediatric Heme/Onc Fellow

Cincinnati Children's

Maria Pereda Ginocchio

Assistant Professor

Colorado Children's

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Equal Outcomes for All

What has JFIP been up to?

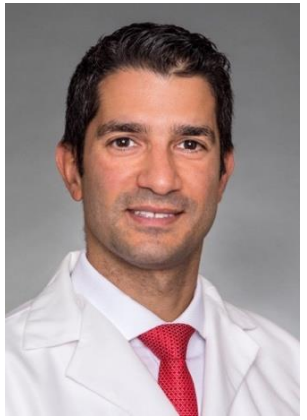
- Meetings with committee co-chairs
  - ✔ Awareness
  - ✔ Racial and Ethnic Inequities
    - Poverty
- Education on advocacy
  - Plan for physician advocacy paper
- Physician exchanges

- Fellow education event
- Workforce diversity survey and paper

Fellow Education Event

- Goal: Educate and raise awareness among hem/onc fellows at community hospitals and clinics about evidence-based practices to address barriers to access transplant and enhance access to care

- First Event: June 10th, 2024 Kings County Hospital, Brooklyn, NY
  - Dr. Nima Ghalehsari and Emily LaMonica met with fellows for a lunch and learn session



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Fellow Education Event

- Topics discussed:
  - Early HLA typing for patients with AML, MDS and other transplantable diseases
    - early donor identification and referral for HCT consultation
  - Streamline the referral process to establish care with HCT group
  - NMDP Resources:
    - HLA Today: Free typing for patients who do not have access
    - Patient education, services and grants
    - Provider education, free CE/CME
    - Clinical Trials Search and Support services

Fellow Education Event

Next Steps:

- Date TBD:
  - Meeting with fellows at Maimonides Hospital, Brooklyn, NY

- Create roadmap w/ other JFIP members/interested physicians within the ACCESS Initiative across the US to expand awareness

Workforce Diversity

- Lack of workforce diversity negatively affects patient outcomes
  - Access to care
  - Communication with physicians
  - Adherence
  - Patient perceptions of the care they receive

- Patient-provider concordance can positively affect health outcomes

Representation Matters

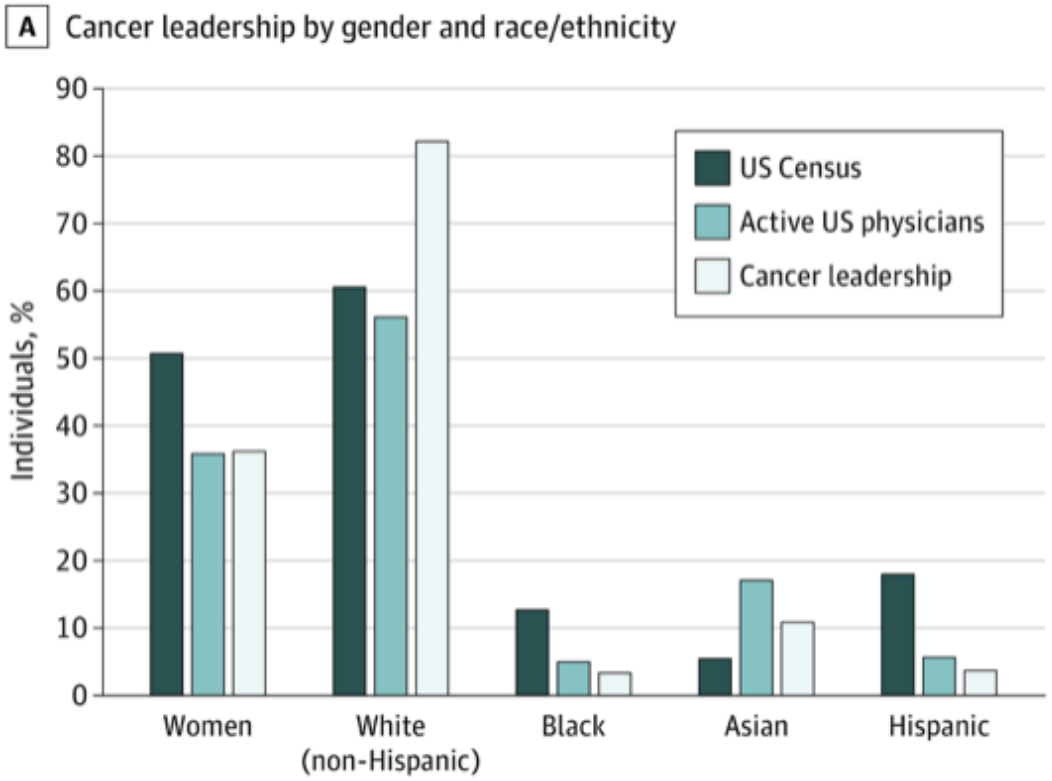
- Diverse workforce attracts diverse trainees
- Can improve mentorship experience
- Minority ‘tax’
- Feeling a lack of inclusion → poor retention

Dinh, JV. *J Grad Med Educ,* 2019.
Rodriguez, JE. *BMC Med Ed,* 2015.

Workforce Diversity in Cancer Care

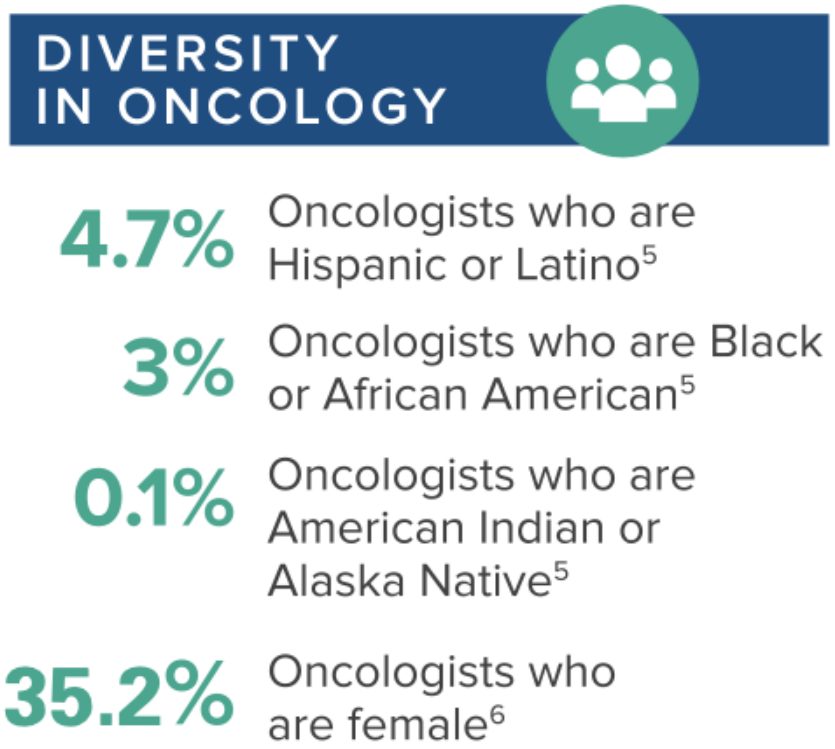
- Lack of diversity in cancer center leadership

- Black and Hispanic physicians underrepresented
  - Especially so in leadership roles
  - 37% of cancer centers: no Black or Hispanic member on leadership team
  - Diverse cities not necessarily likely to have more diverse leaders



Morgan A, et al. *JAMA Netw Open,* 2021.

Workforce Diversity in Cancer Care



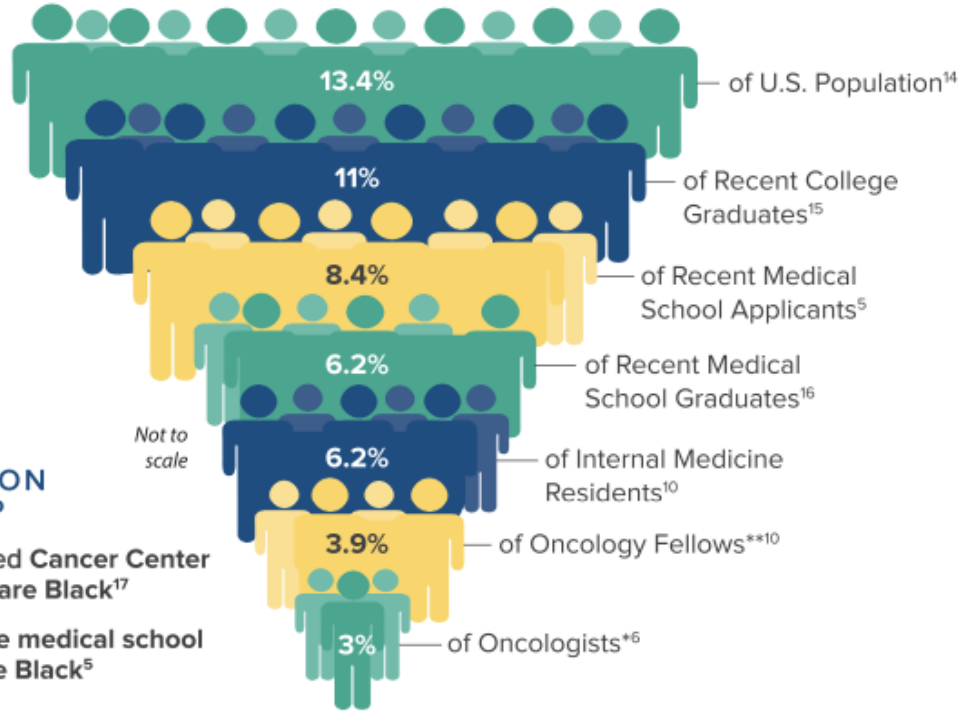
- ASCO Diversity in Oncology Initiative
  - Longitudinal pathway for increasing workforce diversity
  - ASCO leadership diversity
  - Integrate diversity focus across ASCO
- Annual ‘State of the Oncology Workforce in America’ snapshot

Workforce Diversity in Cancer Care

Black Representation in the Oncology Workforce

People who are Black comprise:

At each step towards becoming an oncologist, the percentage of Black participants decreases.



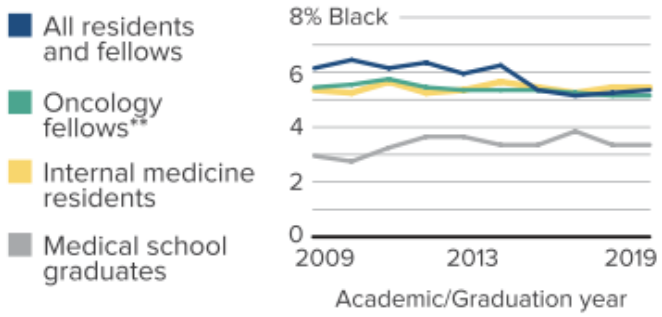
REPRESENTATION IN LEADERSHIP

1.2% of Surveyed Cancer Center Directors are Black[17]

3.6% of full-time medical school faculty are Black[5]

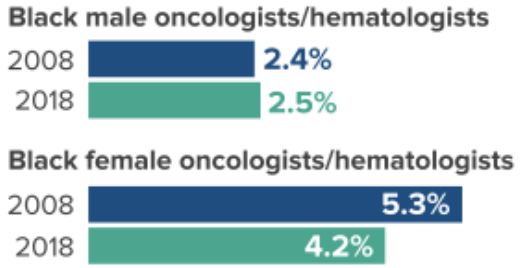
REPRESENTATION IN MEDICAL EDUCATION

Percentages of Black medical school graduates, residents, and fellows have remained low.[10,12,13,16]



REPRESENTATION BY GENDER

The percentage of male oncologists who are Black has remained steady, while the percentage of female oncologists who are Black has declined.[5,12]



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ASCO 2021 Snapshot

Equal Outcomes for All

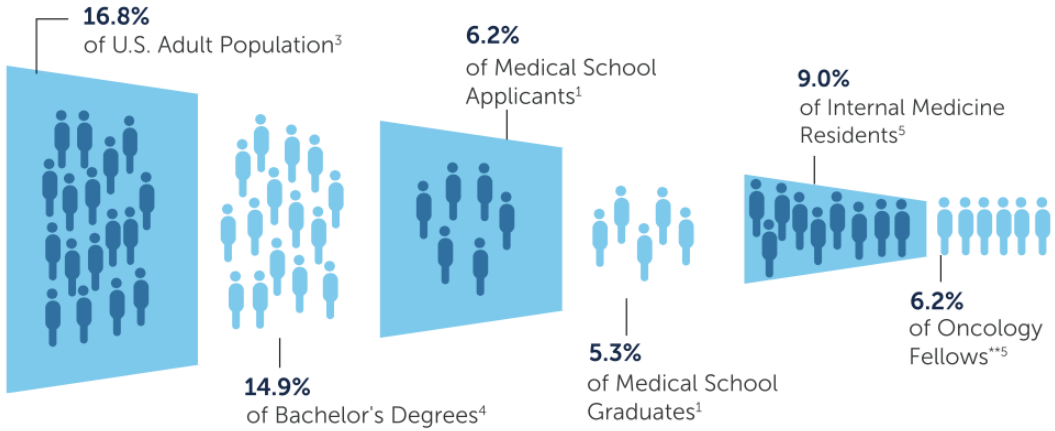
Workforce Diversity in Cancer Care

Hispanic/Latinx Oncologists and Patients

People who identify as Hispanic or Latinx comprise:

Only **4.7%** of U.S. oncologists **vs.** **9.3%** of new cancer cases[10,11]

Hispanic/Latinx participation decreases at nearly every step in the path to becoming an oncologist.



LIMITED REPRESENTATION IN

Leadership

9.9% Cancer center directors[9]

4.5% Cancer center deputy/associate directors[9]

Academia***

3.2% full-time U.S. medical school faculty[1]

Of Hispanic/Latinx full professors:

70% male **vs.** **30%** female[1]

Research***

3.1% say research is a major professional activity[1]

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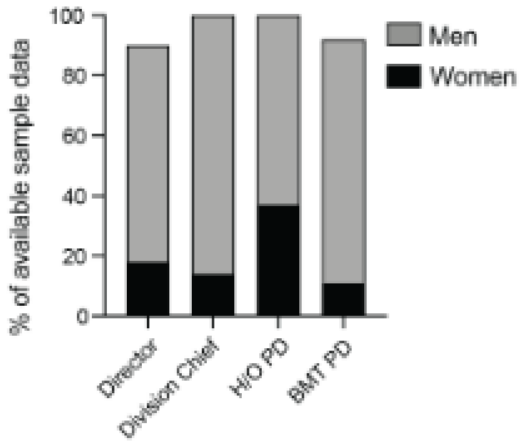
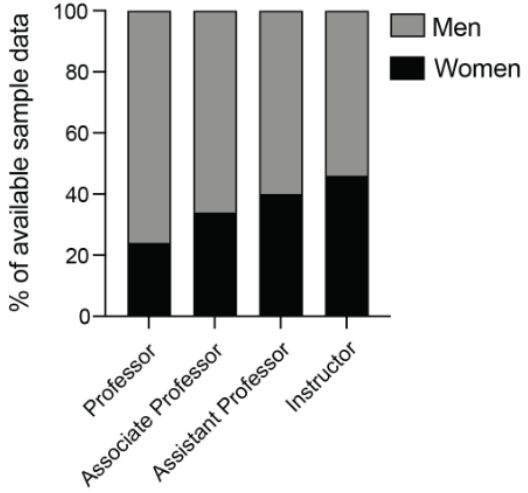
ASCO 2022 Snapshot

Workforce Diversity in Cellular Therapy

- Very sparse data within cellular therapy
- Ananth et al: data from FACT website
  - 70% male
  - M > F in leadership roles, professors





  - Hispanics (5%) and Blacks (2%) underrepresented

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Ananth S, et al. 2022 Tandem Meetings, poster #418.

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Workforce Diversity Survey via ASTCT

- 15-18 question survey distributed through ASTCT listserv
- Includes questions related to:
  - Age
  - Race and ethnicity
  - Gender identity and pronouns
  - International medical graduates
  - Self-identified inclusion in other diverse communities

- Survey currently awaiting review by ASTCT Executive Committee prior to distribution

Thank you!

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ASTCT-NMDP ACCESS Initiative

Health Equity in Practice Update

Delilah Robb, MPH

Program Manager

NMDP

Access Meeting/ Washington, D.C.

July 23, 2024

Equal Outcomes for All

Health Equity in Practice (HEiP) Goals

Increase transplant centers access to data and educational resources to build capacity to implement a data-driven health improvement project

Improve access to transplant for all patients and increase the proportion of racially and ethnically diverse patients transplanted

HEiP Overview

- Support transplant centers in identifying, addressing disparities, and promoting health equity
- Provide a toolkit and health equity data to implement a health improvement project
- 6-month pilot with 5 transplant centers from different regions of the U.S.

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HEiP Scope

Onboarding Meetings

1. How to use the toolkit & health equity market analysis
2. Health equity systems & services assessment
3. Health improvement project implementation

On-going support

Technical assistance

Check-ins

Evaluation

Pre- and post-pilot

HEiP Pilot Progress as of July 15, 2024

Transplant Center	U.S. Region	HCT Volume	Introduction Meeting	Pre-pilot evaluation	Onboarding Meeting 1	Onboarding Meeting 2	Onboarding Meeting 3	Implementation	Post-pilot evaluation
University of Utah	Southwest	Low	X	X	X	X	X		
University of Wisconsin	Central	Low	X	X	X	X			
Emory	Southeast	Medium	X	X	X				
MD Anderson	South	High	X	X	X				
University of Pennsylvania	Northeast	Medium	X						

CIBMTR reported allo transplant volume per year: Low ≤ 50, medium= 51–150 or high > 150

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HEiP 2023 – 2025 Timeline

2023

RESEARCH AND DEVELOPMENT

Create project materials, implementation and evaluation plan

APR. 2025

EVALUATION

Evaluate outcomes, impact and implementation

MAR. – JUL. 2025

DISSEMINATION

Present individual and group findings back to pilot transplant centers

Partner with HEiP pilot sites to disseminate findings at appropriate conferences

IMPLEMENTATION

Pilot HEiP with 5 transplant centers

Provide implementation support

APR. 2024 – MAR. 2025

UPDATE

Modify HEiP materials based on pilot evaluation

JUN. 2025

Scale-Up

Explore options to scale-up and operationalize

Identify transplant centers for next phase

Begin implementation

AUG. – DEC. 2025

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Thank you!

Questions

email: drobb@nmdp.org

ASTCT-NMDP ACCESS Initiative

DEI and Workforce Development

Elias Lemon, VP – Diversity, Equity and Inclusion | NMDP
ACCESS Summer Workshop | 7/23/24

nmdp.org

A Brief Overview of DEI

DEI Definitions

Diversity	All of the elements that make an individual unique, such as ethnicity, gender, sexual orientation, abilities, age and veteran status and other protected classes.
Equity	When everyone in the workplace has the specific support, they need to succeed and grow.
Inclusion	Individual involvement and empowerment, where the inherent worth and dignity of all people are recognized. An inclusive NMDP promotes and sustains a sense of belonging

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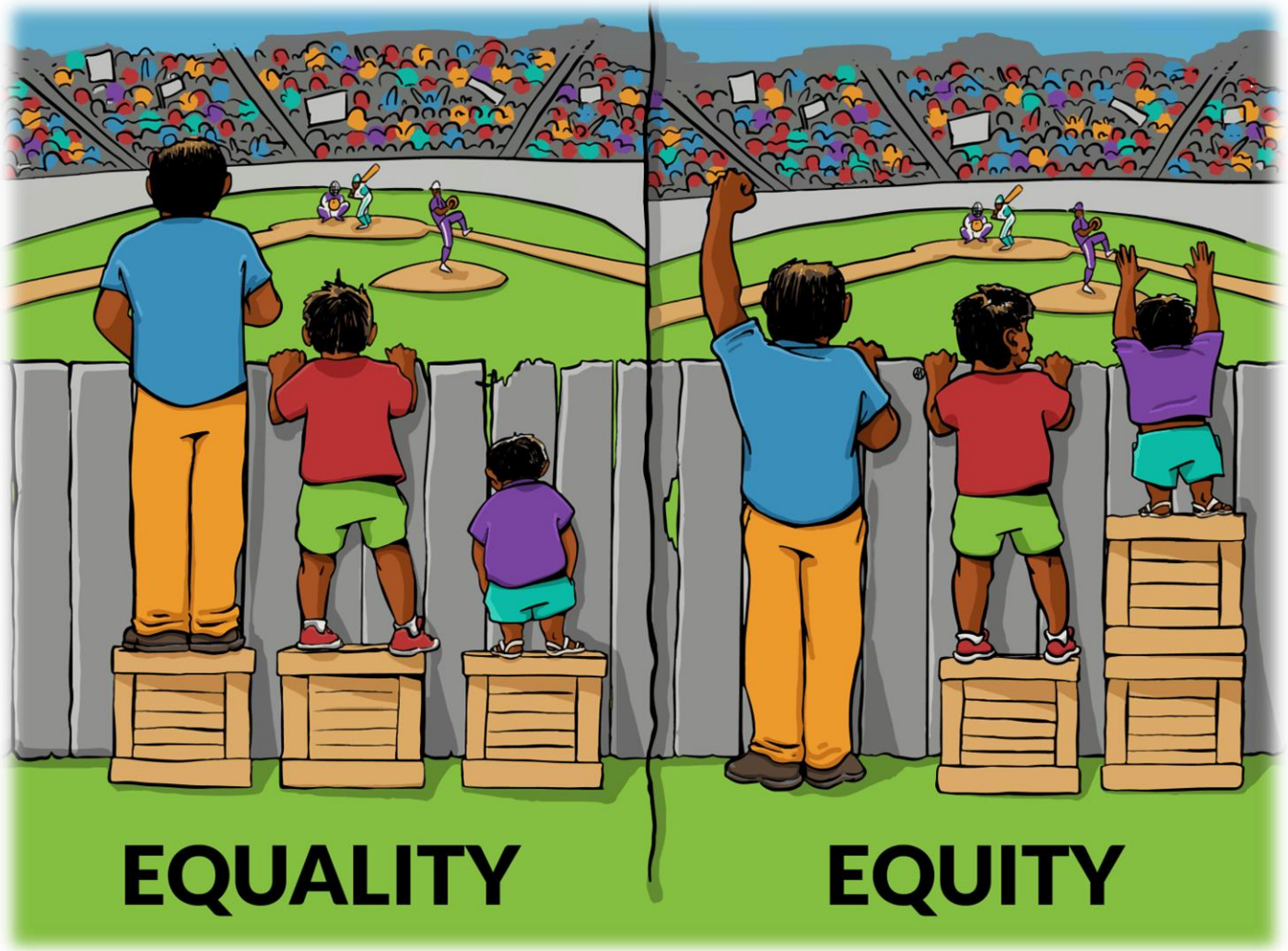

EQUALITY
EQUITY

Why DEI Matters?

- Helps attract and retain talent.
- Builds trust with the members and communities we serve.
- Fosters an inclusive, high-performance culture.
- Strengthens business performance.

