

# *Health*

2024 SOA MEETING

# Session 4G: Improving Data Analysis Using a Health Equity Lens

American Academy of Actuaries  
Health Practice Council—Health Equity Committee

Monday, June 24, 2024, 3:45–4:45 p.m. EDT

## Moderator:

Rebecca Sheppard; FSA, MAAA, MHS

## Presenters:

Rachele Hendricks-Sturup; DHSc, MSc, MA  
Julia Lerche; FSA, MAAA, MSPH



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# Presenters

## **Moderator**

Rebecca Sheppard; FSA, MAAA, MHS  
Co-Chairperson, Health Equity Committee  
American Academy of Actuaries

## **Presenters**

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Research Director, Real World Evidence,  
Duke-Robert J. Margolis, MD, Institute for Health Policy

Julia Lerche; FSA, MAAA, MSPH  
Chief Strategy Officer and Chief Actuary,  
North Carolina Medicaid

# Agenda

- Overview of the American Academy of Actuaries' Health Equity Committee
- Why actuaries care about health equity
- The intersection of data analysis and health equity
- Stakeholder perspectives and policy considerations for novel applications and developments in health research
- Case Study: the impact of applying a health equity lens to Medicaid data



# American Academy of Actuaries Health Equity Committee

- Created to contribute actuarial perspective to health equity
- Focus:
  - Evaluate actuarial practices in the context of health equity
  - Educate actuaries and other stakeholders on health equity issues
  - Apply an equity lens when considering the impact of current or proposed health care policies
- Published issue briefs that explore health equity topics in actuarial practice
- Held a symposium focused on equity-enhancing benefits in the employer coverage space

# Definitions used by the Health Equity Committee

- **Health Equity:** Everyone has a fair and just opportunity to be as healthy as possible. This requires removing obstacles to health such as poverty, discrimination, and their consequences, including powerlessness and lack of access to good jobs with fair pay, quality education and housing, safe environments, and health care.
- **Health Disparities:** Differences in health or its key determinants that adversely affect marginalized or excluded groups. Disparities in health and in the key determinants of health are the metric for assessing progress toward health equity.
- **Social Determinants of Health:** Nonmedical factors such as employment, income, housing, transportation, child care, education, discrimination, and the quality of the places where people live, work, learn, and play, which influence health.

Source: Braveman P, Arkin E, Orleans T, Proctor D, and Plough A, [What Is Health Equity And What Difference Does a Definition Make?](#) Princeton, N.J.: Robert Wood Johnson Foundation, 2017.

# Why actuaries care about health equity

- Key health decision-makers rely on actuaries for advice
- Unique skillset to quantify costs of health disparities to the health care system
- Commitment to identifying and addressing issues on behalf of the public interest
- Desire to explore and understand whether any actuarial practices inadvertently lead to or exacerbate health disparities and inefficient use of health care dollars
- Potential to use actuarial principles to reduce health disparities and improve health outcomes

# The intersection of data analysis and health equity

- Data come from various sources: claims data, clinical data, self-reported data, census data, financial data, etc.
- Data are heavily relied on in analysis: pricing, forecasting, reserving, risk adjustment accruals, population management programs, provider contracting, etc.
- Data analysis drives decisions which impact health outcomes
- Key take-aways for today's discussion:
  - Consider bias in the data
  - Incorporate data empathy
  - Understand the limitations of the data

# The intersection of data analysis and health equity: Bias

- All data have bias
  - Important to understand embedded bias and determine whether/how it impacts results
  - Make adjustments, if needed, to mitigate bias
- Important to incorporate qualitative data to better understand quantitative data
- A population sample may not be representative and generalizable
- The use of averages may mask important information that could be gleaned from analysis of the sub-populations

# The intersection of data analysis and health equity: Empathy

- Data elements represent people and their experiences
  - Important to use a human-centered approach to analyzing data
- Data empathy:
  - Allows for a more holistic analysis and interpretation of data
  - Acknowledges the subjective element of the data collection process
  - Leads to more effective and meaningful results, better decision-making

# The intersection of data analysis and health equity: Limitations

- Claims data:
  - Only reflects claims of those using the health care system
  - For historically marginalized groups, claims understates risk, unmet needs
  - Does not include key information needed to measure disparities
- Combining data from other sources could be helpful; e.g., enrollment data, clinical data, real-world data, and social risk indices
  - Need to understand the bias, limitations, risks of other data sources