Increasingly Changing Workplace

- 47% of millennials consider diversity and inclusion of the workplace in their job search (SHRM)
- Diverse management teams enjoy significantly higher earnings and returns on equity (McKinsey)
- Minnesota has seen a 29% growth in its population of color, 9th highest among states (US Census)

Source: SHRM Research Spotlight on Millennial Employees' Job Satisfaction and Engagement

2019: Increased intentional focus

Took a broader view – Diversity vs. Diversity, Equity, Inclusion

- Diversity expresses our commitment to building a diverse workforce that reflects the diversity within the communities we serve
- Equity expresses our commitment to promoting fairness and equality of opportunity for all employees
- Inclusion expresses our commitment to creating a culture of belonging that recognizes and celebrates the contributions of everyone

DEI at NMDP

2020: Floyd Effect Change at NMDP

Established diversity as a leadership priority

- Promoted HR leader to VP of DEI and brought on a DEI Director
- Equity Metric (Erica Jensen)
- Amy Ronneberg signed the CEO DEI pledge:
  - National movement sponsored by CEO Act!on for Diversity and Inclusion--the largest CEO-driven business commitment to advance diversity and inclusion within the workplace
  - Other Minnesota signers include CEOs from Blue Cross, HealthPartners, UnitedHealth Group, Best Buy, Target, Ecolab, General Mills, Cargill, Children's, Mortenson, Ryan Company and US Bank
- Consulted with a DEI Industry personality (Rainbow Disruption)

Current State DEI Mission & Vision

Mission

Leverage the power of our differences to amplify our culture and fuel the innovation needed to save lives through cell therapy

Vision

Unleash human potential by creating and enabling equitable playing fields for our patients, donors, and employees

State of NMDP DEI

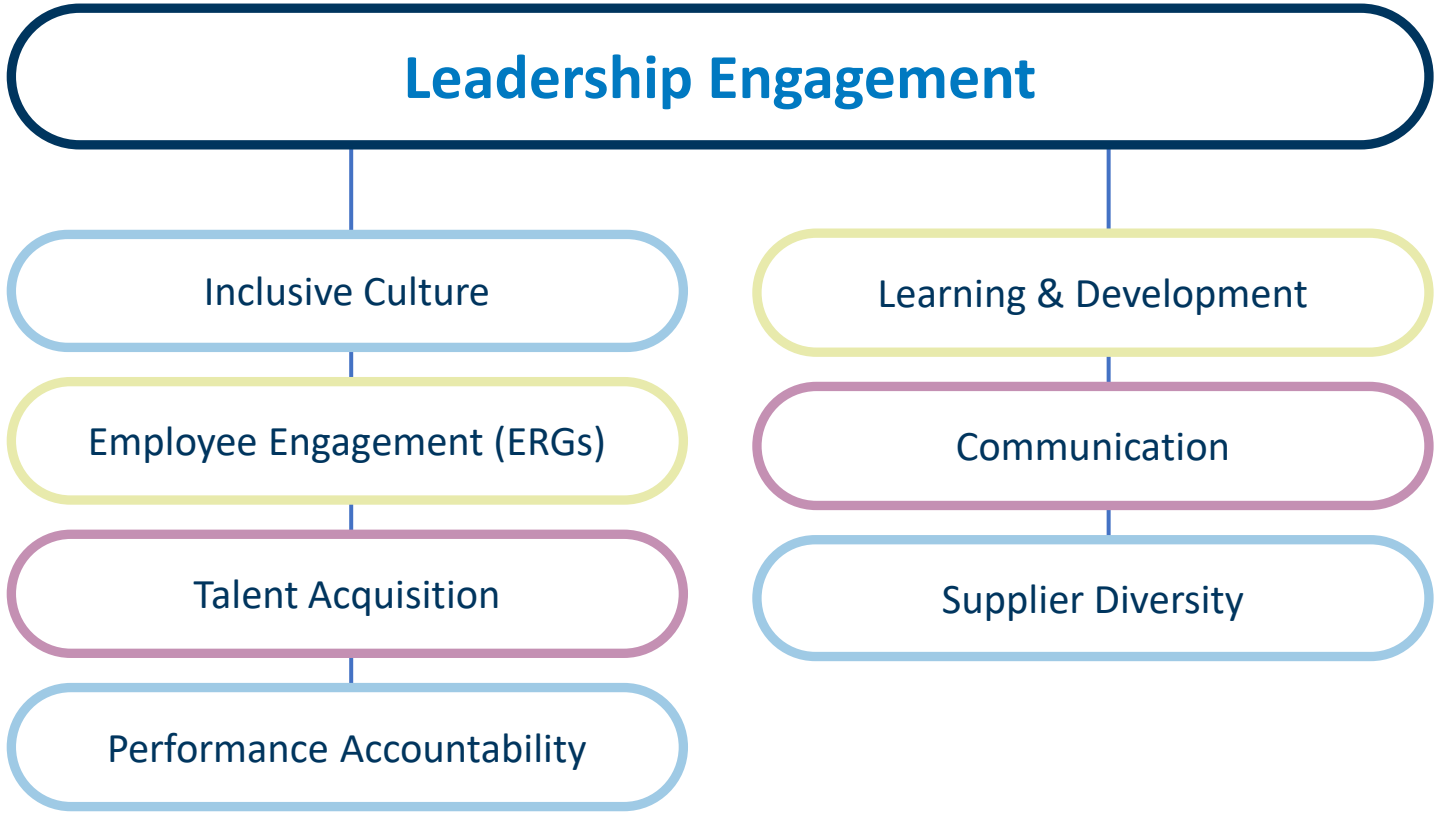
Strengths

- **EEOC Compliance:** Doing well with gender and minority representation across job levels
- **Overall Diversity:** Rates have been trending upward (2019-2024)
- **Minority Promotions:** Promotion rates closely align with the percentage of total headcount for each ethnicity group
- **Applicants:** Applicant pool is ethnically diverse

Opportunities

- **Ethnically Diverse:** Applicant pool is more diverse than the candidates being hired
- **Job Level-Gender:** Women are 74% of our workforce; however sr. manager, director & executive levels have lower percentages
- **Job Level-Minority:** Manager, directors & executive levels are 9x% white
- **Turnover:** No confirmed data

DEI Strategic Priorities



Human Resources Focus Areas

Elevate our best workplace culture with the best workforce that enables us to achieve our organizational 5-year strategy

Employee Engagement & Experience

- **Culture management**: DEI, change, decision-making, hire to retire milestones, recognition, communications
- Best job ever employee value proposition
- Total rewards and performance management
- Health and wellness strategies

Leadership & Employee Development

- **Strengths** and Lencioni based development programs
- NMDP Leader Academy
- **DEI programs**
- Talent reviews, **career development**, IDPs and succession planning

Workforce Planning

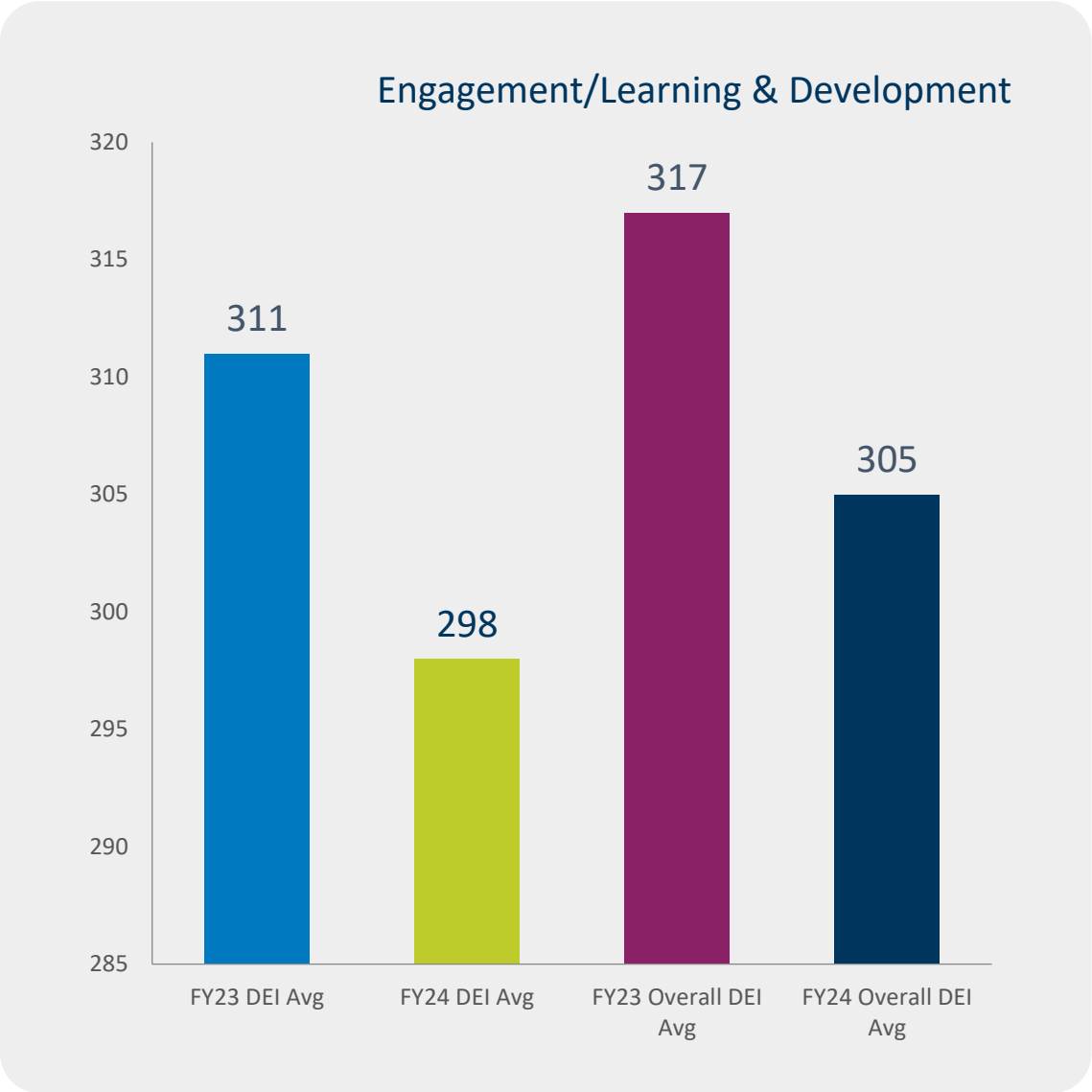
- Right people. right place. right time. within budget.
- **Emerging businesses** structured and profitable
- Organizational alignment with 5-year plan

HR Systems & Compliance

- Upgraded systems, reporting and analytics capabilities
- Labor and employment law risk management and mitigation
- Self service system with a white glove employee experience

DEI Engagement

- DEI Engagement is ahead of pace vs FY23
- We are 13 employee engagement points away with almost another quarter remaining
- We are anticipating over 300 engagements w/IDI and a significant number of engagement points w/DEIC, ERG and remaining August and September events.



DEI Strategic Priorities

Category	All Responses (n=689)	ADMINISTRATION (n=10)	CORPORATE MARKETING (n=19)	DONOR (n=176)	FACILITIES (n=6)	FINANCE (n=21)	FOUNDATION (n=21)	HUMAN RESOURCES (n=20)	INFORMATION TECHNOLOGY (n=103)	LEGAL (n=41)	ME3 (n=76)	POE (n=77)	PROVIDER (n=119)
Career Growth & Development	83.74%	95.00%	78.95%	83.24%	75.00%	80.95%	88.10%	82.50%	84.47%	85.37%	81.58%	83.77%	84.87%
Communication & Resources	78.77%	100.00%	63.16%	80.68%	79.17%	82.14%	80.95%	70.00%	85.92%	86.59%	73.68%	75.32%	73.74%
Diversity & Inclusion	80.70%	100.00%	72.37%	81.68%	87.50%	78.57%	79.76%	70.00%	85.92%	89.02%	76.64%	76.95%	78.57%
Engagement Outcomes	90.73%	98.89%	87.72%	90.72%	90.74%	88.36%	88.89%	85.00%	90.18%	93.22%	90.06%	91.92%	91.50%
Future Outlook	86.36%	100.00%	78.95%	87.36%	95.83%	90.48%	83.33%	78.75%	88.11%	87.80%	89.47%	82.47%	84.03%
Individual Needs	79.78%	91.67%	71.93%	77.37%	80.56%	84.92%	81.75%	80.83%	84.63%	86.18%	77.85%	77.92%	78.15%
Manager Effectiveness	82.95%	97.50%	67.11%	85.94%	83.33%	79.76%	80.95%	75.00%	80.34%	87.20%	87.83%	80.19%	81.51%
Team Dynamics	89.31%	100.00%	77.19%	88.26%	77.78%	93.65%	92.06%	81.67%	89.64%	93.50%	87.72%	92.21%	89.92%
Trust in Leadership	86.45%	100.00%	91.23%	90.15%	100.00%	87.30%	88.89%	76.67%	86.41%	90.24%	86.40%	80.52%	82.07%

DEI Strategic Priorities

Category	All Responses (n=689)	ADMINISTRATION (n=10)	CORPORATE MARKETING (n=19)	DONOR (n=176)	FACILITIES (n=6)	FINANCE (n=21)	FOUNDATION (n=21)	HUMAN RESOURCES (n=20)	INFORMATION TECHNOLOGY (n=103)	LEGAL (n=41)	ME3 (n=76)	POE (n=77)	PROVIDER (n=119)
Career Growth & Development													
Communication & Resources													
Diversity & Inclusion	80.70%	100.00%	72.37%	81.68%	87.50%	78.57%	79.76%	70.00%	85.92%	89.02%	76.64%	76.95%	78.57%
Engagement Outcomes													
Future Outlook													
Individual Needs													
Manager Effectiveness													
Team Dynamics													
Trust in Leadership													

ASTCT-NMDP ACCESS Initiative

Patient Participation: Consideration and Challenges

Heather Blackwell

Jackie Foster

Jessie Sanders

Karen DeMairo

Lauren Tokarewich

Tania Jain

Rayne Rouce

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ASTCT-NMDP ACCESS Initiative

Sensitivity to the Patient Perspective

Jackie Foster, MPH, RN, OCN

Senior Manager, Patient Services, NMDP

Washington, D.C.

July 23rd, 2024

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Recap From 2023 Access Initiative
Top Learnings from Leading 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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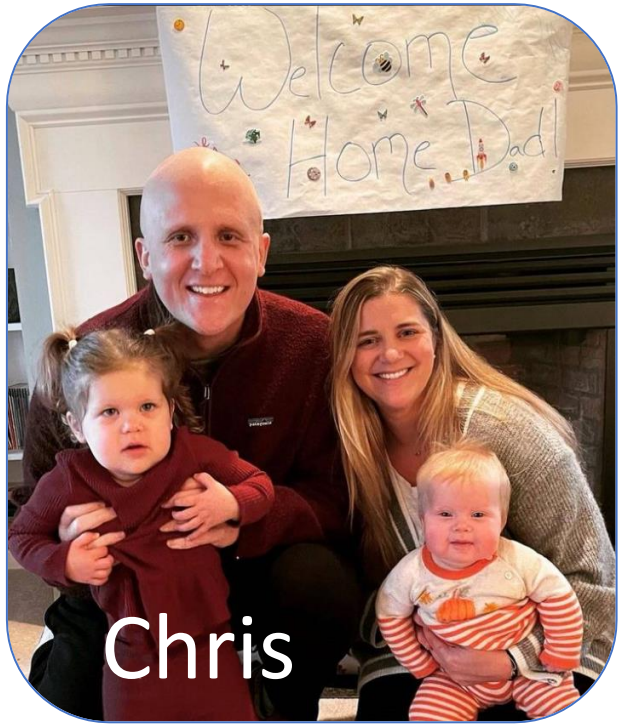
Sensitivity to the Patient Perspective

- Requesting patient feedback
- Taking in patient feedback
- Closing the loop
- NMDP Voice of the Community



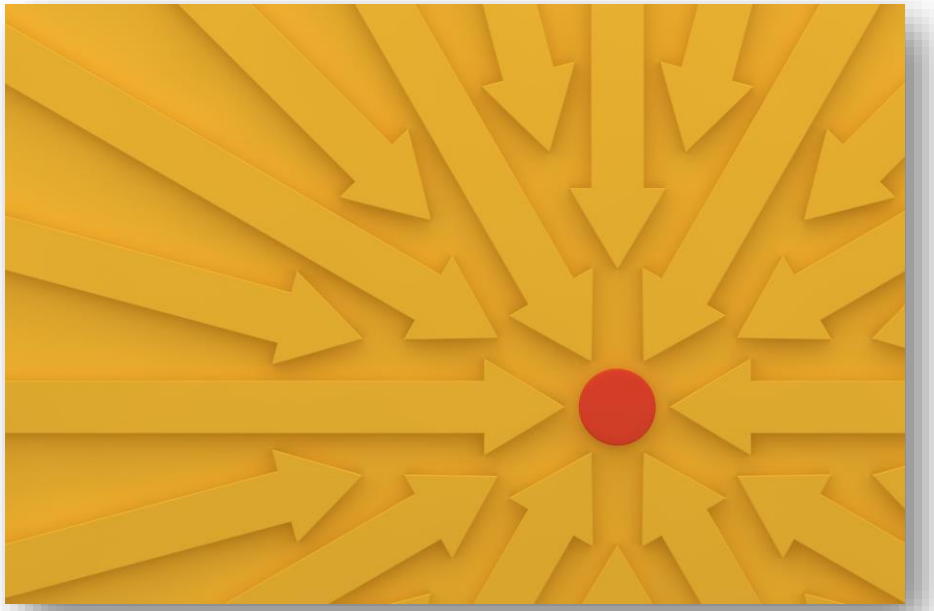
Gathering Feedback

Expectation

Reality

Gathering Feedback

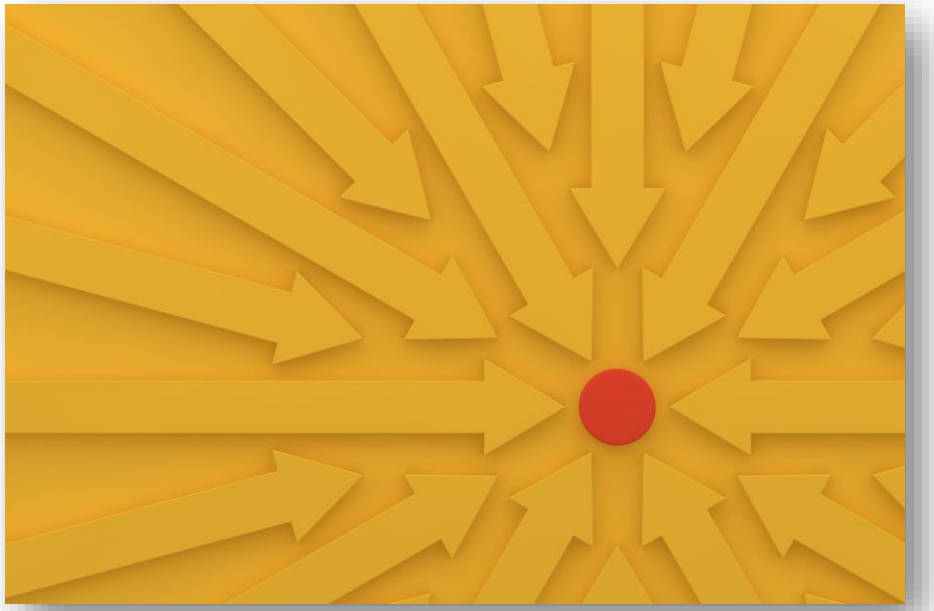
Expectation



Reality

Gathering Feedback

Expectation



Reality

Requesting Patient Feedback

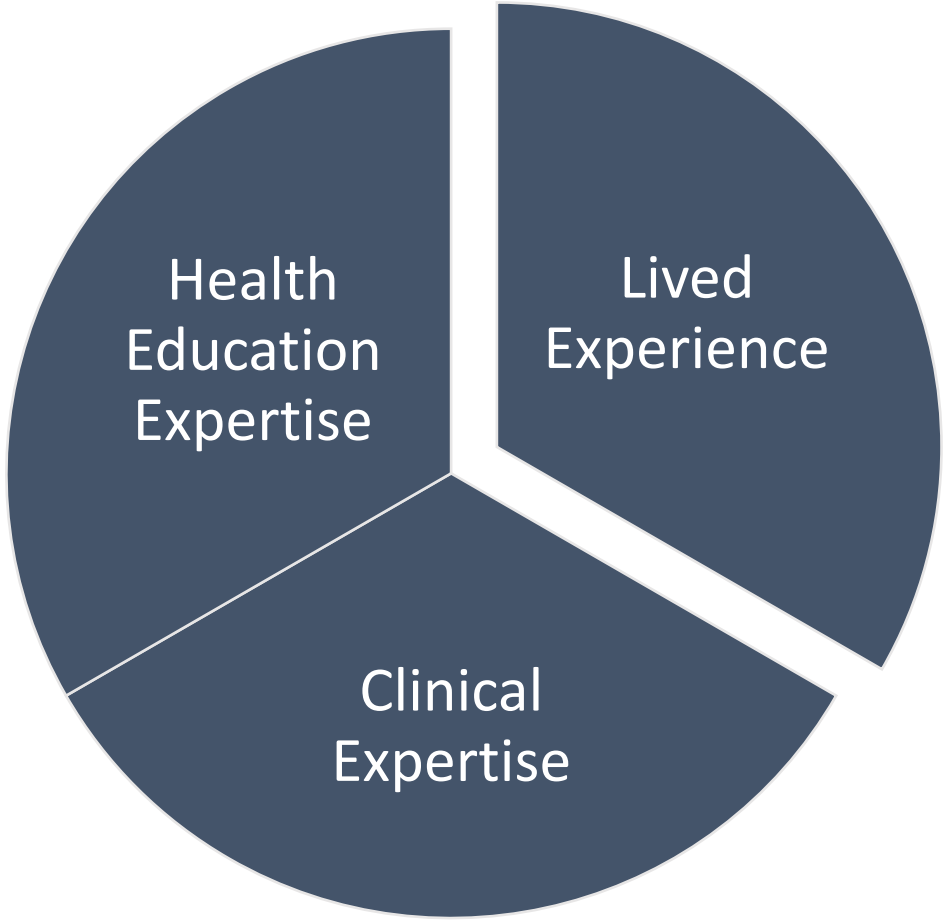
1. **Clarity in your purpose**
   - Insight into what is unclear, confusing, or hard
   - Highest priority information or problems for patients and caregivers
   - Top questions or concerns for patients and caregivers
   - Lived experience perspective on new initiatives to enhance the impact

Armstrong, 2017; Klingmann, 2018

Requesting Patient Feedback

2. Appropriate scope

- ✓Patient-friendly
- ✓Plain language
- ✓Accessible design
- ✓Useful content
- ✓Accurate and current



Requesting Patient Feedback

3. Assure anonymity

✓Encourages honesty

✓Acknowledges power imbalance

✓Demonstrates respect

Requesting Patient Feedback

4. Open ended… with focus and alignment

Ask

- What's confusing or unclear about this?
- What were the most important things for you to know before transplant?
- What do you think after hearing about this problem? What was your experience?

Not…

- How should we edit this?
- What is missing from transplant patient education?
- What do you think we should do about this problem?

Taking In Patient Feedback

Etchegary, 2023; Vanderhout, 2022

- ✓ **Listen to understand** – be curious, hold back your own conclusions, say ‘tell me more about that’
- ✓ **Check personal biases** – about what can or can’t be done, about what you’ve heard from other patients, about what you think is right or feasible
- ✓ **Stay focused on the primary goal** – Does the feedback answer your question? Or is it answering a different question?
- ✓ **Consider who are you <u>not</u> hearing from** – Very low literacy, high poverty, other language speakers, different cultures

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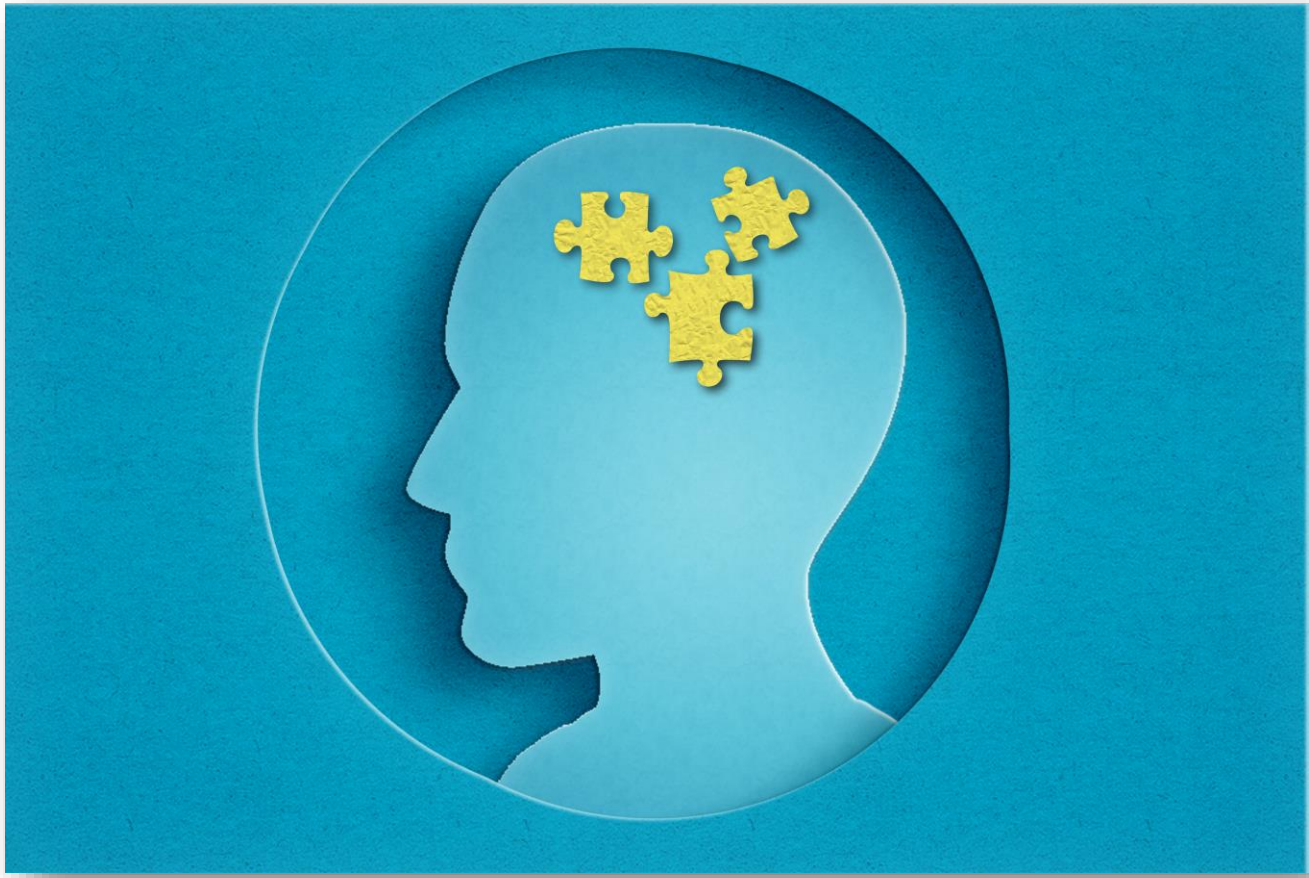
Closing the Loop – Expressing Gratitude

<u>ALWAYS</u> close the loop

1. What did you hear?
2. What will or have you done?

   (Ensuring anonymity!)
3. Why it matters
4. Appreciation



NMDP Voice of the Community Volunteers

- Cohort of 53 volunteers (and growing!):
  - 70% patients and 30% caregivers
  - 23% leukemias/MDS, 11% lymphomas, 17% SCD, XX% other
  - 34% non-Hispanic white, 66% racially ethnically diverse
  - 32% 20-39 years old, 25% 40-59 years old, 43% 60+ years old
  - 100% speak and read English
- One program manager, Certified Health Education Specialist
- Cross functional task force focused on recruitment and engagement
- Average of 1 project per month via email
- Periodically interview opportunity with honoraria

Diverse Lived Experiences = An Important Piece of the Puzzle

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ASTCT-NMDP ACCESS Initiative

Community Engagement

Rayne Rouce, MD

Texas Children's Cancer Center

Washington, D.C.

July 23rd, 2024

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INSERT Dr. Rouce’s Slides

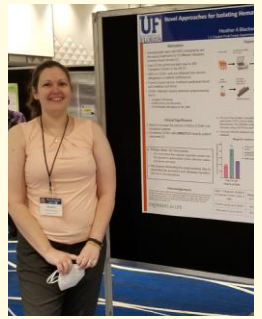
Heather A Blackwell MSc, MLS(ASCP)cm

MEDICAL TECHNOLOGIST IN LIFESOUTH TCT LABORATORY

OVERCAME A RARE LEUKEMIA WITH A HSC TRANSPLANT

TCT FULL CIRCLE

RETURNING TO LEAD CLINICAL CELL THERAPY LABORATORY



BIOMEDICAL ENGINEER MSC, TCT RESEARCHER, AND DOCTORAL STUDENT

Panel Discussion

Moderator: Tania Jain, MBBS

Panelists:

- Heather Blackwell, MSc, MLS, (ASCP)cm
- Jessie Sanders
- Karen DeMairo, MHSA
- Lauren Tokarewich, MLIS

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ASTCT-NMDP ACCESS Initiative

Kaiser Permanente Dataset Project Update

Sanghee Hong, MD

Duke University

2024 ACCESS Initiative Summer Workshop/ Washington DC

July 24, 2024

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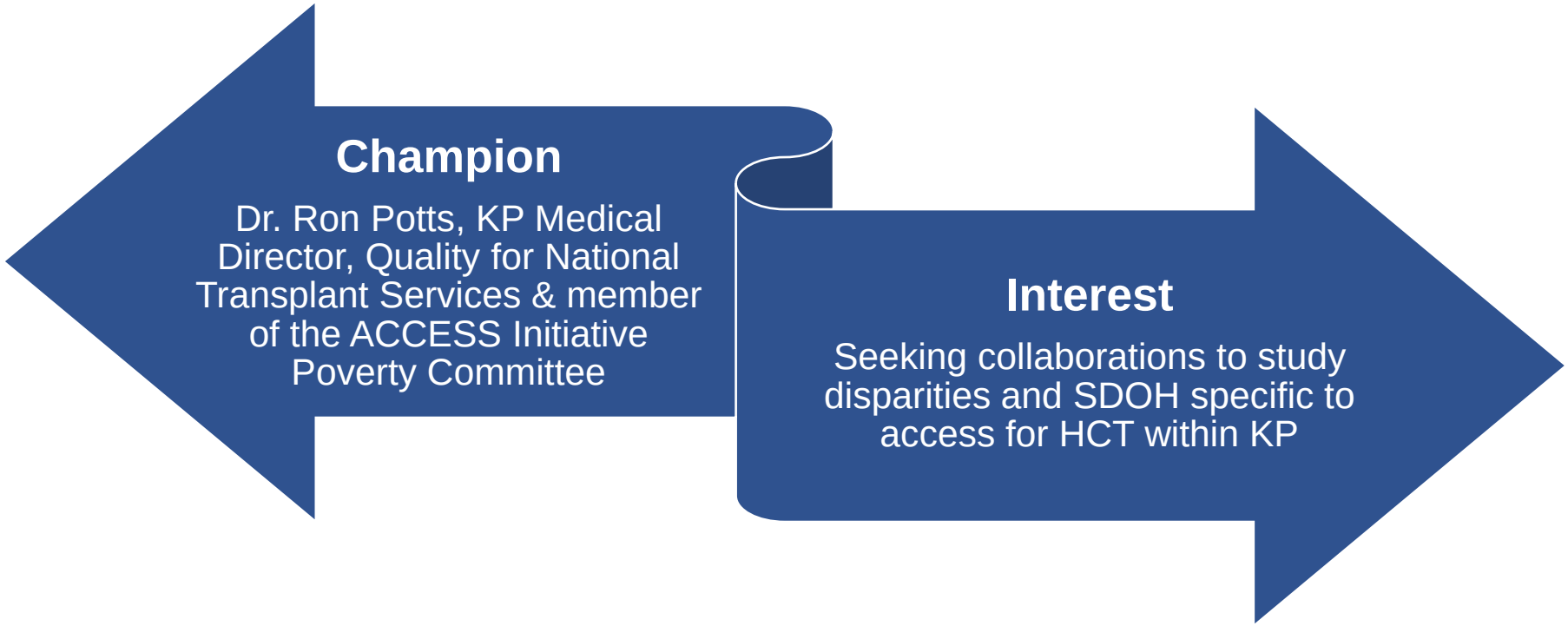
Agenda

- KP dataset overview
- Research question and proposal process
- Proof-of-concept project progress

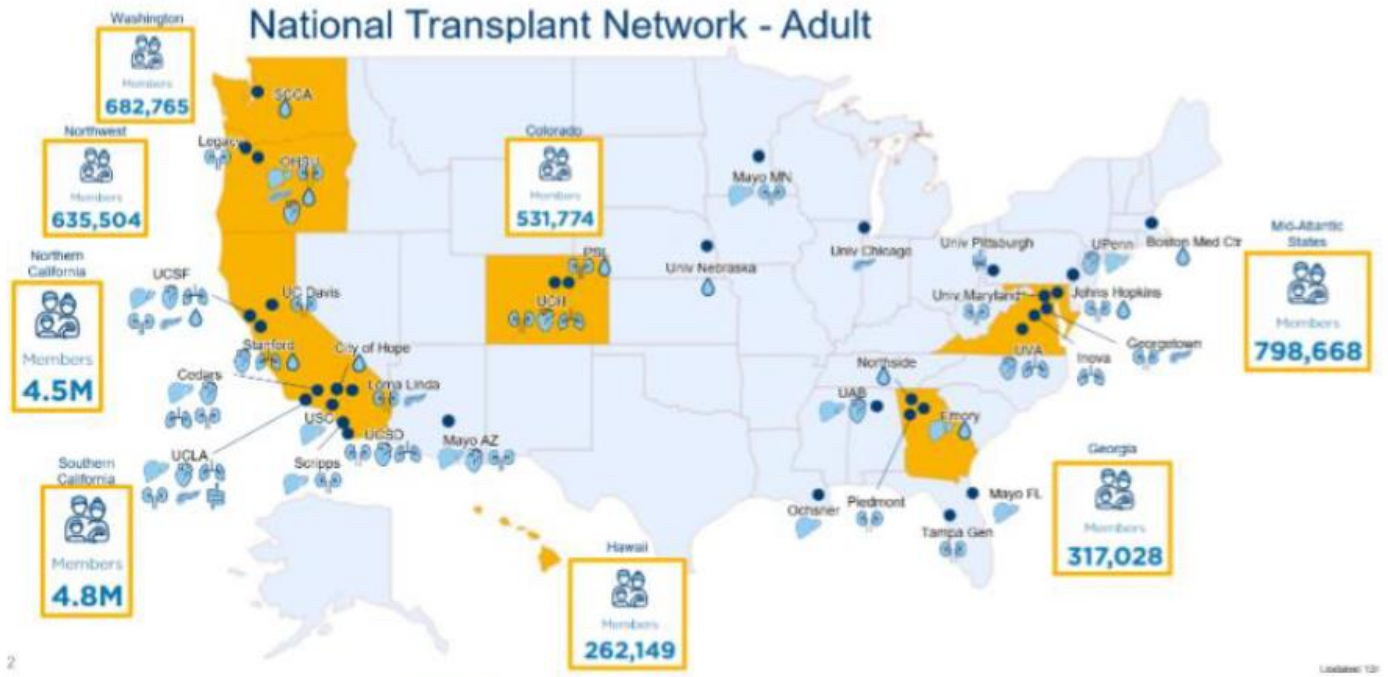
Ongoing Goals of KP Dataset Working Committee

- Through partnerships with KP SRTR, investigate race and other social factors in barriers to access in HCT/CT.



KP SRTR

- Largest integrated healthcare system in the US
- KP serves 12.8 million members in 8 regions
    1. Colorado
    2. Hawaii
    3. Mid-Atlantic States
    4. Georgia
    5. Washington
    6. North West
    7. Southern California
    8. Northern California



Proposal & Funding Opportunities

- Merge of patient-level SRTR and KP data to create a novel database to describe care continuum
- Blood & marrow, solid organ & mechanical circulatory support transplant data
- >900 unique attributes & data types including

KP SRTR	KP Clinical data (linked)
Recipient referral date, results	Recipient demographics
Recipient evaluation center, date, results	Recipient diagnosis, treatment history
Recipient transplant – type, conditioning, collection, stem cell amount, infusion	Recipient comorbidities and functional status
Disease status at transplant	*Able to tell “denominator”

KP SRTR + Clinical data

- We continue accepting proposals, and several protocols are currently under development

Project

- Social Factors and Access to Hematopoietic Cell Transplantation and Cellular Therapy
- Research Questions
  - How social factors influence referral vs. non-referral to transplant, and ultimate receipt vs. non-receipt of transplant?
    - Allogeneic HCT for AML
    - Autologous HCT or immune effector cell (IEC) therapies for PCN
  - In patients where a transplant is indicated, at which step(s) of the referral and pre-transplant process are social factors a barrier to proceeding with transplant?

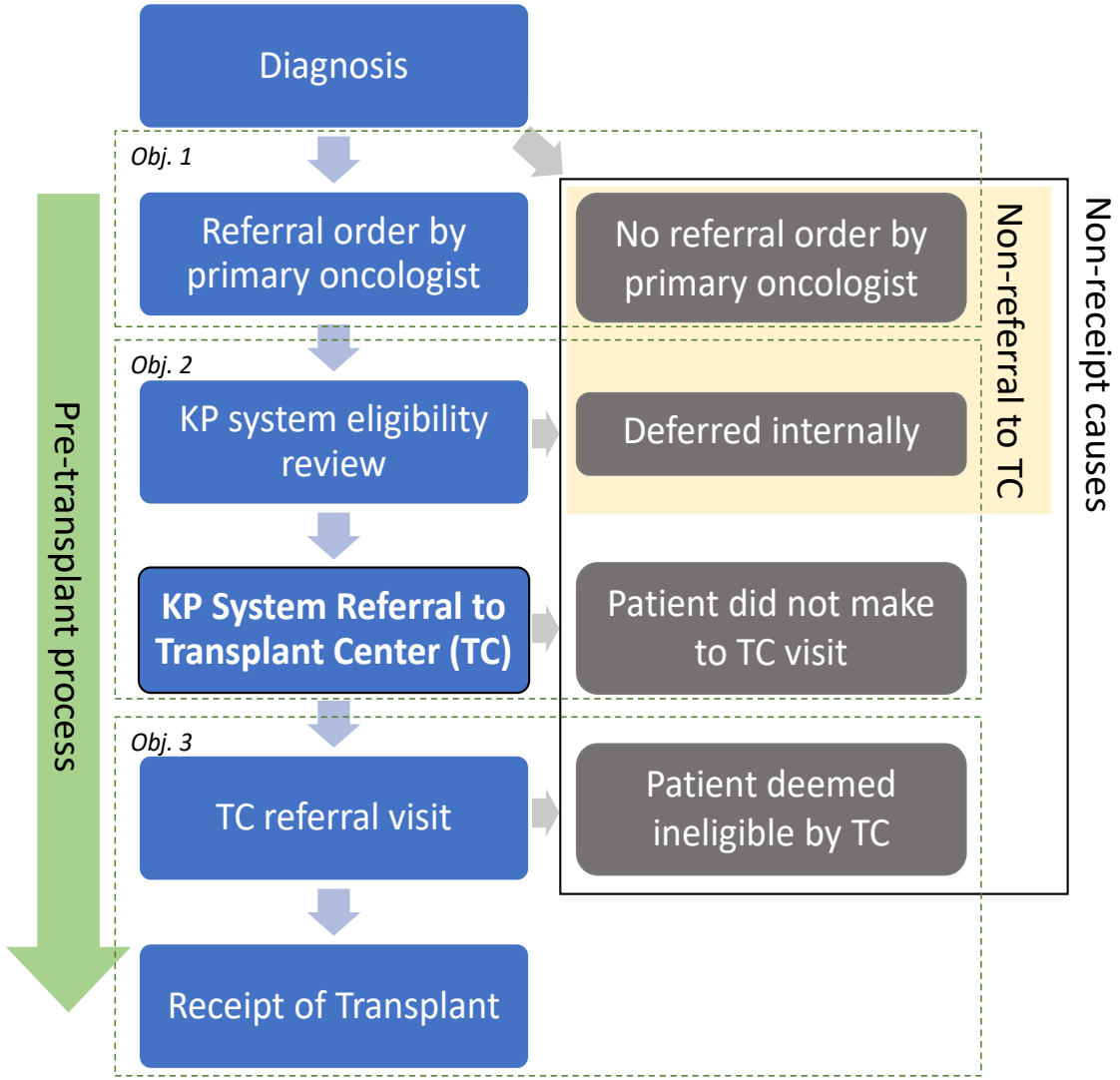
Objectives

O1: What % of whom are indicated are “referred” for HCT/CT? What social factors associated with “referral”?

O2: Compare sociodemographic factors those who were not referred vs. referred but did not make to referral visit vs. referred and had an eval visit

O3: Factors behind deferring HCT procedures after referral

Study period 2010-2022



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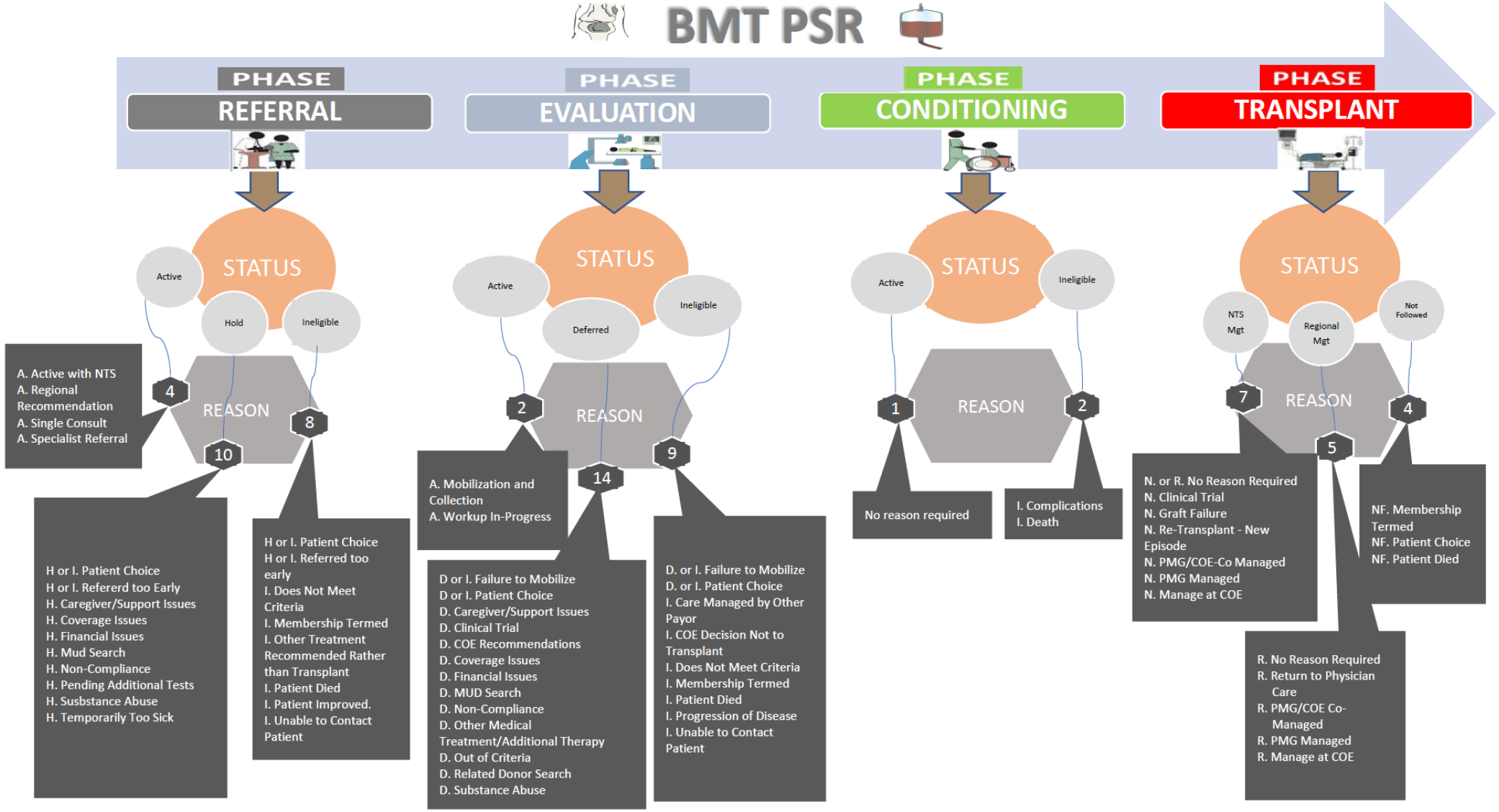
Research Hypothesis

- Social factors are associated with referral to allogeneic and autologous HCT in a large integrated healthcare system for patients with AML and PCN, respectively.
- Social factors are associated with receipt of allogeneic and autologous HCT for this patient population in a large integrated healthcare system.

KP BMT Svstem and Potential Barriers in Access



KP SRTR

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Proof-of-Concept Projects

- Working with KP Quality Improvement data analytics team
- Inclusion Criteria:
  - Adult patients (>=18 yrs at diagnosis) with AML and MM
  - Diagnosed in between 1/1/2020-12/31/2023
  - In Southern California KP Region: almost all pts (>95%) will be referred to City of Hope for transplant
  - Alive with KP membership for at least 3 months post-diagnosis
- Definition:
  - Referral Status: Any patient with a transplant episode are in the 'Referred' category. Patients without a transplant episode (prior/current) are in the 'Non-Referred' category.
- ICD 10 codes used:
  - AML: C92.0, C92.3, C92.5, C92.6, C92.7, C92.8, C92.9, C93.0, C93.7, C93.9, C94.0, C94.2
  - MM: C90.00, C90.01, C90.02

Proof-of-Concept Project

	AML	MM
Total	627	1281
Non-referred	289 (48%)	1092 (57%)
Referred	312 (52%)	826 (43%)
Time from Diagnosis to Referral (Days, median [IQR])	*149 [129]*	*181 [125]*

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Univariable Analyses 1

	Acute Myeloid Leukemia (AML)								Multiple Myeloma (MM)							
	Referred		Non-Referred		Univariate Model Results				Referred		Non-Referred		Univariate Model Results			
	N	%	N	%	OR	LL	UL	p-value	N	%	N	%	OR	LL	UL	p-value
Age at Diagnosis (yrs)																
Mean (SD)	56 (14)		69 (16)						63 (9)		74 (10)					
Median [IQR]	60 [19]		74 [17]						65 [12]		75 [13]					
18-29	16	55%	13	45%	21.10	7.46	59.66	<.0001	1	50%	1	50%	8.87	0.55	143.46	0.1243
30-44	45	74%	16	26%	47.59	18.75	120.83	<.0001	30	79%	8	21%	31.76	14.11	71.44	<.0001
45-54	58	77%	17	23%	57.70	23.14	143.85	<.0001	106	74%	37	26%	25.13	16.00	39.48	<.0001
55-64	90	72%	35	28%	44.00	19.09	101.43	<.0001	272	67%	133	33%	18.06	13.02	25.07	<.0001
65-74	96	55%	79	45%	20.95	9.45	46.46	<.0001	351	52%	325	48%	9.56	7.11	12.84	<.0001
75+	7	5%	129	95%	1				66	10%	588	90%	1			
Sex																
Female	137	50%	135	50%	0.89	0.65	1.23	0.4918	350	44%	455	57%	1.03	0.86	1.24	0.7555
Male	175	53%	154	47%	1				476	43%	637	57%	1			
Race																
Asian/Pacific Islander	35	49%	37	51%	0.85	0.50	1.42	0.5250	83	43%	112	57%	1.00	0.73	1.38	0.9951
Black/African American	25	44%	32	56%	0.70	0.40	1.24	0.2237	149	36%	267	64%	0.75	0.59	0.97	0.0253
Hispanic/Latino	90	55%	74	45%	1.09	0.74	1.60	0.6798	267	51%	261	49%	1.38	1.10	1.73	0.0056
Other/Unknown[1]	13	50%	13	50%	0.89	0.40	2.00	0.7827	24	35%	44	65%	0.74	0.44	1.24	0.2571
White	149	53%	133	47%	1				303	43%	408	57%	1			

1 'Other' category includes Multiracial, Native Americans/Eskimos.

Univariable Analyses 2

	Acute Myeloid Leukemia (AML)								Multiple Myeloma (MM)							
	Referred		Non-Referred		Univariate Model Results				Referred		Non-Referred		Univariate Model Results			
	N	%	N	%	OR	LL	UL	p-value	N	%	N	%	OR	LL	UL	p-value
Marital Status																
Single/Never Married	70	61%	45	39%	1.324	0.864	2.029	0.197	110	39%	171	61%	0.669	0.513	0.872	0.003
Divorced/Separated	28	47%	31	55%	0.773	0.446	1.341	0.3598	64	36%	114	64%	0.585	0.422	0.81	0.0013
Widowed	11	24%	35	76%	0.277	0.137	0.559	0.0003	56	25%	166	75%	0.352	0.255	0.487	<.0001
Other/Unknown	4	33%	8	67%	0.452	0.135	1.512	0.1976	16	29%	39	71%	0.434	0.24	0.783	0.0056
Married/Domestic Partner	199	54%	170	46%	1				580	49%	602	52%	1			
Employment Status																
Full Time	157	96%	137	84%	1.24	0.70	2.21	0.463	231	72%	92	29%	1.52	1.03	2.24	0.0352
Part Time/Self Employed	26	31%	34	40%	1.73	0.74	4.06	0.2102	57	62%	35	38%	0.98	0.59	1.65	0.9502
Retired	144	93%	92	59%	0.22	0.13	0.37	<.0001	363	32%	762	68%	0.29	0.21	0.40	<.0001
Other/Unknown[2]	488	63%	568	74%	0.34	0.16	0.69	0.0032	66	33%	137	68%	0.29	0.19	0.45	<.0001
Unemployed	25	68%	26	70%	1				109	62%	66	38%	1			
Rural-Urban Commuting Area (RUCA)																
Metropolitan	308	52%	286	48%	0.84	0.19	3.76	0.8165	822	43%	1,082	57%	1.77	0.56	5.58	0.3279
Non-metropolitan	4	57%	3	43%	1				4	29%	10	71%	1			
Comorbidity Severity Index (Charlson)																
Mild: 1-2	240	61%	151	39%	2.16	1.29	3.61	0.0033	521	52%	478	48%	2.19	1.75	2.75	<.0001
Moderate: 3-4	38	34%	73	66%	0.71	0.39	1.32	0.2784	123	38%	200	62%	1.24	0.92	1.66	0.1549
Severe: >=5	4	14%	24	86%	0.25	0.08	0.77	0.0158	22	19%	92	81%	0.49	0.30	0.81	0.0050
No Comorbidities/Unknown	30	42%	41	58%	1				160	33%	322	67%	1			

2 'Other' category includes Student (part/full time).