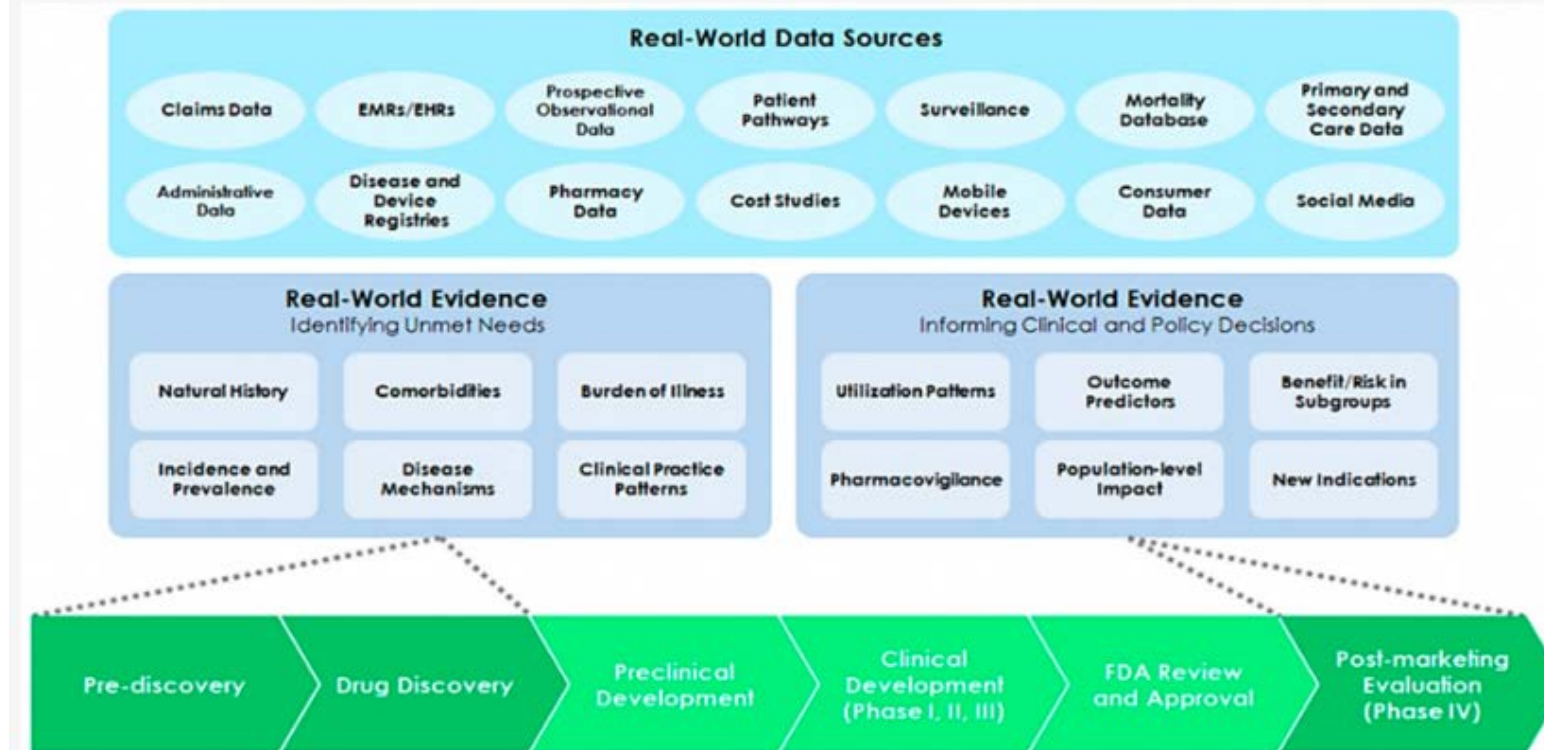
# Stakeholder Perspectives and Policy Considerations for Novel Applications and Developments in Health Research

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Research Director, Real-World Evidence  
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# Overview of Real-World Data Sources

**Figure 1.** Summary of diverse real-world data sources and evidence used to inform drug discovery and clinical and policy decision-making (Reprinted/adapted with permission from Galson and Simon, 2016. National Academies Press) [3].



Hendricks-Sturup, R. M., Zhang, F., & Lu, C. Y. (2022). A Survey of Research Participants' Privacy-Related Experiences and Willingness to Share Real-World Data with Researchers. *Journal of Personalized Medicine*, 12(11), 1922.