Univariable Analyses 3

	Acute Myeloid Leukemia (AML)								Multiple Myeloma (MM)							
	Referred		Non-Referred		Univariate Model Results				Referred		Non-Referred		Univariate Model Results			
	N	%	N	%	OR	LL	UL	p-value	N	%	N	%	OR	LL	UL	p-value
ECOG Performance Status																
1-Restricted in Strenuous Activity	59	61%	38	39%	0.916	0.507	1.657	0.7725	110	49%	112	51%	0.77	0.528	1.123	0.1748
2-Restricted in Work Activity but Ambulatory, Capable of Self-Care	15	41%	22	59%	0.408	0.186	0.895	0.0252	45	41%	66	59%	0.537	0.337	0.854	0.0087
3-Capable of Limited Self-Care	7	37%	12	63%	0.356	0.128	0.99	0.0478	18	34%	35	66%	0.409	0.218	0.766	0.0052
4-Completely Disabled	3	27%	8	73%	0.244	0.062	0.96	0.0435	6	40%	9	60%	0.537	0.185	1.557	0.2523
Unknown	172	49%	176	51%	0.579	0.359	0.935	0.0254	527	40%	776	60%	0.533	0.398	0.713	<.0001
0-Fully Active	56	63%	33	37%	1				120	56%	94	44%	1			
Disease Status																
Not Achieved Remission	271	52%	251	48%	1.26	0.75	2.13	0.3836	796	43%	1,071	57%	0.85	0.40	1.80	0.6785
Relapse	12	75%	4	25%	3.25	0.96	10.96	0.0576	17	74%	6	26%	3.09	0.95	10.08	0.0613
Complete Remission	29	46%	34	54%	1				13	46%	15	54%	1			
Insurance at Diagnosis																
Medicare	89	32%	191	68%	0.198	0.139	0.281	<.0001	370	30%	867	70%	0.206	0.168	0.253	<.0001
Medicaid/Special Programs	12	57%	9	43%	0.557	0.227	1.367	0.2014	25	60%	17	40%	0.704	0.372	1.332	0.2807
Commercial	211	70%	89	30%	1				431	67%	208	33%	1			

Univariable Analyses 4

	Acute Myeloid Leukemia (AML)								Multiple Myeloma (MM)							
	Referred		Non-Referred		Univariate Model Results				Referred		Non-Referred		Univariate Model Results			
	N	%	N	%	OR	LL	UL	p-value	N	%	N	%	OR	LL	UL	p-value
Primary Oncologist Location																
BALDWIN PARK	20	53%	18	47%					38	37%	64	63%				
DOWNEY	11	44%	14	56%					63	40%	94	60%				
KERN COUNTY	10	56%	8	44%					17	36%	30	64%				
LOS ANGELES	28	62%	17	38%					52	42%	71	58%				
ORANGE COUNTY	35	54%	30	46%					107	48%	116	52%				
OUT OF AREA											1	100%				
PANORAMA CITY	42	59%	29	41%					67	45%	82	55%				
RIVERSIDE	27	45%	33	55%					86	39%	132	61%				
SAN BERNARDINO COUNTY	31	48%	34	52%					123	51%	118	49%				
SAN DIEGO	53	52%	49	48%					107	44%	138	56%				
SCR OOA	1	100%									1	100%				
SOUTH BAY	18	56%	14	44%					55	39%	86	61%				
WEST LOS ANGELES	12	41%	17	59%					59	36%	104	64%				
WOODLAND HILLS	24	48%	26	52%					52	49%	55	51%				
	Median	IQR	Median	IQR					Median	IQR	Median	IQR				
Distance from Patient Residence to Center (Miles)	32.9	43.4	33	34.1	1.003	0.999	1.007	0.1918	30	25.8	28	25.4	1.000	0.999	1.001	0.8854
Neighborhood Deprivation Index (NDI)	0.048	1.214	0.002	1.326	0.901	0.749	1.083	0.2671	-0.051	1.157	0.094	1.214	0.857	0.770	0.954	0.0047

Next Steps

- Proof of concept – additional analyses
- Funding source
- Full proposal
- Additional protocol development

Thank you! Questions?

ASTCT-NMDP ACCESS Initiative

Identifying clinical and sociodemographic factors associated with HCT/CT utilization using Optum database

Nandita Khera MD

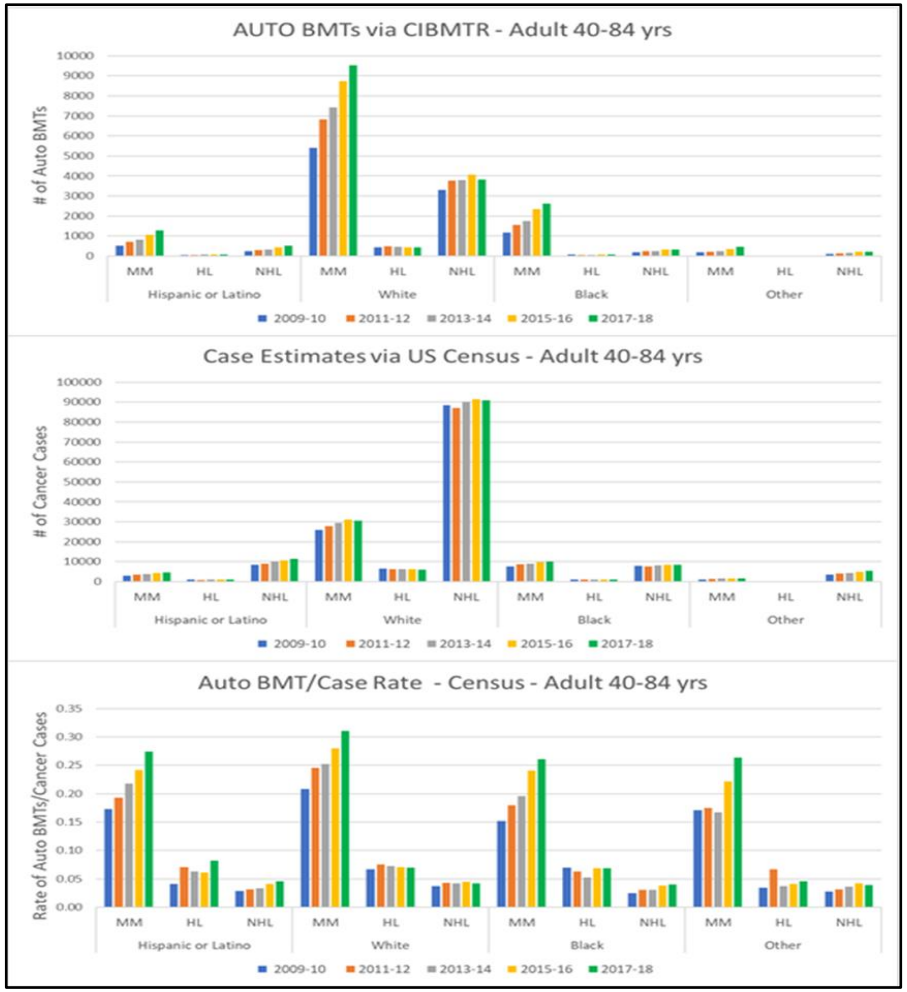
Mayo Clinic AZ

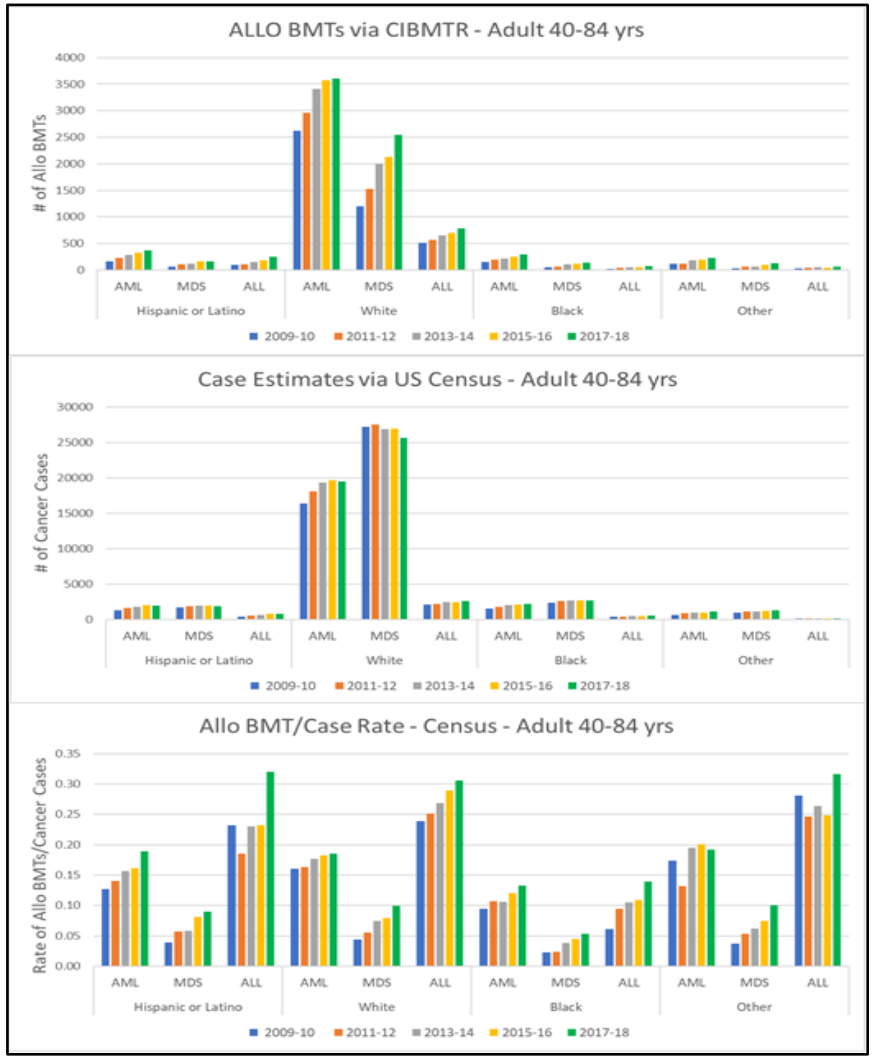
ACCESS Workshop

7/23/24

Equal Outcomes for All

Disparities in utilization of auto and allo HCT





Optum provides a cohort of patients that can be followed longitudinally to determine who proceeds to HCT/CT

Hahn et al. JAMA Netw Open. In press

Objectives

- Determine the proportion of patients with specific diseases who receive HCT/CT: allogeneic HCT (alloHCT) for acute leukemia; autoHCT for multiple myeloma and autoHCT and CAR-T therapy for Non-Hodgkin's lymphoma
- Compare characteristics of patients who receive HCT/CT to those who don't, focusing on clinical and sociodemographic factors.

Methods

- Optum database will be queried to obtain the number and characteristics of patients with acute leukemia, multiple myeloma, and NHL from 2010 to 2022
  - continuous health plan coverage for at least 1 year before and after the date of diagnosis.
- Proportion of patients receiving HCT/CT for each diagnosis will be calculated and clinical and sociodemographic characteristics will be compared for those receiving a CT vs no CT.
- Either Optum's "SES view" (which provides benefit design & SES data but no mortality data) or "National View" (which provides benefit design, SES data & mortality data) will be utilized

Preliminary numbers

pe	N of cases	Within 12 months after diagnosis		From Diagnosis to End of Coverag	
		N (%) with HCT	N (%) with CART	N (%) with HCT	N (%) with CAI
ALL	8132	832 (10.2)	16 (0.2)	1017 (12.5)	45 (0.6)
AML	9195	1192 (13.0)	23 (0.3)	1411 (15.4)	49 (0.5)
Follicular Lymphoma	23332	534 (2.3)	27 (0.1)	839 (3.6)	88 (0.4)
Non-follicular Lymphoma	25736	740 (2.9)	109 (0.4)	1049 (4.1)	263 (1.0)
Mature T/NK-cell lymphomas	6375	210 (3.3)	*	279 (4.4)	*
Other specified types of T/NK-cell lymphoma	1281	73 (5.7)	0 (0.0)	88 (6.9)	*
Malignant immunoproliferative diseases and other B-cell	6544	156 (2.4)	*	221 (3.4)	11 (0.2)
Specified and unspecified non-Hodgkin lymphomas	36764	573 (1.6)	113 (0.3)	886 (2.4)	280 (0.8)
Multiple Myeloma	23341	2095 (9.0)	26 (0.1)	2531 (10.8)	72 (0.3)
Sickle Cell	9664	24 (0.3)	0 (0.0)	40 (0.4)	*
Other and unspecified malignant neoplasms of lymphoid	5389	168 (3.1)	*	213 (3.9)	18 (0.3)

*cell size less than 11 suppressed to protect patient confidentiality

Cost and Limitations

- Cost: 15 to 20K
- Limitations
  - Detailed clinical data will not be available
  - Interval between diagnosis and HCT/CT may be quite variable and may need some set thresholds to identify our cohort (will need some assumptions)

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California Cancer Registry-CIBMTR linkage Insights into access for HCT for AML: Christa Meyer

Presenter

NMDP

2024 Summer Workshop / Washington D.C.

07/24/2024

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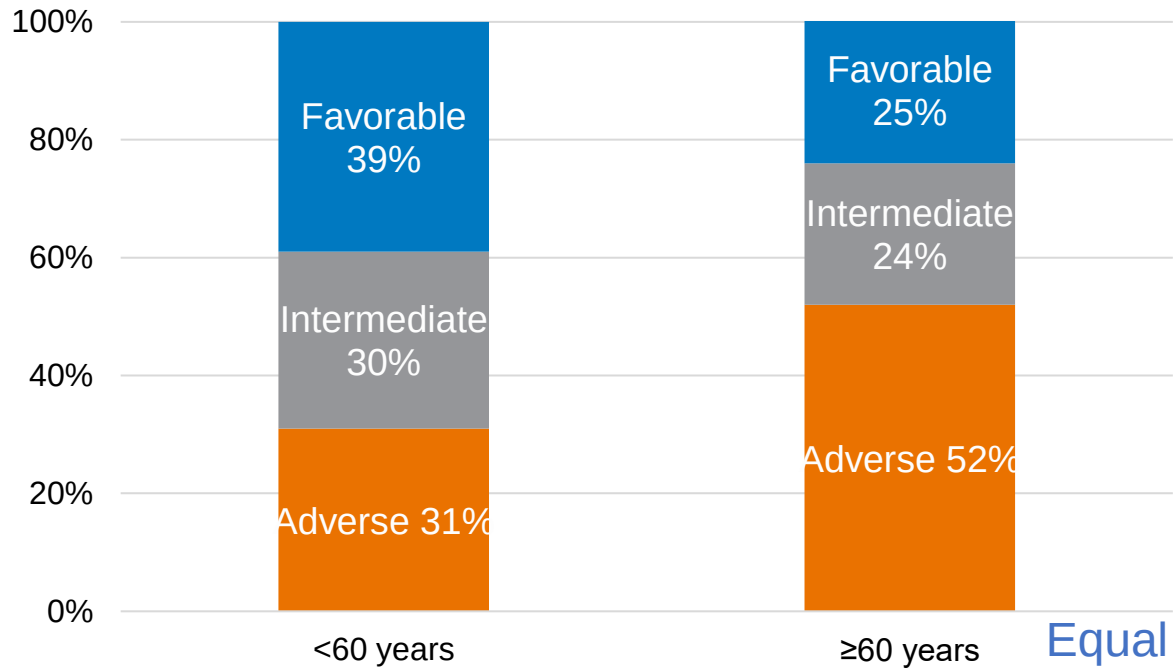
Background

- Acute myeloid leukemia (AML) predominantly affects older adults
- Patient fitness & risk classification used to guide treatment
  - % adverse risk increases with age
  - Intermediate and adverse risk should be evaluated for hematopoietic stem cell transplan (HCT)

2022 European LeukemiaNet (ELN) AML Risk Classification



Data from Herold et al. Leukemia (2020)

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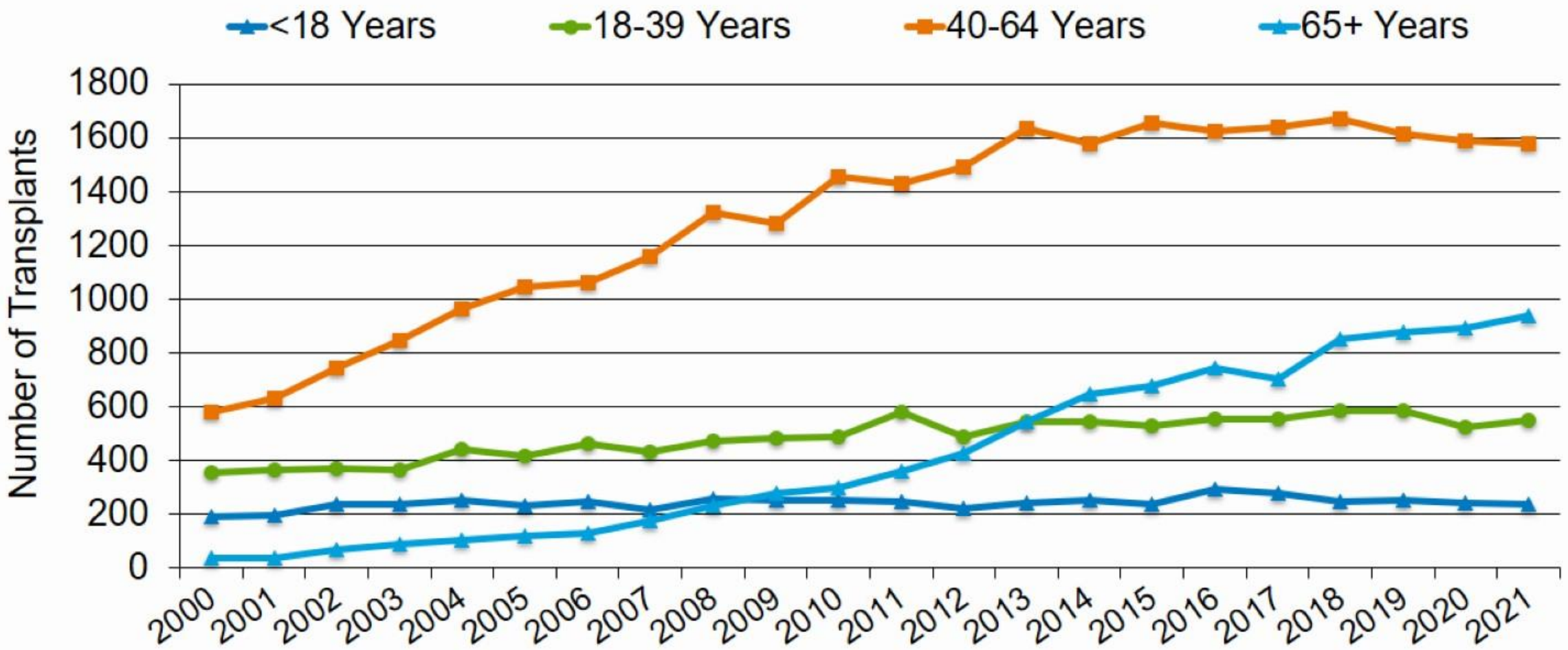
Number of Allogeneic HCTs for Acute Myeloid Leukemia (AML) by Recipient Age in the U.S.



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Bolon YT, Atshan R, Allbee-Johnson M, Estrada-Merly N, Lee SJ. Current use and outcome of hematopoietic stem cell transplantation: CIBMTR summary slides, 2022.

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Previous work

- Relied on payer-based studies
  - Mau et al. (2022) found that 1-year alloHCT utilization for Medicare increased from 12% in 2010 to 20% in 2015

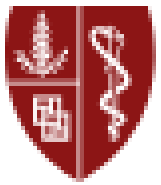
- Limited to smaller datasets
  - Mock et al. (2021) found that alloHCT utilization for patients with AML in Virginia were associated with age, region, Social vulnerability Index, marital status, and payer

Multi-institutional Collaboration

NATIONAL CANCER INSTITUTE
Division of Cancer Epidemiology & Genetics

UCDAVIS HEALTH

CIBMTR®
A RESEARCH COLLABORATION BETWEEN THE MEDICAL COLLEGE OF WISCONSIN AND NMDP



Stanford MEDICINE | Health Care

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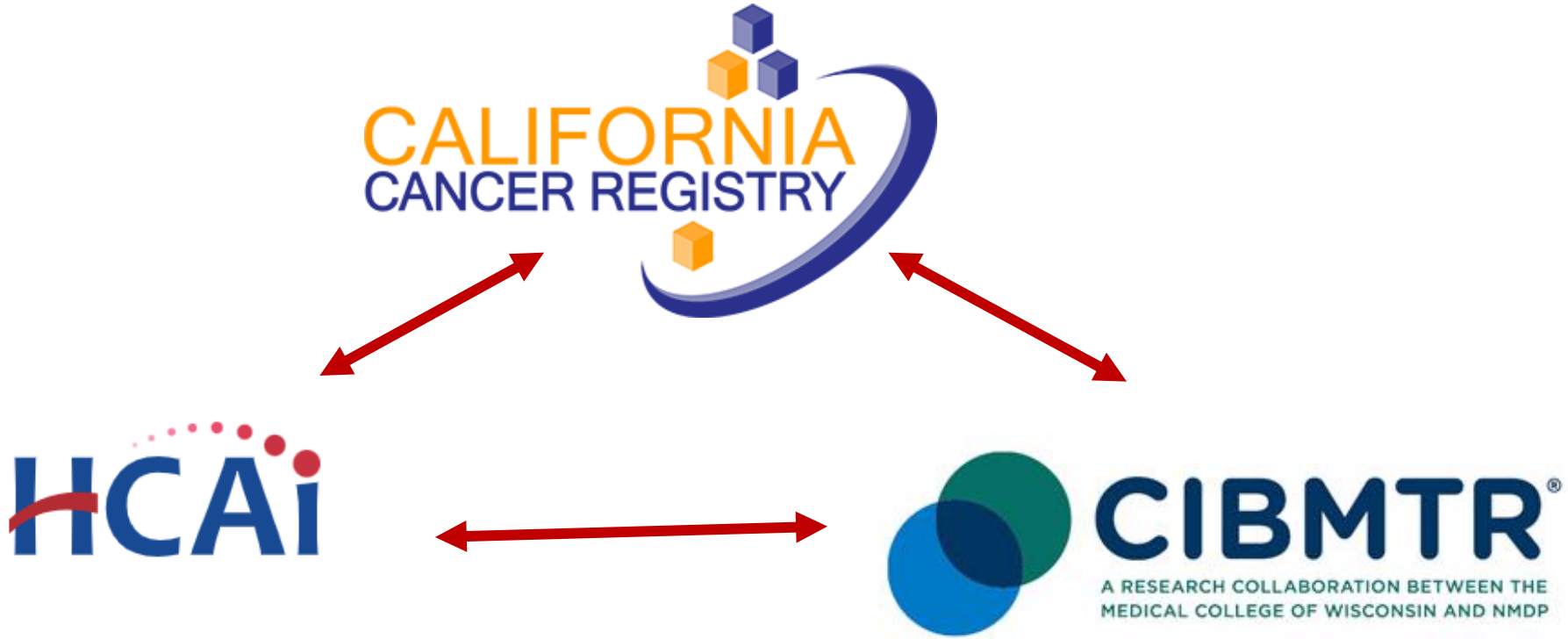
Data Sources

- This study uses a linked dataset:



Keegan et al. Transplantation and Cellular Therapy (2022)

Linkage Goals

- Assess Completeness of outcomes data
- Obtain data not collected by CIBMTR
- Provide comparison groups

AML study aims

1. Examine trends in HCT utilization for three age groups;
   - AYA (15-39 years)
   - Adult (40-64 years)
   - Older adult (65-79 years)
2. Determine sociodemographic factors associated with HCT utilization by age group

Methods

- Cohort :
  - Newly diagnosed with AML between 2001 and 2016
  - Received induction therapy
  - Excluded patients treated with autoHCT
- Analysis
  - 3 separate multivariable Fine-Gray regression models according to age
  - Accounted for competing risk of death

Baseline characteristics by Age Group

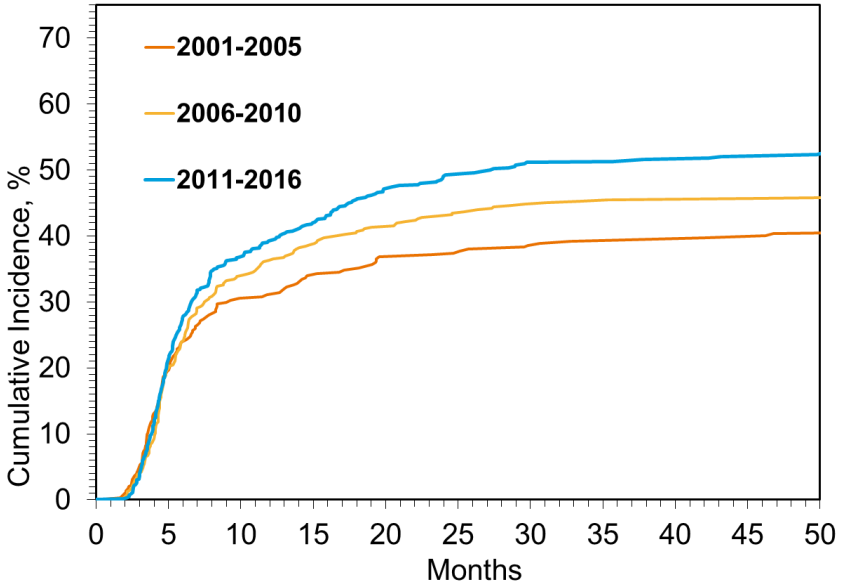
Characteristics	AYA (n=1432)	Adult (n=3678)	Older adult (n=2815)
Age (years)			
Median (SE); IQR	29 (0.19); 12	55 (0.11); 11	71 (0.08); 7
Race, n (%)			
Non-Hispanic White	535 (37.4)	2024 (55)	1874 (66.6)
Non-Hispanic Black	86 (6)	226 (6.1)	111 (3.9)
Hispanic	583 (40.7)	864 (23.5)	454 (16.1)
Asian	210 (14.7)	525 (14.3)	346 (12.3)
Unknown/Other	18 (1.3)	39 (1.1)	30 (1.1)

Characteristics by Age Group – cont.

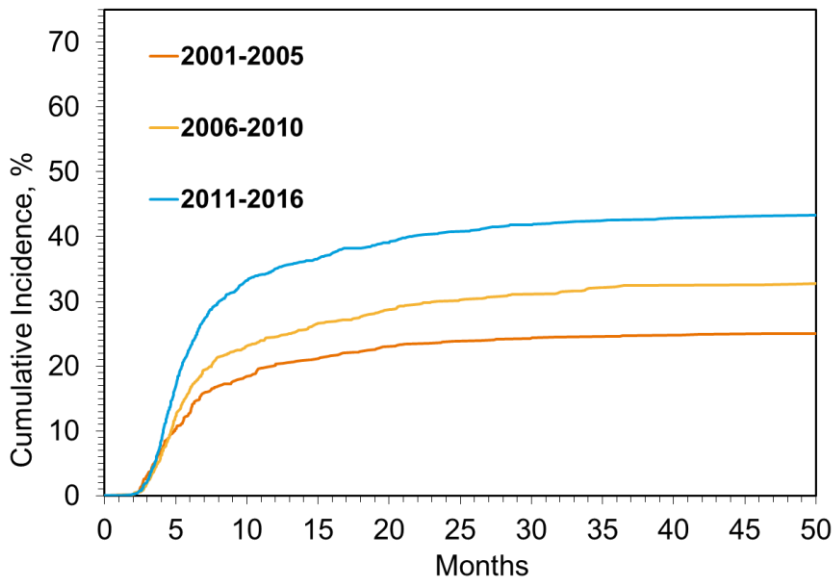
Characteristics	AYA (n=1432)	Adult (n=3678)	Older adult (n=2815)
Insurance category			
Self-pay, not insured	41 (2.9)	94 (2.6)	24 (0.9)
Private	747 (52.2)	2406 (65.4)	779 (27.7)
Medicaid	482 (33.7)	724 (19.7)	119 (4.2)
Medicare	34 (2.4)	257 (7)	1804 (64.1)
Military	31 (2.2)	86 (2.3)	42 (1.5)
Indian/Public Health Services/County, NOS	57 (4)	33 (0.9)	11 (0.4)
Unknown	40 (2.8)	78 (2.1)	36 (1.3)
Distance to HCT (miles)			
<50	1107 (77.3)	2852 (77.5)	2076 (73.7)
50-99	149 (10.4)	405 (11)	400 (14.2)
100+	176 (12.3)	421 (11.4)	339 (12)
Median distance (SE); IQR	22.2 (1.28); 31.3	23.3 (0.8); 32.2	24.3 (1.0); 40

Cumulative incidence of HCT utilization among patients with AML in California, by diagnosis era, 2001-2016, accounting for the competing risk of death

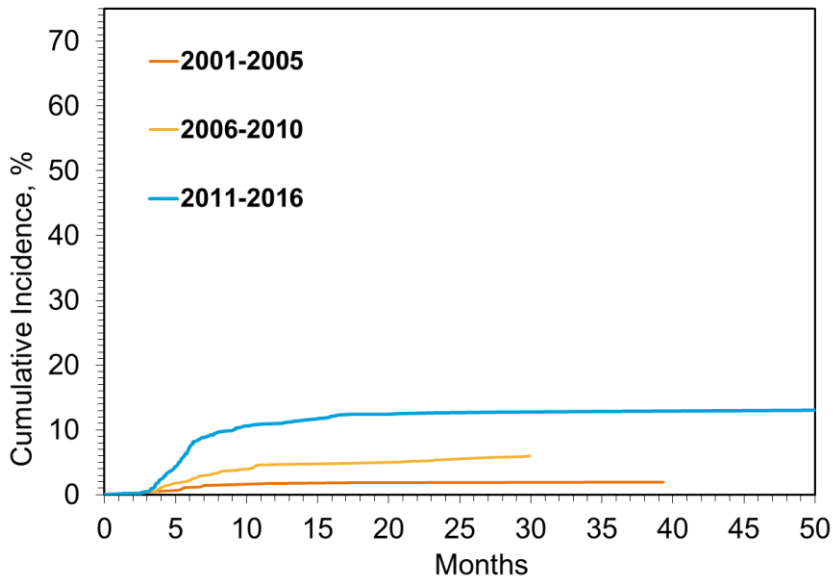
AYA
Age 15-39



Adult
Age 40-64



Older adult
Age 65-79



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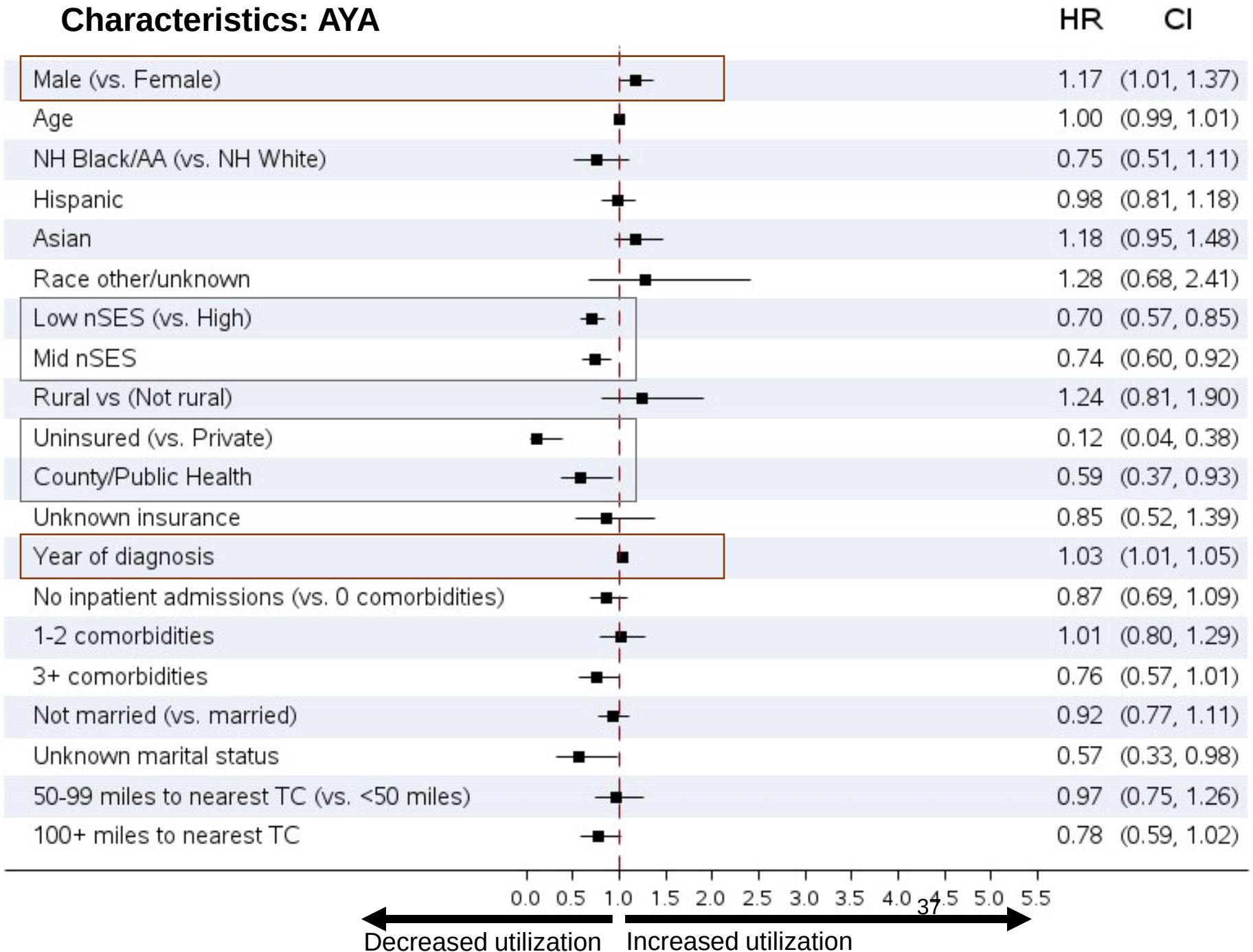
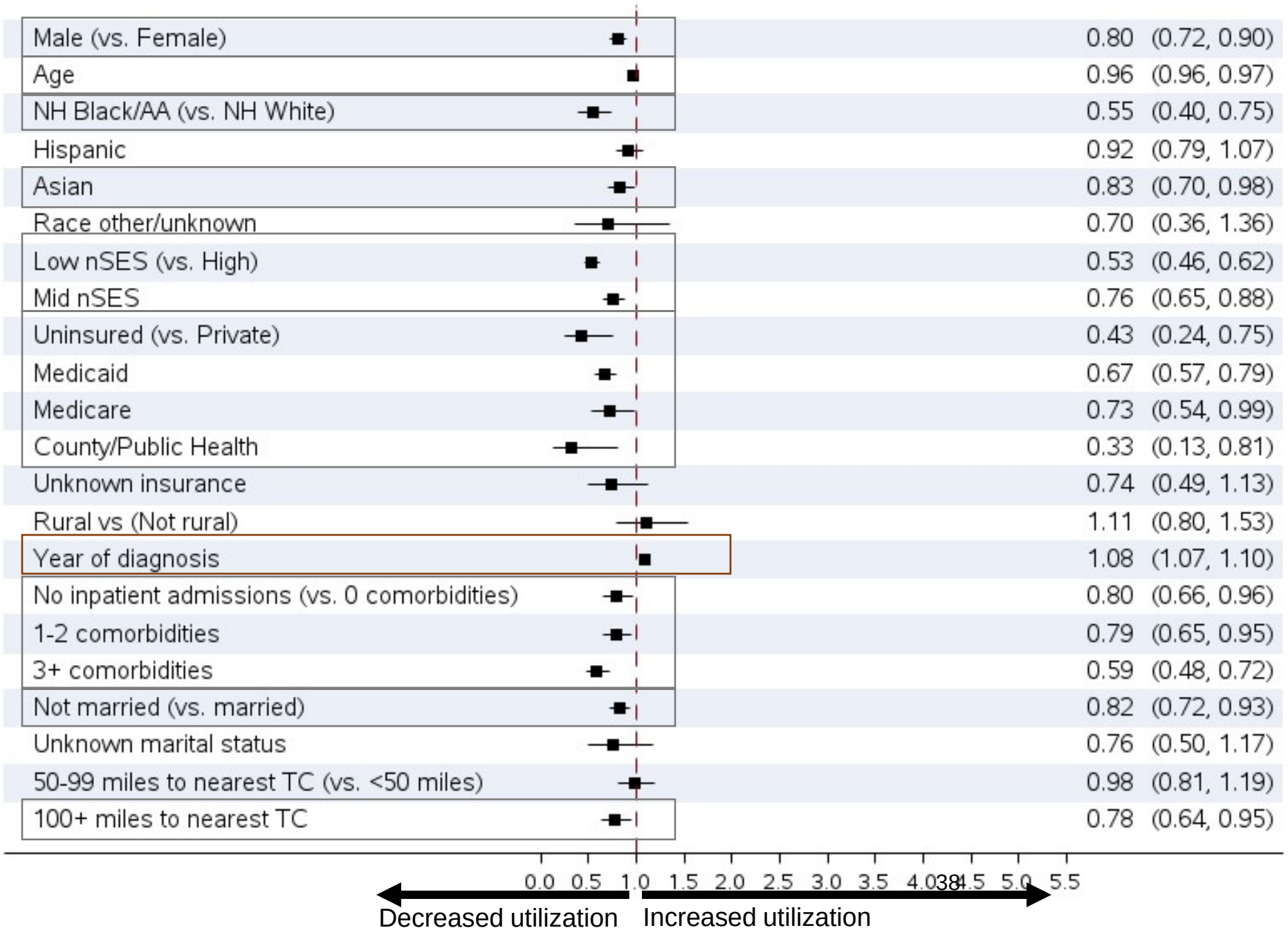
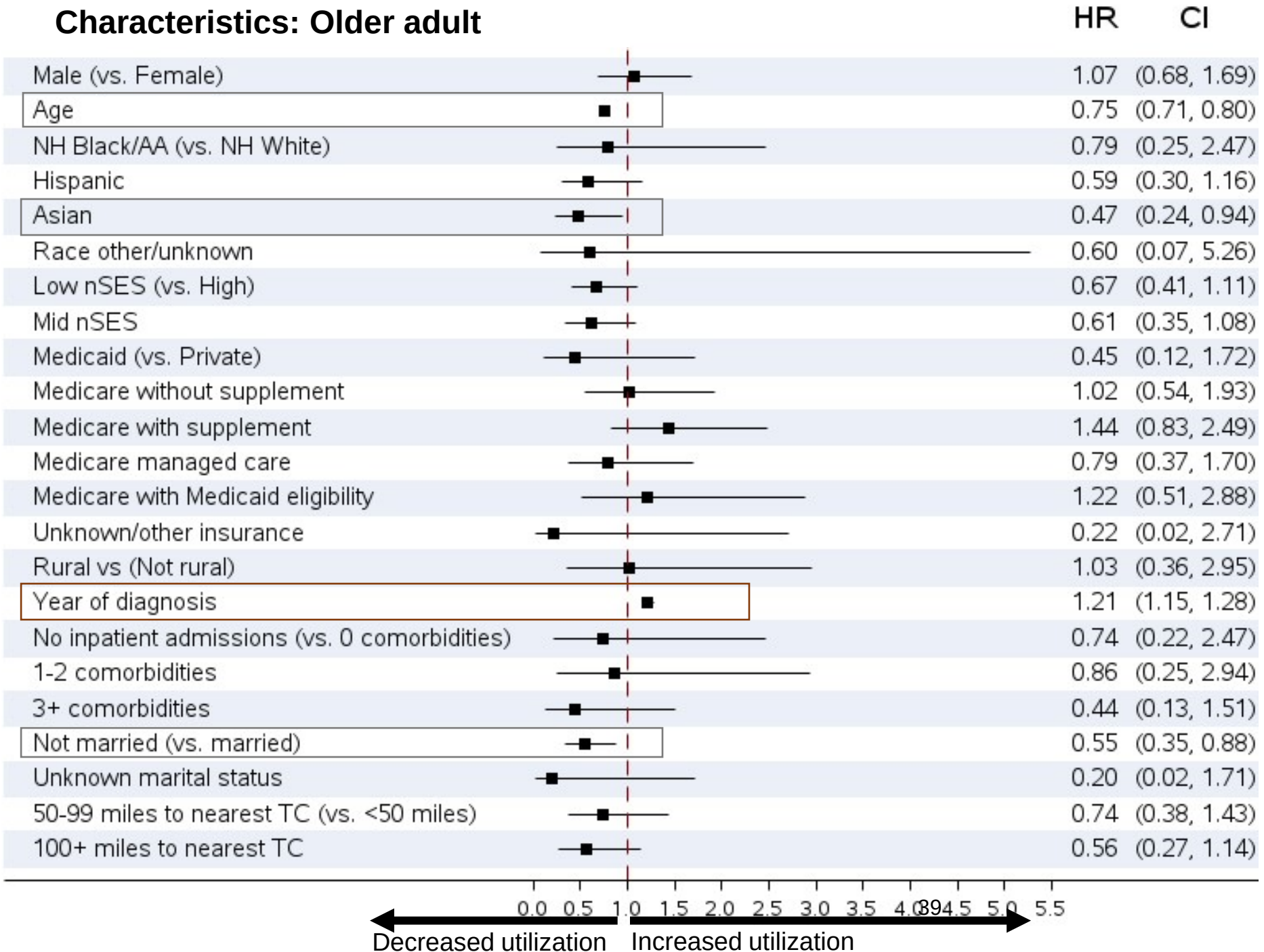
Characteristics: AYA



Characteristics: Adult



Characteristics: Older adult



Limitations

- Lacking key information on initial diagnosis
  - Cytogenetic/molecular characteristics
  - Induction response
  - Referral to HCT
- Proxy data is used
  - Marital Status
  - Census block group and ZIP code
- State of California Only

Conclusions

- HCT utilization among newly diagnosed AML patients in California increased in all age cohorts over time;
  - 13% of older adults received HCT between 2011-2016
- Factors associated with HCT utilization differed by age group:
  - Marital status (adults & older adults)
  - SES and Insurance (AYA & adult patients)
  - Race (Asian and Black adults and Asian older adults)
  - Distance to the nearest transplant center (adults)
- Population-based linkages overcome limitations of payer-based studies

Next Steps

- Future research should focus on:
  - Updating the linkage with newer data
  - Patient diagnosis and physician referral patterns
  - Caregiver and social support
  - Medical deserts
- Collaborations with stakeholders are necessary to further understand, diminish and eliminate barriers to HCT

Thank you

- Study team
  - University of California Davis Comprehensive Cancer Center
  - Stanford University
  - National Cancer Institute, National Institutes of Health
  - Center for International Blood and Marrow Transplant Research/NMDP
- Contact: Cmeyer@nmdp.org

ASTCT-NMDP ACCESS Initiative

Database linkage examples for health equity: Medicare and AML

Jaime Preussler

NMDP, CIBMTR

ACCESS Meeting, Washington DC

July 24, 2024

Equal Outcomes for All

Patient

- Age
- Sex
- Race
- Comorbidities
- U.S. Census region
- Socioeconomic status

Physician

- Years since medical school graduation
- Sex
- Specialty

Hospital

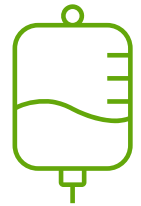
- Overall hospital rating
- Geography (rural/urban)
- Ownership type
- Chemotherapy service

Access to treatment

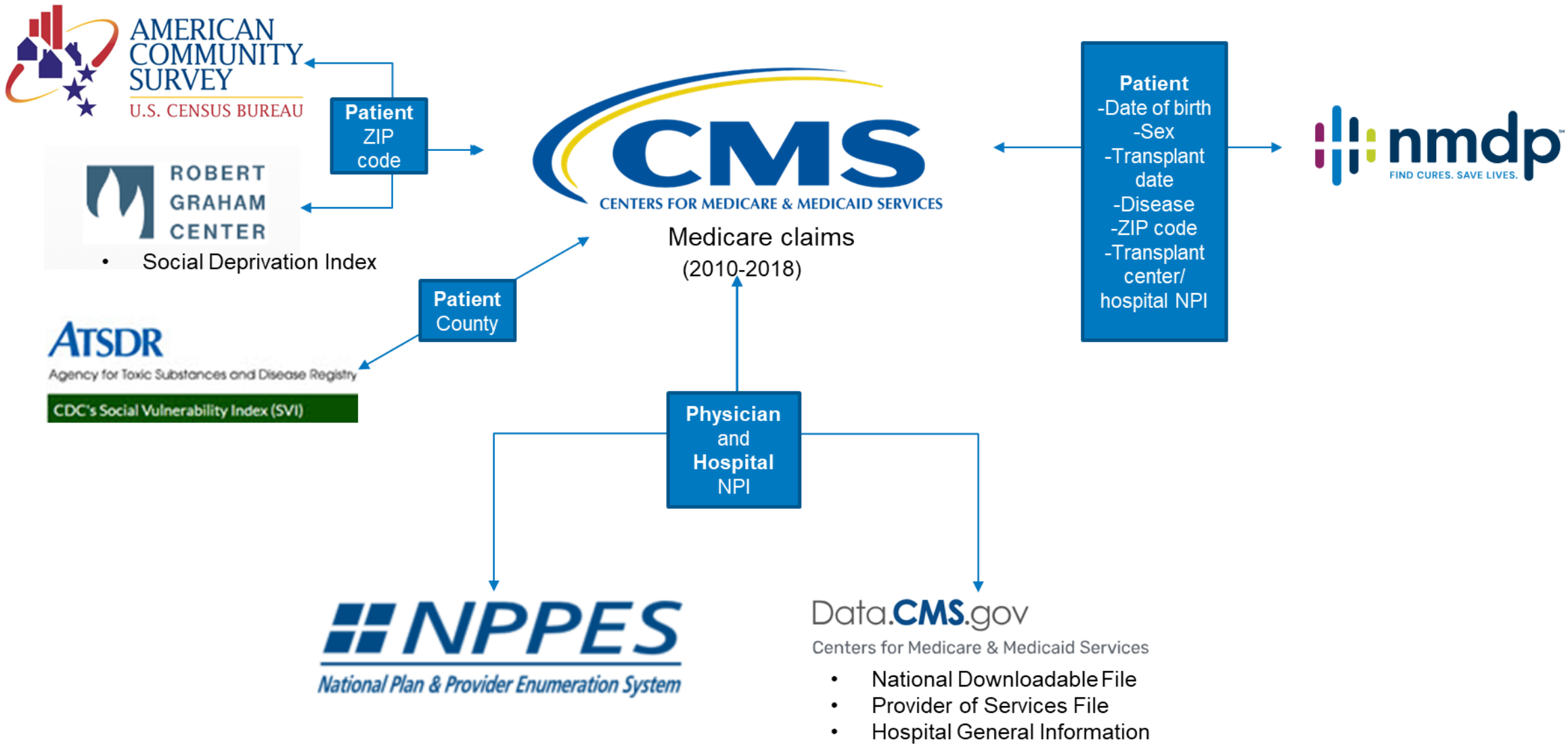
No active treatment/ supportive care

Chemotherapy without donor search

Chemotherapy with donor search (search)



Allogeneic hematopoietic cell transplant (alloHCT)