# Intervention Effectiveness in the Real-World

**Table 1**

**Differences between efficacy and effectiveness studies**

	<b>Efficacy study</b>	<b>Effectiveness study</b>
Question	Does the intervention work under ideal circumstance?	Does the intervention work in real-world practice?
Setting	Resource-intensive 'ideal setting'	Real-world everyday clinical setting
Study population	Highly selected, homogenous population Several exclusion criteria	Heterogeneous population Few to no exclusion criteria
Providers	Highly experienced and trained	Representative usual providers
Intervention	Strictly enforced and standardized No concurrent interventions	Applied with flexibility Concurrent interventions and cross-over permitted

**Understanding real-world effectiveness requires real-world data**

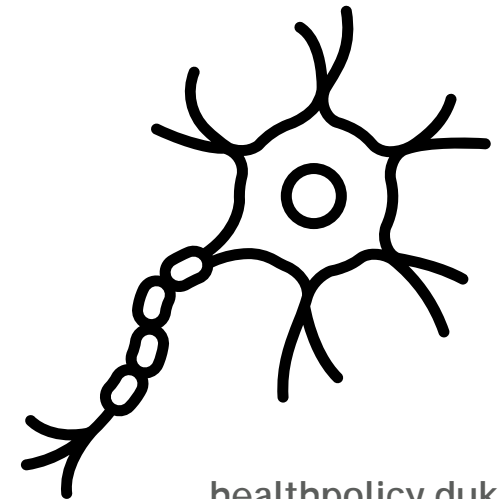
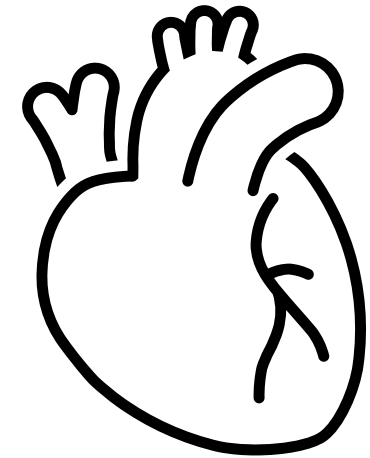


# Ethical Challenges to Real-World Evidence Implementation in Regulatory and Health Plan Pricing Settings

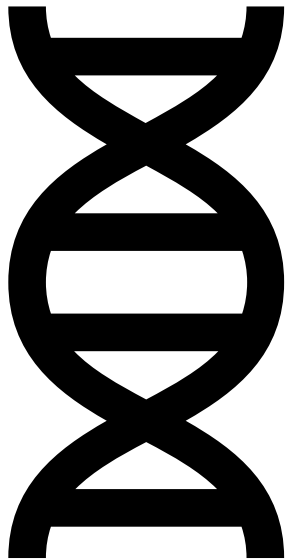
- Like regulatory settings, data are the cornerstone for actuarial science and the practice of pricing health plans (e.g., projecting health care spending, creating health plan benefit designs, calculating premiums, and developing models to assess risk)
- Yet, data from a variety of traditional and non-traditional sources may be presented to health actuaries in practice, despite their concerns about data privacy, bias, etc., and downstream implications for beneficiaries.
- A thoughtful analysis on sourcing and leveraging RWD or alternative sources of data, which directly impact insurance beneficiary access to diagnosis and care, is warranted.

## Use Case: Transthyretin Amyloidosis

- Amyloidosis is a rare and often fatal disease caused by an insoluble fibril known as amyloid.
  - There are over 30 precursor proteins known to date; amyloidosis typically arises from misfolded transthyretin or immunoglobulin light-chain aggregation.
- Transthyretin amyloidosis (ATTR) is a type of amyloidosis in which amyloid fibrils are produced due to precursor protein misfolding and precipitation in various tissues and organs, causing organ system (i.e., cardiovascular and nervous system) damage.
  - Misfolded precursor protein form cross- $\beta$ -sheet-rich amyloid fibrils that accumulate in several tissues.