NPI: National Provider Identifier

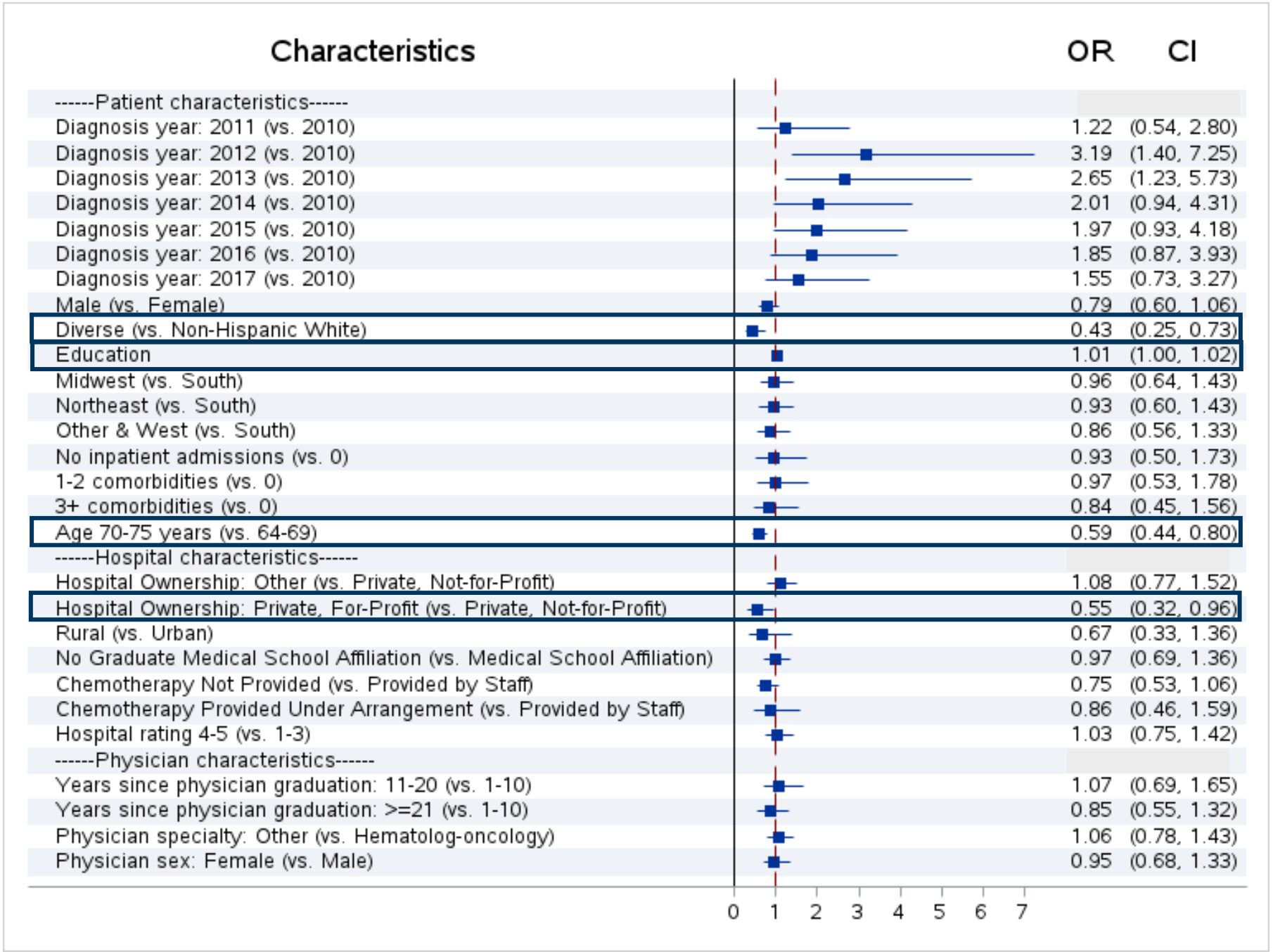
Methods

- Population:
  - Age 65-75 diagnosed with AML between 2010 and 2017
  - Enrolled in fee-for-service (Part A and B) Medicare for at least one year after diagnosis or until death
- Analysis:
  - Hierarchical Logistic Regression Model
    - Accounts for nesting within each hospital, with hospital as the random effect
    - Patient, hospital, and physician characteristics as fixed effects

Characteristics (at diagnosis)

Characteristics	HCT (n=487)	Chemotherapy with NMDP donor search (n=437)
Patient Age Group (years)		
65-69	321 (65.9)	244 (55.8)
70-75	166 (34.1)	193 (44.2)
Chemotherapy Provision at Hospital		
Not provided	133 (27.3)	143 (32.7)
Provided by staff	325 (66.7)	266 (60.9)
Provided under arrangement	29 (6.0)	28 (6.4)
Physician Specialty		
Hematology-Oncology	281 (57.7)	262 (60.0)
All other	206 (42.3)	175 (40.0)

Results


Characteristics
OR
CI
------Patient characteristics------
Diagnosis year: 2011 (vs. 2010) 1.22 (0.54, 2.80)
Diagnosis year: 2012 (vs. 2010) 3.19 (1.40, 7.25)
Diagnosis year: 2013 (vs. 2010) 2.65 (1.23, 5.73)
Diagnosis year: 2014 (vs. 2010) 2.01 (0.94, 4.31)
Diagnosis year: 2015 (vs. 2010) 1.97 (0.93, 4.18)
Diagnosis year: 2016 (vs. 2010) 1.85 (0.87, 3.93)
Diagnosis year: 2017 (vs. 2010) 1.55 (0.73, 3.27)
Male (vs. Female) 0.79 (0.60, 1.06)
Diverse (vs. Non-Hispanic White) 0.43 (0.25, 0.73)
Education 1.01 (1.00, 1.02)
Midwest (vs. South) 0.96 (0.64, 1.43)
Northeast (vs. South) 0.93 (0.60, 1.43)
Other & West (vs. South) 0.86 (0.56, 1.33)
No inpatient admissions (vs. 0) 0.93 (0.50, 1.73)
1-2 comorbidities (vs. 0) 0.97 (0.53, 1.78)
3+ comorbidities (vs. 0) 0.84 (0.45, 1.56)
Age 70-75 years (vs. 64-69) 0.59 (0.44, 0.80)
------Hospital characteristics------
Hospital Ownership: Other (vs. Private, Not-for-Profit) 1.08 (0.77, 1.52)
Hospital Ownership: Private, For-Profit (vs. Private, Not-for-Profit) 0.55 (0.32, 0.96)
Rural (vs. Urban) 0.67 (0.33, 1.36)
No Graduate Medical School Affiliation (vs. Medical School Affiliation) 0.97 (0.69, 1.36)
Chemotherapy Not Provided (vs. Provided by Staff) 0.75 (0.53, 1.06)
Chemotherapy Provided Under Arrangement (vs. Provided by Staff) 0.86 (0.46, 1.59)
Hospital rating 4-5 (vs. 1-3) 1.03 (0.75, 1.42)
------Physician characteristics------
Years since physician graduation: 11-20 (vs. 1-10) 1.07 (0.69, 1.65)
Years since physician graduation: >=21 (vs. 1-10) 0.85 (0.55, 1.32)
Physician specialty: Other (vs. Hematolog-oncology) 1.06 (0.78, 1.43)
Physician sex: Female (vs. Male) 0.95 (0.68, 1.33)
0 1 2 3 4 5 6 7

Limitations

- Claims data are collected for billing; not for research
- NMDP donor search only
- Medicare fee-for-service only
- Patient socioeconomic factors identified at the ZIP code or county level, not the individual level

Conclusions

- Patient characteristics and hospital ownership were associated with receipt of alloHCT
- Donor availability may contribute to the decreased odds of alloHCT by race/ethnicity, but studies to increase HLA-mismatched unrelated alloHCT are helping to decrease this barrier
- Reasons patients don’t proceed to alloHCT are complex and multifactorial
- Linked datasets allow for robust research questions

ASTCT-NMDP ACCESS Initiative

Advancing Equitable Healthcare Through Community-centered Data-driven Research

Salvatore Alesci, MD, PhD

SVP, Center for Clinical & Social Research

NMQF

2024 Summer Workshop / Washington, DC

July 24, 2024

Equal Outcomes for All

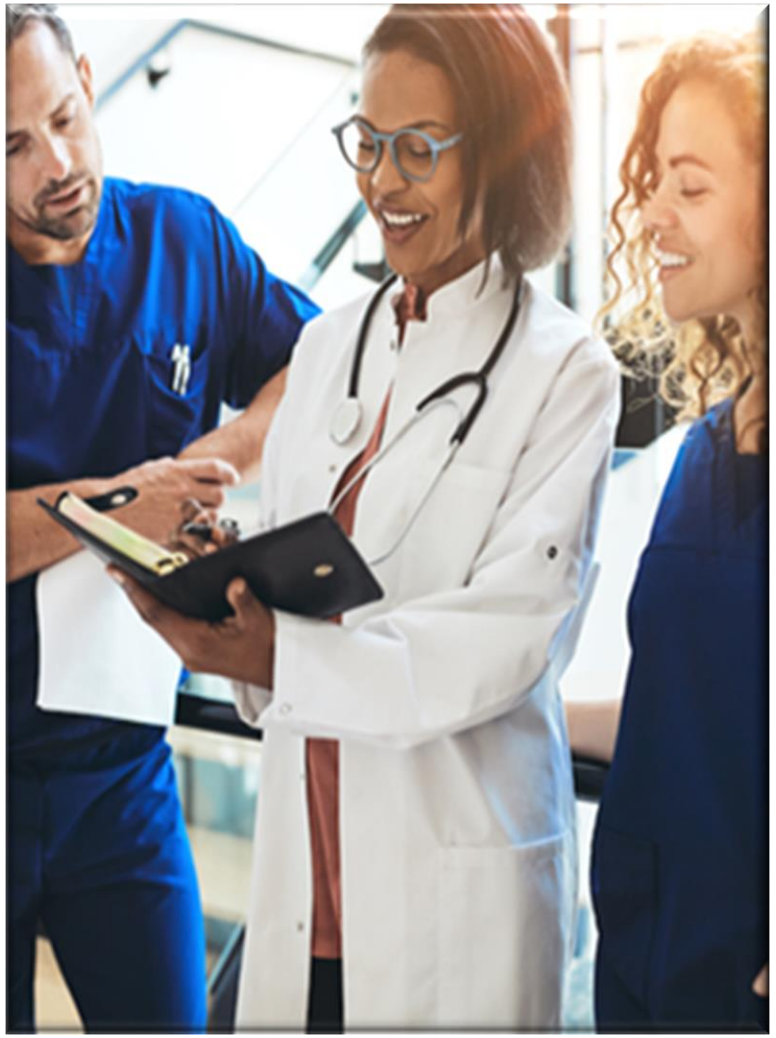
Founded in 1998, National Minority Quality Forum (NMQF) is a United States-based, health care research, education and advocacy organization whose mission is to reduce patient risk and advance health equity by assuring optimal care for all.

VISION

To achieve a just and fair American health system that ensures equitable access to optimal care.

NMQF Centers

- Offices of the President
  - Administrative Services and Operations
  - Office of Grants Management
- The Center for Health Information Strategy and Services
  - Our private cloud data warehouse, consisting of 5 billion patient records, advances health equity through evidence-based, data-driven methods.
- The Center for Clinical and Social Research
  - Advances equitable healthcare through rigorous scientific exploration, enabling data-driven generation of deep insights on the intersection between clinical and social determinants of health.
- The Center For Sustainable Health care Quality and Equity
  - Promotes healthy communities by working with health systems, faith leaders, barbers/stylists and pharmacists to deliver community interventions.
- The Center for Public Policy
  - Provides leadership to advance changes to policies that impact the health of minoritized populations.
- The Center for Communications and Public Affairs
  - Promotes health equity through patient education, health communication, health advocacy, stakeholder partnerships, coalition building and community events that educate on a variety of health topics.



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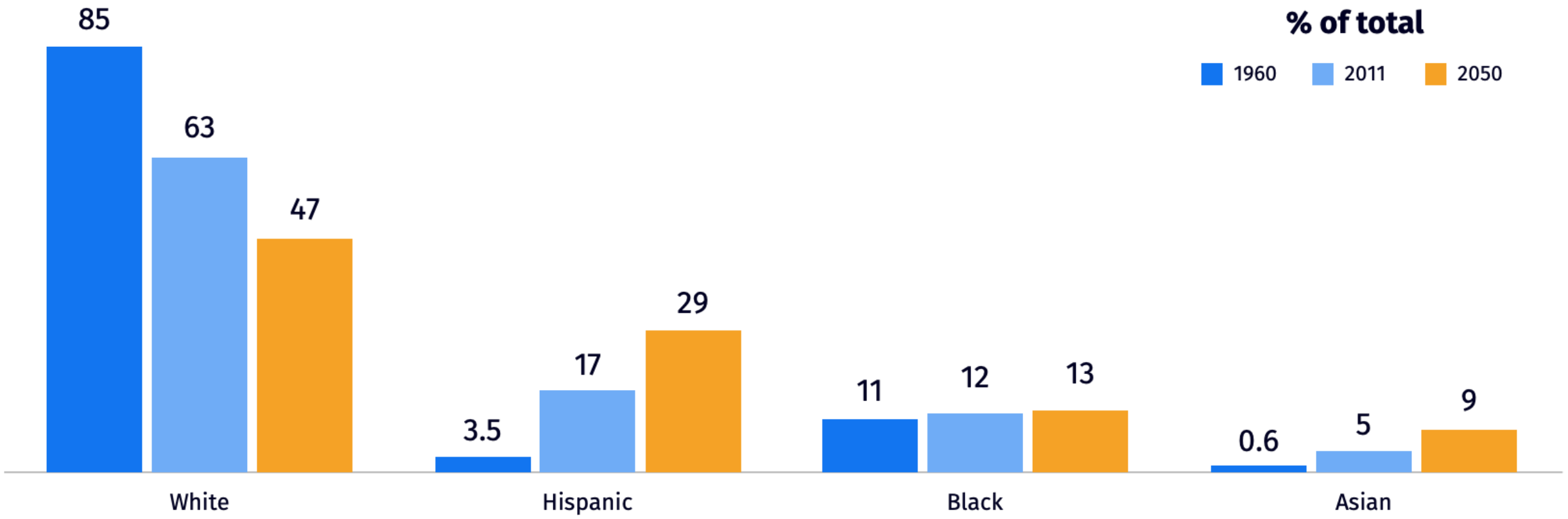
Population by Race and Ethnicity, Actual and projected, 1960, 2011 and 2050



Note: All races are non-Hispanic; American Indian/Alaska Native not shown. Projections for 2050 indicated by light green bars.

Source: Passel, Jeffrey and D'Vera Cohn. 2008. "U.S. Population Projections: 2—5-2050." Washington, D.C.: Pew Hispanic Center, February; Census Bureau 2011 population estimates.

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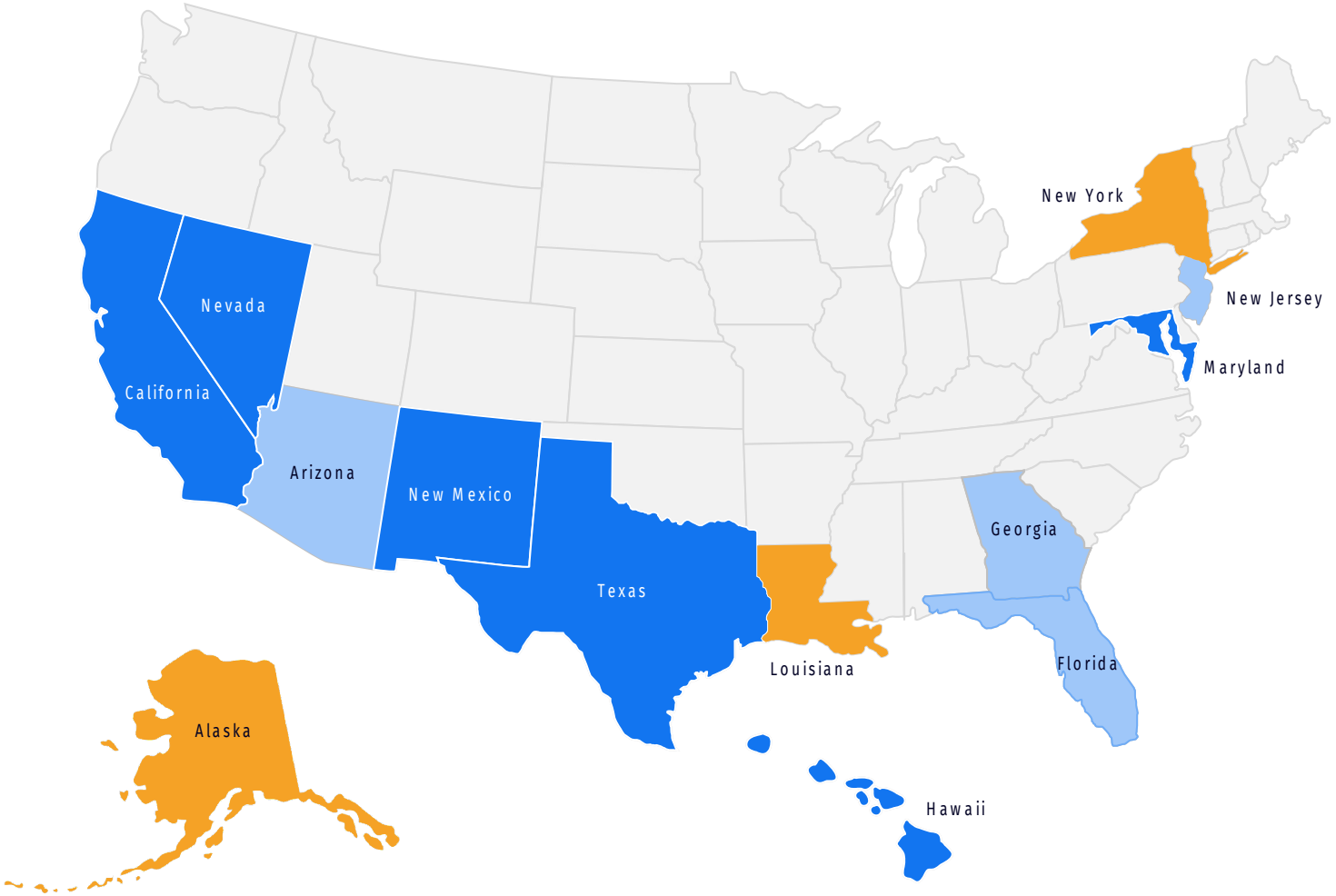
The Emerging Consumer Demand for Equitable Healthcare



- Existing Majority Minority States
- Will Turn Majority Minority in 2020s
- Will turn Majority Minority in 2030s

Currently in **18 states** the minority population is **40% or higher**.

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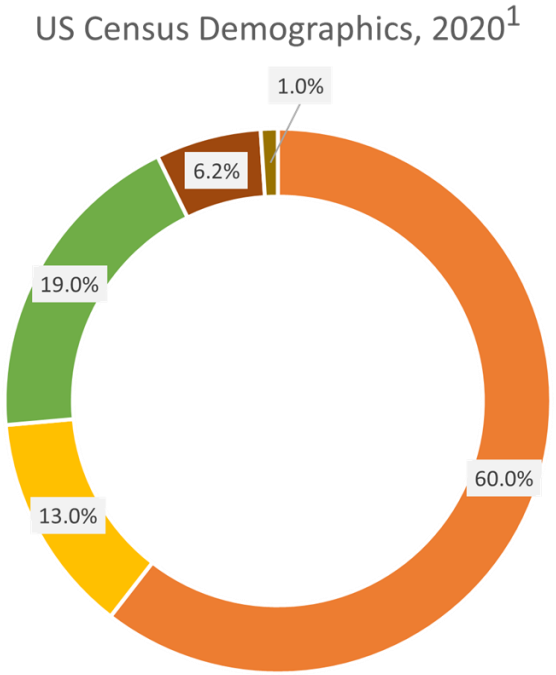
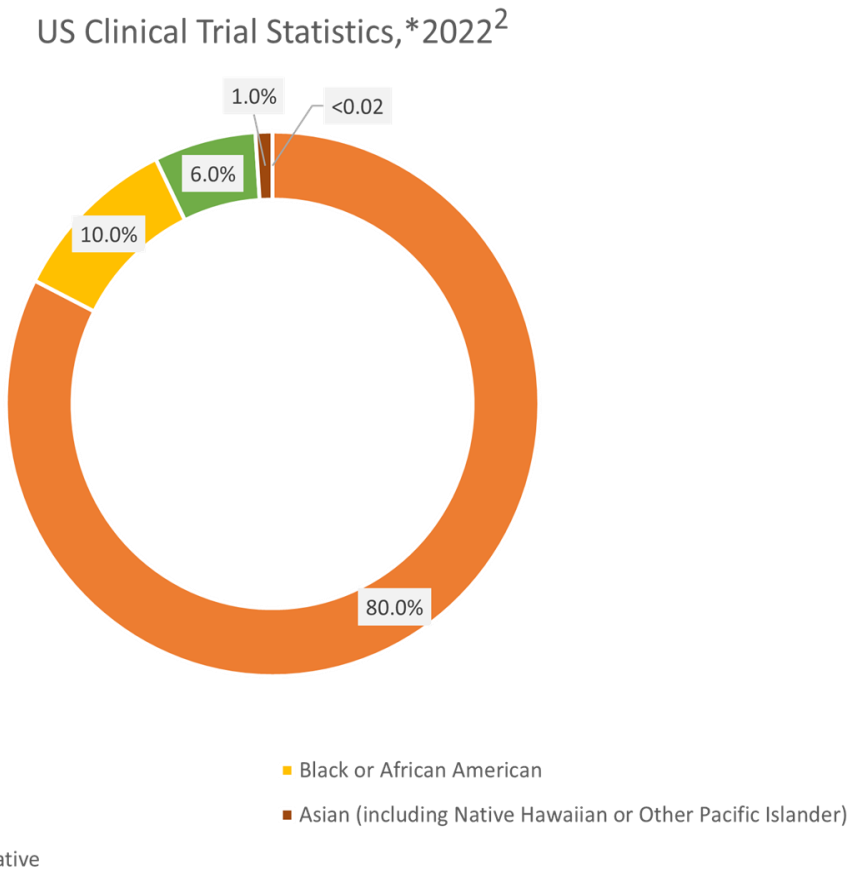
US Demographics *vs.* Clinical Trial Participation





** Note: Of the 20,692 US-based trials represented, only 43% (8,898) reported any race/ethnicity data.*

1. *US Census, Quickfacts*
2. *E.B. Turner et al., "Race/Ethnicity Reporting and Representation in US Clinical Trials: A Cohort Study," The Lancet Regional Health: Americas 8.100252 (2022).*

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NMQF Data Lake

5 Billion Patient Records

NMQF has developed a comprehensive database comprised of over 5 billion patient records, which it uses to define disease prevalence, costs and outcomes for demographic subpopulations by geography (zip code, state, county, congressional and state legislative districts).

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NMQF Data Lake (cont'd)

48%

All Americans are Insured by either Medicare or Medicaid

29%

of (97 million) of Americans are currently enrolled in Medicaid

36%

African Americans are currently enrolled in Medicaid

32%

Hispanics are currently enrolled in Medicaid

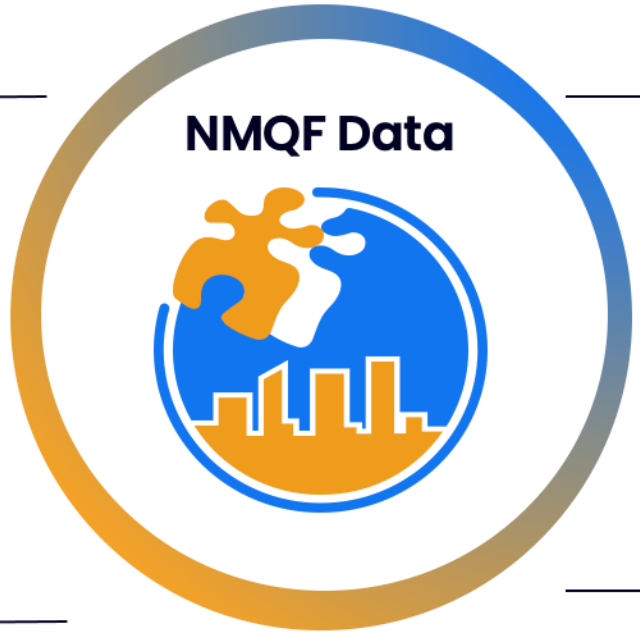
17%

Whites are currently enrolled in Medicaid

23%

Americans aged 19-64 are currently enrolled in Medicaid

NMQF Data Lake (cont'd)



Patient Identification and Location of Care

Provider Identification and Visits

- Physician
- Pharmacy Rx
- ED Visits
- Hospitalizations

Patient Demographic Characteristics

- Geography
- Gender
- Race /Ethnicity
- Age

Diagnosis Data

- ICD codes
- Common comorbidities in summary file

Formulary Plans

- Health plan
- Total costs
- Costs per type of care
- Out of pocket costs

Treatment Data

- Rx Medications
- Rx Fill Locations
- Rx Fill Rates

Social Drivers of Health Data

- Income
- Education
- Environmental quality
- Community resources such as hospitals/pharmacies

NMQF Data Analytics Approaches

COHORT AND PATIENT DATA ANALYTICS

In-depth insights into the prevalence of chronic conditions, comorbidities, healthcare utilization, and care gaps within specific patient populations | Geographic variations at the zip code or county level to portray patients' overall health, the prevalence of multi-chronic condition beneficiaries, as well as cost and utilization patterns.

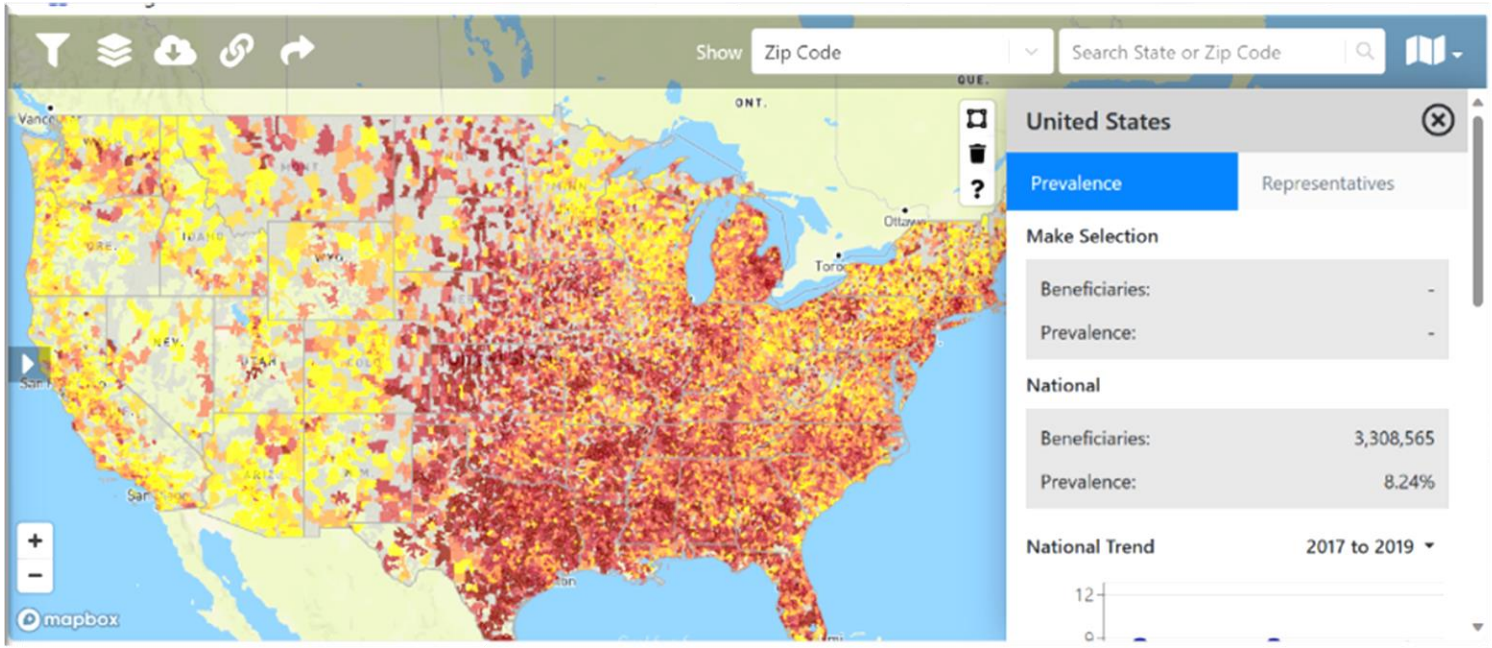
PHARMACY DATA ANALYTICS

Our pharmacy data analytics services range from evaluating drug access and prescribing patterns to understanding patient risk profiles. We also focus on medication adherence and compliance, offering actionable insights for healthcare providers and policymakers.

PROVIDER DATA ANALYTICS

We employ provider data analytics to establish connections between patients and their healthcare providers, including physicians and care settings. This enables us to analyze healthcare utilization by specialty and assess its impact on the overall performance of healthcare networks.

NMQF Indices



Cancer

- Breast Cancer
- Colorectal Cancer
- Endometrial Cancer
- Lung Cancer
- Prostate Cancer
- Skin Cancer

Cardiometabolic

* Diabetes
* Heart Failure
* Atrial Fibrillation
* Chronic Kidney Disease
* Chronic Gout

And more!

1. Easy-to-navigate User Interface ✓
2. Claims data from CMS ✓
3. Clinicaltrials.gov site overlays ✓
4. Demographic breakdowns ✓
5. Utilization Statistics ✓
6. Congressional District Reports ✓

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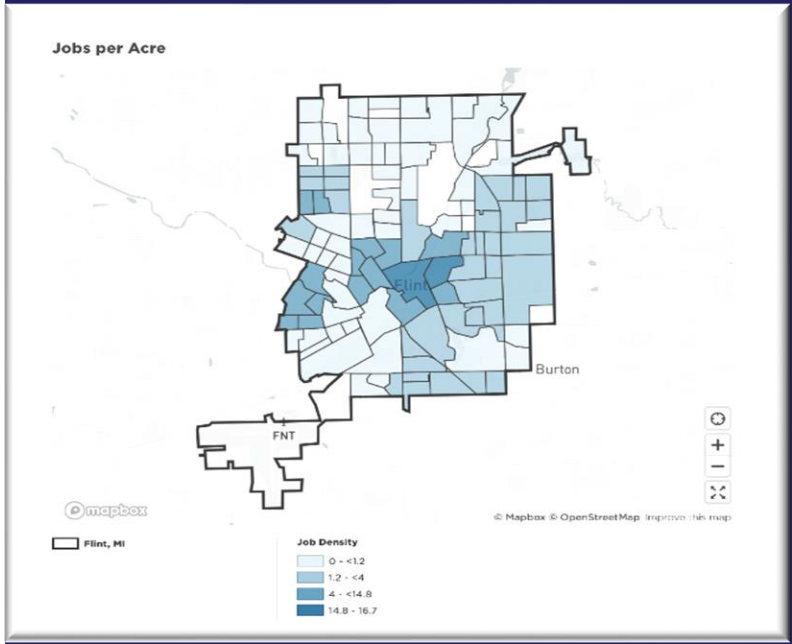
Addition of Social Determinants of Health (SDOH) Data Library

Data sourced from a multitude of federal and state data warehouses, including the US Census Bureau, CDC, FDA, etc.



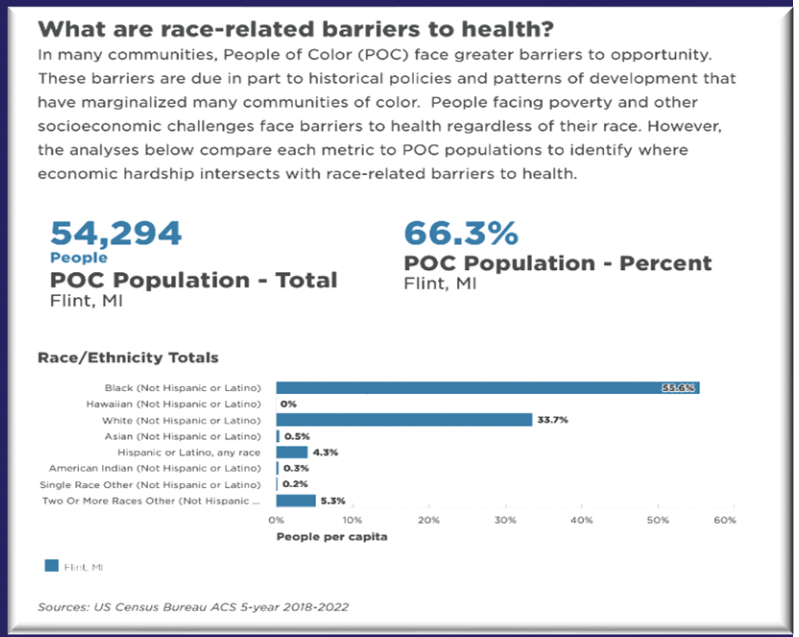
The mapping feature allows to visualize social conditions that drive health

Vulnerable Populations

Flint, MI	People
Population Age Under 5	5,506
Population Age 65 and Over	11,082
Population Living with a Disability	19,332
Educational Attainment: Less than 9th Grade	1,937
Ratio of Income to Poverty Level: 150% and Under - Very Low Income Population	38,284
Ability to Speak English - Less Than Very Well	1,001

Sources: US Census Bureau ACS 5-year 2018-2022

The customized report generator allows to pinpoint the most important factors driving inequities in communities



The custom dashboards can be generated to better inform our initiatives and work on the ground

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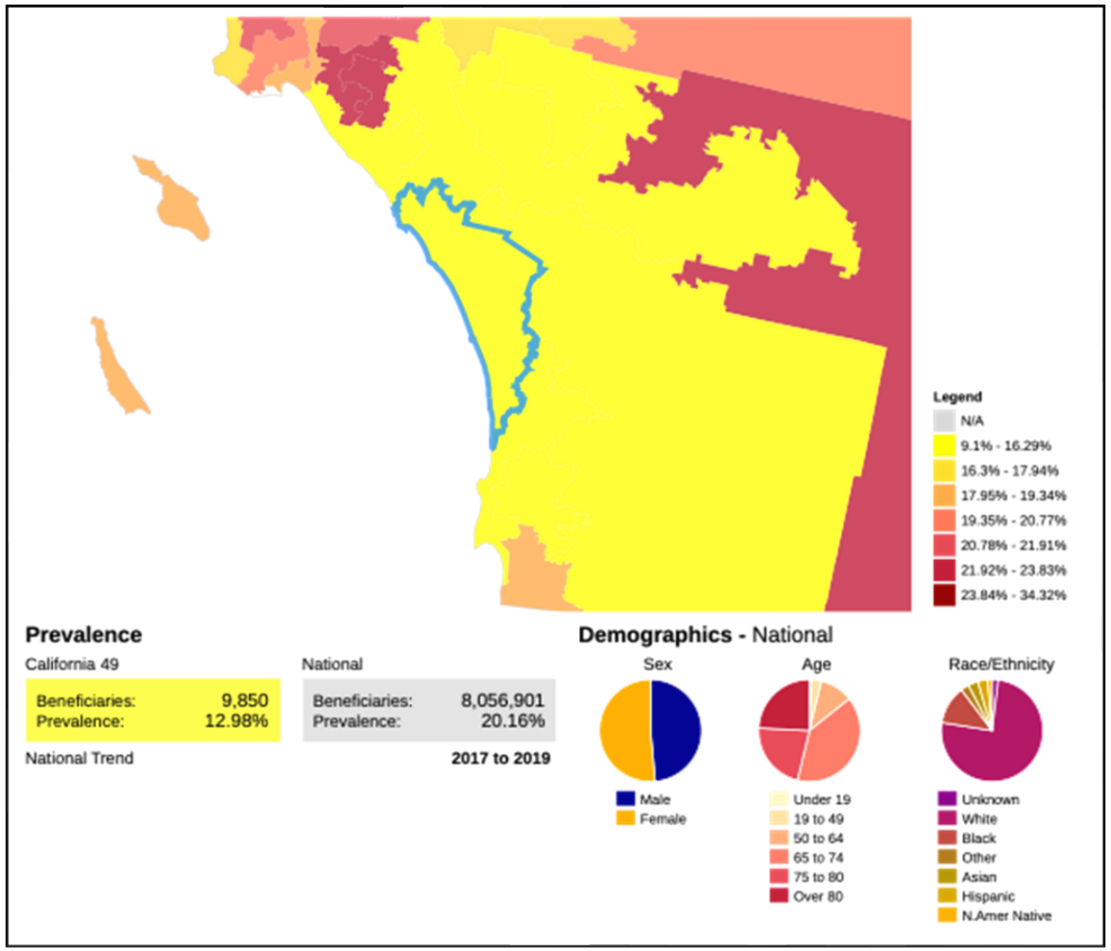
Diabetes Among 2019 Medicare FFS Beneficiaries Residing in the 49th US Congressional District in CA



Demographic	Beneficiary Prevalence	Beneficiary Count
Overall	12.98%	9,850
Gender		
Male	52%	5,103
Female	48%	4,747
Race/Ethnicity		
Unknown	2%	178
White	80%	7,857
Black	3%	295
Other	6%	564
Asian	5%	514
Hispanic	4%	421
North American Native	0%	21
Age		
Under 19	N/A	N/A
19 to 49	1%	146
50 to 64	5%	505
65 to 74	39%	3,842
75 to 80	24%	2,402
Over 80	N/A	N/A

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Diabetes Among 2019 Medicare FFS Beneficiaries Residing in the 49th US Congressional District in CA

Prevalence and Percent of all Cost

Total Number of Medicare FFS Beneficiaries	Total Medicare FFS Costs	Total Number of FFS Beneficiaries Living with Diabetes	Diabetes Prevalence of Medicare FFS	Total Diabetes Beneficiaries Costs	Diabetes as a Percentage of Medicare FFS Costs
75,913	$710,721,882	9,850	12.98%	$191,138,972	27%

2019 Diabetes Medicare FFS Fees in 49th of California by Race and Ethnicity

Hospitalizations

Beneficiaries	Number of FFS Beneficiaries	Percent of FFS Beneficiaries	Number of Inpatient Stays	Percent Inpatient Stays	Inpatient Costs	Percent of Inpatient Costs	Average Cost Per Beneficiary
Unknown	178	2%	46	1%	$1,044,292	2%	$5,867
White	7,857	80%	3,321	81%	$51,864,787	81%	$6,601
Black	295	3%	152	4%	$1,944,764	3%	$6,592
Other	564	6%	163	4%	$2,683,923	4%	$4,759
Asian	514	5%	191	5%	$3,020,339	5%	$5,876
Hispanic	421	4%	209	5%	$3,495,971	5%	$8,304
North American Native	21	0%	6	0%	$52,283	0%	$2,490
Totals	9,850		4,088		$64,106,359		

ER Visits

Beneficiaries	Number of FFS Beneficiaries	Percent of FFS Beneficiaries	Number of ER Visits	Percent ER Visits	ER Costs	Percent of ER Costs	Average Cost Per Beneficiary
Unknown	178	2%	54	1%	$434,407	1%	$2,440
White	7,857	80%	3,848	78%	$21,354,653	69%	$2,718
Black	295	3%	227	5%	$1,704,502	6%	$5,778
Other	564	6%	183	4%	$1,937,671	6%	$3,436
Asian	514	5%	230	5%	$1,858,306	6%	$3,615
Hispanic	421	4%	298	6%	$3,482,248	11%	$8,271
North American Native	21	0%	64	1%	$115,492	0%	$5,500
Totals	9,850		4,904		$30,887,279		

2019 Diabetes Medicare FFS Fees in 49th of California by Race and Ethnicity

Death Rate

Beneficiaries	Number of FFS Beneficiaries	Percent of FFS Beneficiaries	Number of Deaths	Percent Deaths
Unknown	178	2%	4	1%
White	7,857	80%	478	86%
Black	295	3%	14	3%
Other	564	6%	17	3%
Asian	514	5%	19	3%
Hispanic	421	4%	20	4%
North American Native	21	0%	2	0%
Totals	9,850		554	

Readmission Rate

Beneficiaries	Number of FFS Beneficiaries	Percent of FFS Beneficiaries	Readmission Rate	Percent Readmissions
Unknown	178	2%	9	1%
White	7,857	80%	587	79%
Black	295	3%	33	4%
Other	564	6%	33	4%
Asian	514	5%	30	4%
Hispanic	421	4%	49	7%
North American Native	21	0%	1	0%
Totals	9,850		742	

Costs

Beneficiaries	Number of FFS Beneficiaries	Percent of FFS Beneficiaries	Total Medicare FFS Costs of FFS Beneficiaries	Percent Medicare FFS Costs
Unknown	178	2%	$2,885,073	2%
White	7,857	80%	$153,663,631	80%
Black	295	3%	$6,308,997	3%
Other	564	6%	$8,762,773	5%
Asian	514	5%	$9,108,206	5%
Hispanic	421	4%	$10,128,728	5%
North American Native	21	0%	$281,562	0%
Totals	9,850		$191,138,970	

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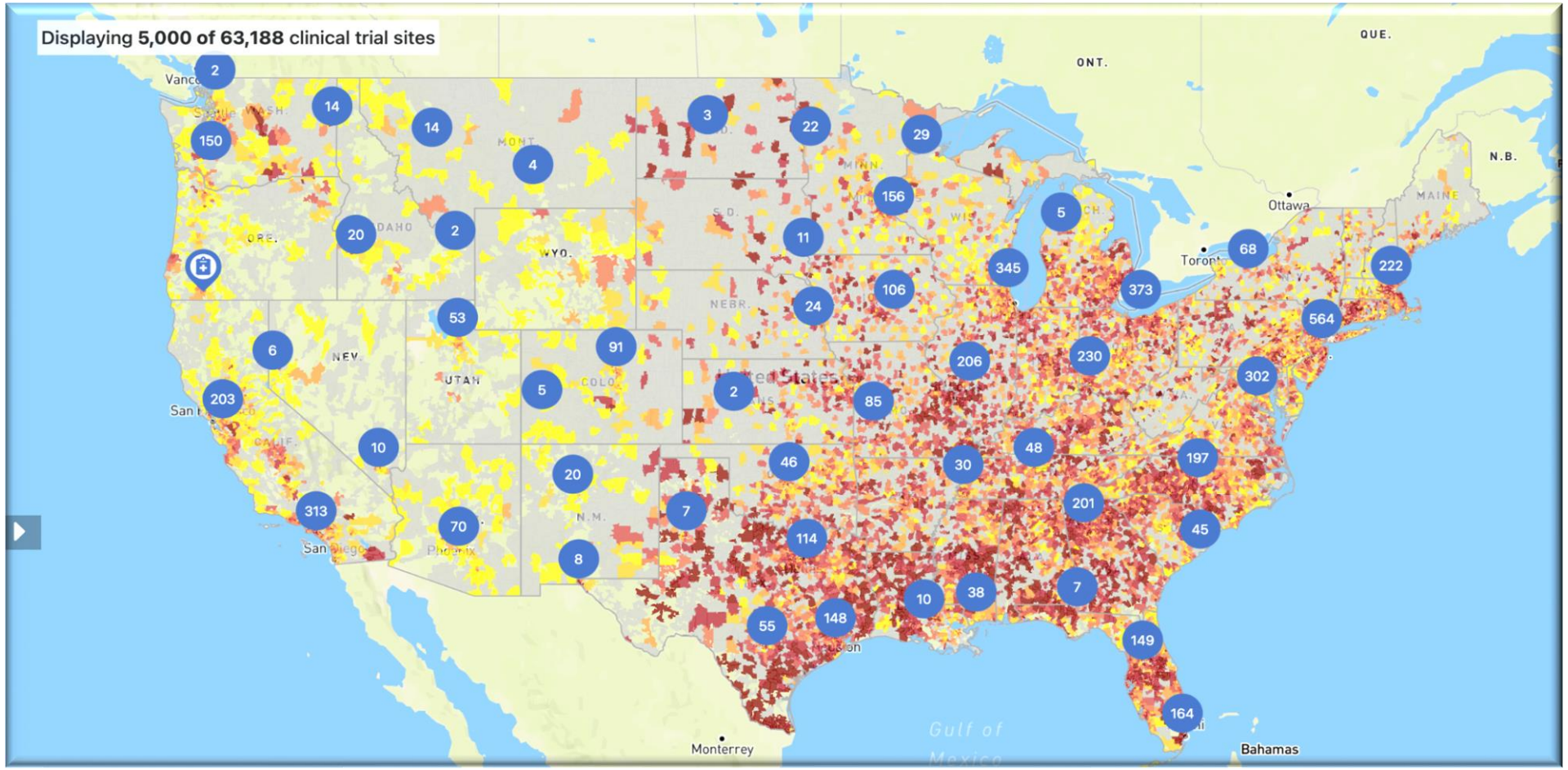
Alzheimer's Disease (AD) Among Beneficiaries Enrolled in 2020 Medicare FFS



High prevalence in the southern US when analyzing state-level claims in Medicare FFS, 2020

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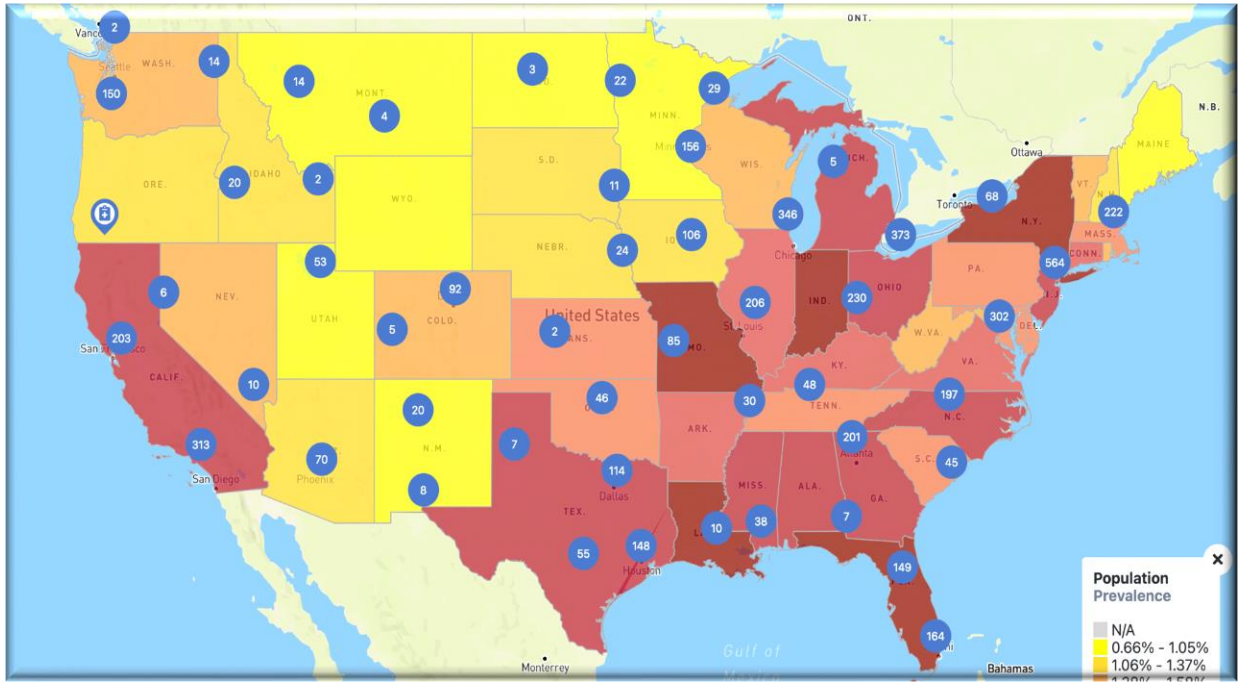
AD Among Minoritized Beneficiaries Enrolled in 2020 Medicare FFS



Prevalence by Zip Code

Zip Code	State	Patient Population	Patient Count	Prevalence
07848	New Jersey	100	52	52%
38036	Tennessee	39	11	28.21%
36652	Alabama	60	12	20%
07821	New Jersey	66	12	18.18%
32440	Florida	114	19	16.67%
48081	Michigan	302	46	15.23%
48072	Michigan	448	67	14.96%
62232	Illinois	90	13	14.44%
07648	New Jersey	188	27	14.36%
32424	Florida	108	15	13.89%
31780	Georgia	80	11	13.75%
78384	Texas	112	15	13.39%
85929	Arizona	113	15	13.27%
33174	Florida	699	83	11.87%
33166	Florida	611	72	11.78%
33128	Florida	290	34	11.72%
33010	Florida	1,169	136	11.63%

When analyzing data by state, we see high prevalence of Alzheimer's among minoritized beneficiaries in 2020 Medicare FFS, especially in Louisiana, Missouri, Indiana, New York, Florida and California

When analyzing data by five digit zip code, we see high prevalence among 2020 Medicare FFS beneficiaries in several states, especially in New Jersey, Michigan, and Florida.

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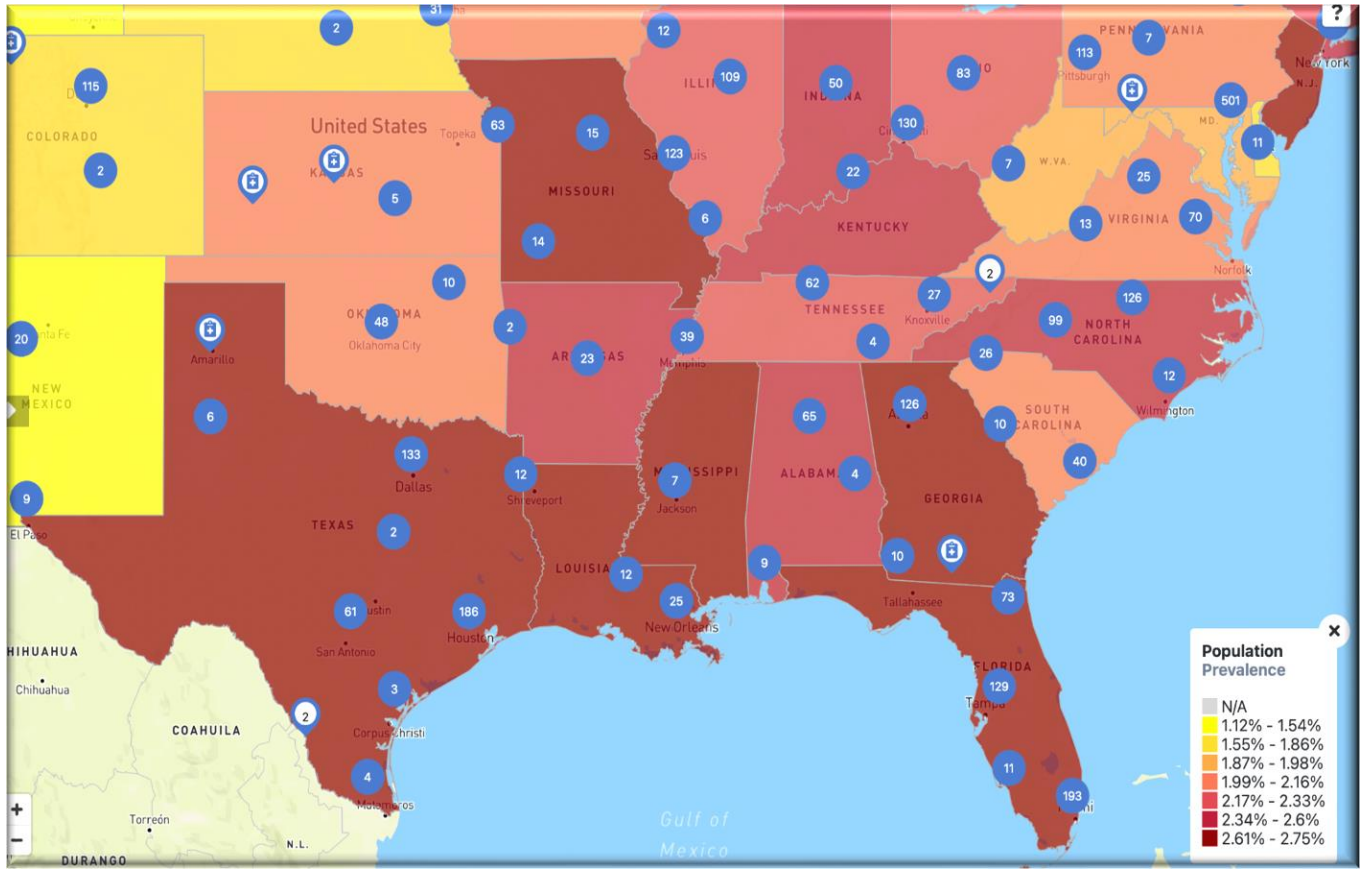
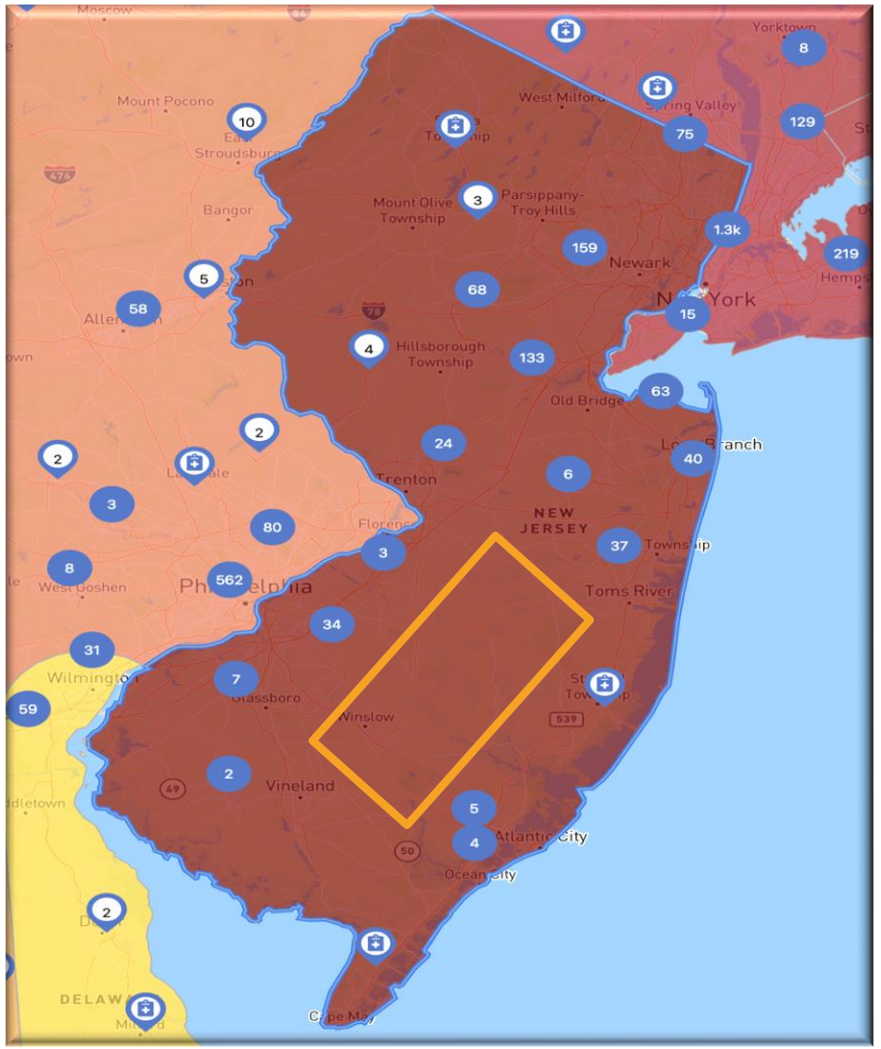
Concerns on Equitable Access to AD Clinical Trials for Minoritized Beneficiaries Enrolled in 2020 Medicare FFS





There were are approximately 5,000 Alzheimer's clinical trials active across the country in 2020

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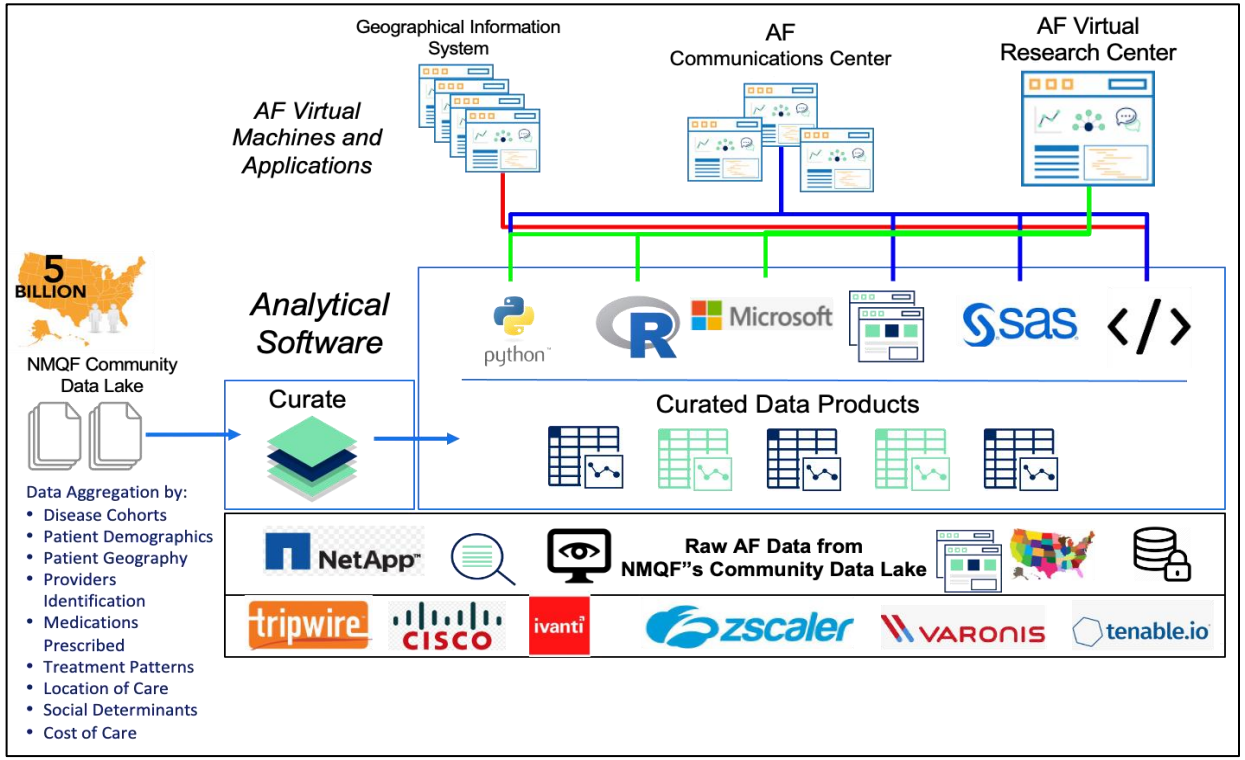
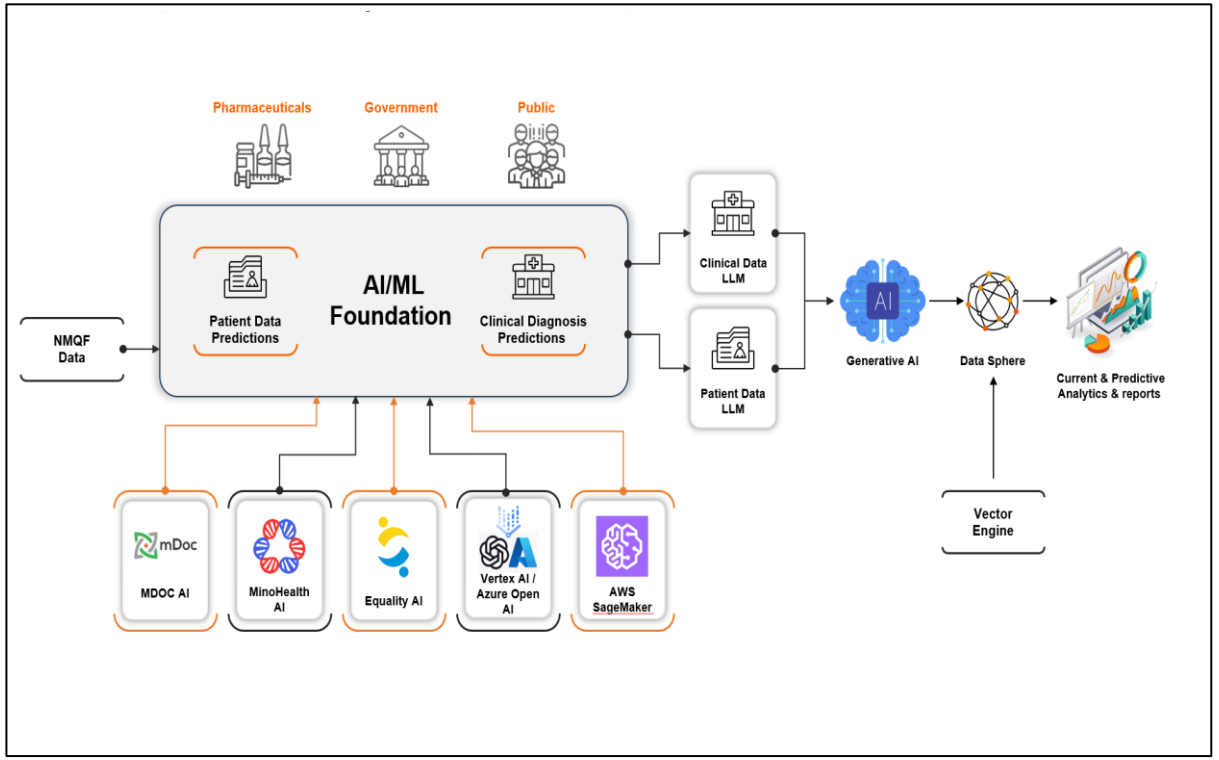
Strengthening NMQF Data Infrastructure and Capabilities

Private Cloud



AI Platform



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ASTCT-NMDP ACCESS Initiative

Policy is Key in Health Equity

Alycia Maloney, JD, ASTCT

Jess Knutson- Director, Government Affairs, NMDP

Ellie Beaver- Sr. Policy Manager, NMDP

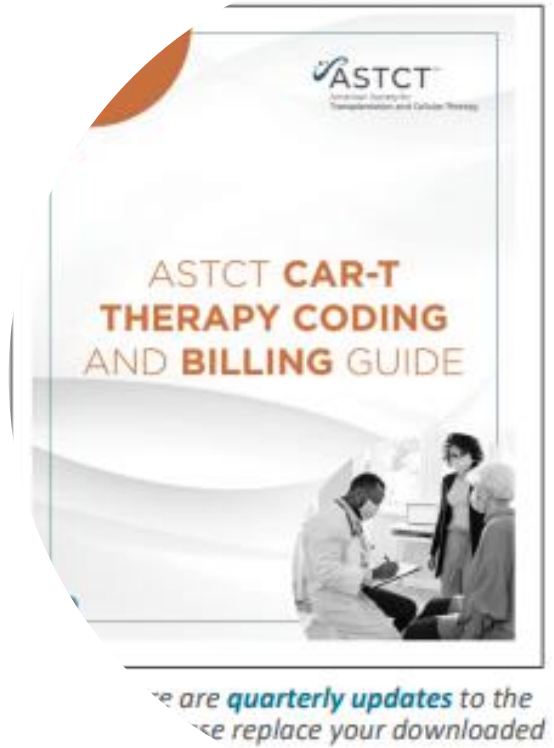
Washington D.C.

July 23rd, 2024

Equal Outcomes for All

What are recent advocacy wins?

- National Coverage Determination for MDS – CIBMTR – BMT CTN – ASH – ASTCT collaborations for policy change and implementation of policy
- CMS coverage of dental services for cell therapy patients
- The **C.W.Bill Young Cell Transplantation Program funding:** received full funding amount for FY24 and FY25 (budget passage pending)



ASTCT Hill Day 2023 Asks

- Urged Congress to support patient access to cell therapies by:
  - Assisting with FDA drug shortages
  - Supporting the Life Saving Leave Act (H.R. 3024)
  - Requiring state Medicaid programs that authorize out-of-state care, to accept active Medicare enrollment to make payments
  - Increased funding for the NIH

2023
HILL DAY

ASTCT URGES CONGRESS TO SUPPORT PATIENT ACCESS TO CELL THERAPIES

1. By assisting with FDA drug shortages
2. Supporting the Donor Leave Act (H.R 3024)
3. Requiring state Medicaid programs that authorize out-of-state care, to accept active Medicare enrollment to make payment
4. Increased funding for the National Institutes of Health (NIH)

BACKGROUND ON THE AMERICAN SOCIETY FOR TRANSPLANTATION AND CELLULAR THERAPY (ASTCT)

The ASTCT is a professional membership association of more than 3,700 physicians, scientists, and other health care professionals promoting blood and marrow transplantation and cellular therapy through research, education, scholarly publication, and clinical standards. Our Society's clinical teams have been instrumental in developing and implementing clinical care standards and advancing cellular therapy science, including participation in trials that led to current Food and Drug Administration (FDA) approvals for chimeric antigen receptor T-cell (CAR-T) therapy and hematopoietic stem cell-based gene therapies for genetic immune system and blood disorders.

For more than 25 years, ASTCT members have focused on innovation in the treatment of hematologic malignancies, hematologic disorders, and other immune system diseases. ASTCT members very much rely on team care for the complex cancers and other disorders requiring hematopoietic stem cell transplants (HSCTs) and newer cell therapies like CAR-T.

WHAT ARE CELL AND GENE THERAPIES?

Cell therapies, of which CAR-T therapy is one type, are innovative, personalized, and life-saving immunotherapy for patients with cancers and other acquired and inherited conditions. Often these therapies are for patients who have exhausted all other therapies. Since 2017, the Food and Drug Administration (FDA) has approved 6 CAR-T products for multiple indications.

Gene therapies are innovative, personalized, treatments often for rare inherited disorders. There have been multiple gene therapies approved, with several more expected in the next 1-2 years. ASTCT members focus on hematopoietic stem cell (HSC) gene therapies, which used gene addition or gene editing to correct blood disorders and other metabolic and/or autoimmune disorders. HSC gene therapies are delivered via autologous stem cell transplants.

ASTCT®
American Society for Transplantation and Cellular Therapy


REPRESENTATIVE
Al Green
Texas
2347


U.S. CAPITOL

Grassroots Advocacy Platform

- New grassroots advocacy platform
  - Launched a campaign for Hill Day 2023
  - Will be utilized again for Hill Day 2024
- Easy messaging options to contact state and federal legislators
- ASTCT can track campaigns and engage members as needed

Policy campaigns in progress

Life Saving Leave Act (HR 3024/S 3685)

- Job-protected time off for BMT donors
- Introduced a Senate bill in February with Sens. Casey (PA) and Cassidy (LA)
- Continue to add co-sponsors
- Held an NMDP Fly in in February

Policy campaigns in progress

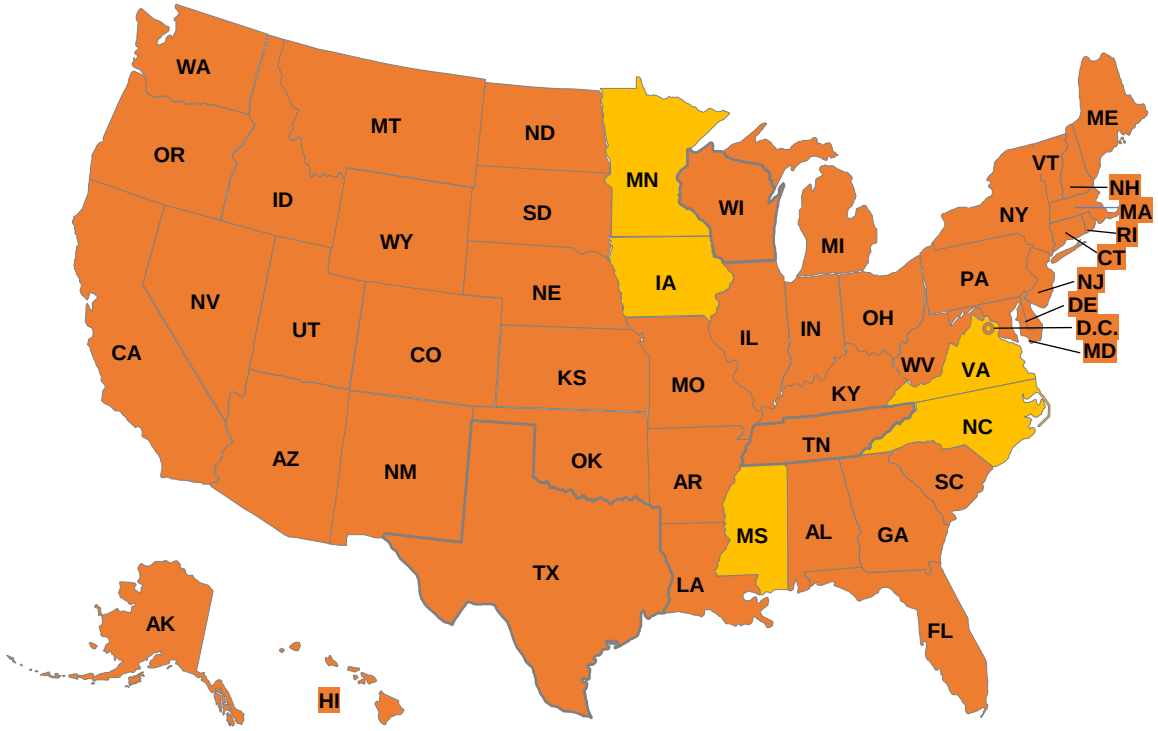
Accelerating Kids Access to Care Act (HR 7458/S 2372)

- Requires Medicaid to simplify cross-boarder enrollment for children
- 123 sponsors in the House, 40 sponsors in the Senate
- Awaiting a floor vote in the House
- Focus moves to Senate

Policy Campaigns in Progress

Increasing Access to Medicaid at the State Level

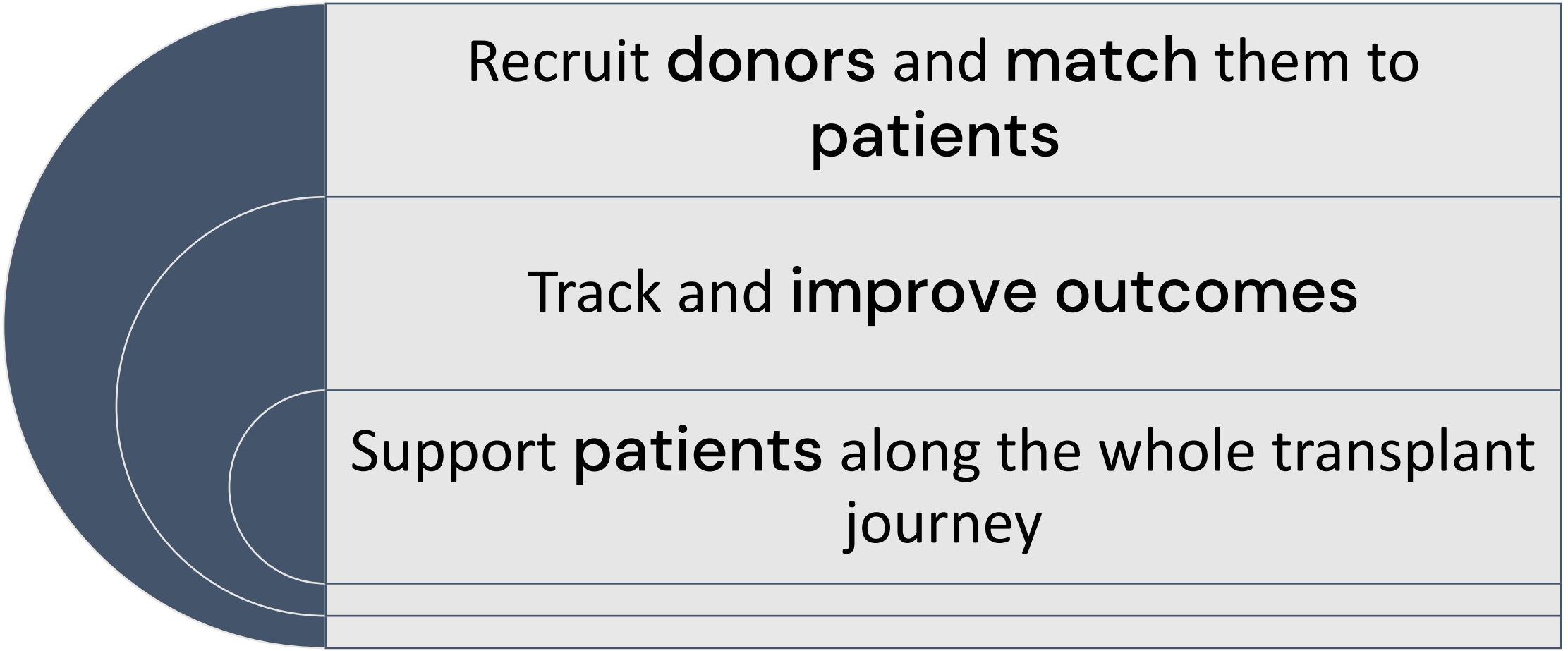
- Outreach to 5 states to add standard indications to coverage documents
- Former NC Medicaid Director Dave Richards met with all 5 current state directors in June
- Continuing outreach and conversations about changes
- Submitted comments to NC Medicaid about coverage for non-selected donors



What's next…


Reauthorization of the CW Bill Young Transplantation Program

C.W. Bill Young Cell Transplantation Program



Panel Discussion

Moderator Gary Goldstein

Senior Manager, Stanford BMT and Cellular Therapy Program

Next

- Working lunch 11:00-11:45 AM
  - Focus Area Committees: Discuss new opportunities, prepare report-outs
- Report Outs 11:45 AM -12:45 PM
  - Focus Area Committees report out next steps/opportunities, providing timelines and resources needed (20 min each committee)
- Wrap-up 12:45-1:00 PM
- Workshop Adjourns 1:00 PM