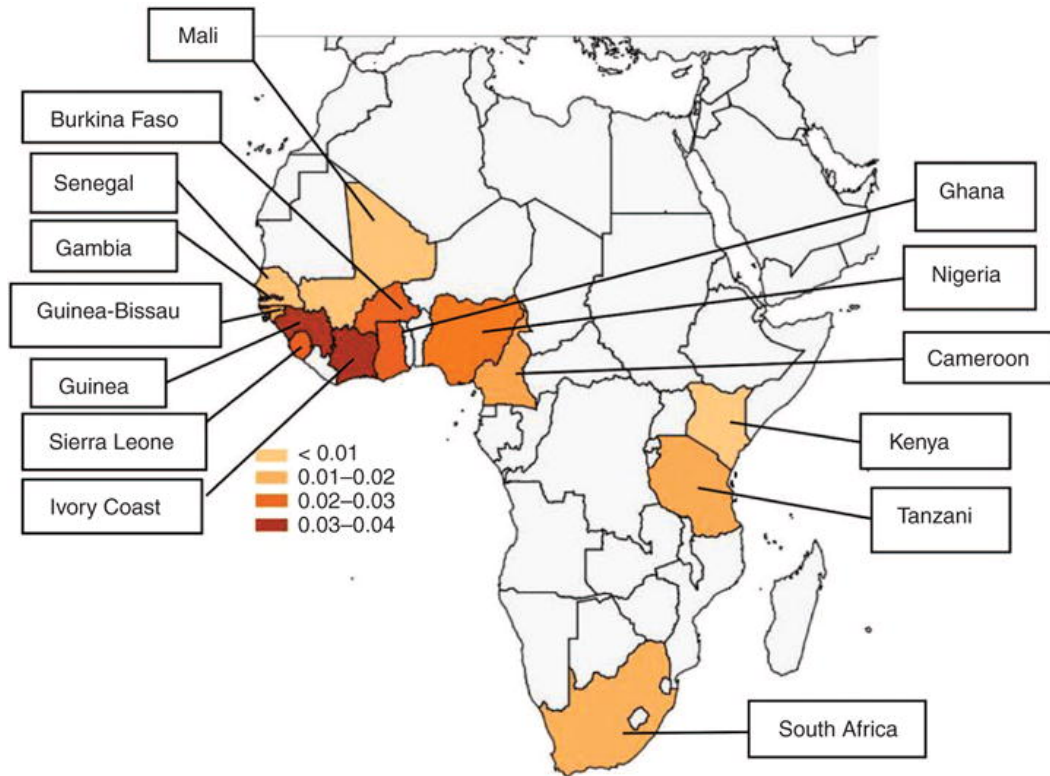


## Hereditary ATTR



- Hereditary ATTR (hATTR) is an under-recognized, underdiagnosed, and often fatal genetic condition that disproportionately affects those of African, African-American and Afro-Caribbean descent and requires early diagnosis and treatment.
- Early clinical or molecular diagnosis of hATTR is key to prolonging life of those carrying a certain genetic variation of V122I (pV142I)-coupled with phenotypical expression.
  - Valine-to-isoleucine substitution at position 122 (TTR V122I; pV142I) in transthyretin (TTR)-derived fibrils.
- **The most common mutation associated with hATTR (Val122Ile) is present in ~3.4% of African Americans as part of the African diaspora.**
  - 1.5 million individuals in the United States are hATTR carriers.


## Transthyretin amyloid cardiomyopathy (ATTR-CM)



- ATTR-CM is a potentially fatal disease that affects the heart muscle; heart failure is common.
- A late diagnosis of ATTR-CM could mean having 2-3 years of remaining life expectancy.
- The greatest frequency of the TTR V122I (pV142I) allele is present in countries along coastal West Africa.


Image credit: Jacobson et al., 2016

- The Amyloidosis Research Consortium, in partnership with QualityMetric and Global Perspectives, developed and validated a patient focused and derived **ATTR Quality of Life PRO tool**.
- Published in 2023.

 Open Access Full Text Article

ORIGINAL RESEARCH

## The Transthyretin Amyloidosis – Quality of Life (ATTR-QOL) Questionnaire: Development of a Conceptual Model and Disease-Specific Patient-Reported Outcome Measure

Meaghan O'Connor <sup>1</sup>, Kristen Hsu <sup>2</sup>, Lynne Broderick <sup>1</sup>, Kristen L McCausland <sup>1</sup>,  
Kaitlin LaGasse <sup>1</sup>, Sabrina Rebello <sup>2</sup>, Michelle Carty <sup>1</sup>, Isabelle Lousada <sup>2</sup>

## Leveraging Amyloidosis African American Patients Stories

- Prior work and African American amyloidosis patient stories have highlighted important themes on which to build and that likely capture the range of lived experiences among populations managing genetic diseases and their comorbidities:
  - Access to clinical, molecular diagnostic testing for *TTR* mutations, as lack of access to testing may hinder prior/initial authorization for pharmacogenomic treatment for health-compromised patients with hATTR.
  - Diagnosed populations may lose life insurance coverage, especially if molecularly diagnosed (i.e., genetic testing) during late disease stages.
  - Access to follow-up testing and/or care (i.e., tissue biopsy, echocardiogram, cardiac magnetic resonance imaging, radionuclide imaging, technetium pyrophosphate scan, etc.).
  - Lack of personal and family understanding of amyloidosis.

Leveraging stories of cardiac amyloidosis patients of African ancestry or descent to support patient-derived data elements for efficient diagnosis and treatment

 Rachele M. Hendricks-Sturup<sup>1,2,3\*</sup>  Lauren M. Edgar<sup>4</sup>  Christine Y. Lu<sup>2,5,6</sup>



## Leveraging Amyloidosis African American Patients Stories

- Struggle to maintain and active lifestyle in later life.
- Clinical signs tend to include a mixture of carpal tunnel syndrome, arrhythmia, gastrointestinal issues, and common signs of heart failure.
- Underdiagnosis of the disease in African American populations results in late-stage diagnosis, contributing to poor outcomes and prognosis due to poor stabilization that is needed to seek and engage in preventive care.
- Chronic, acute, and prolonged stress, including general malaise, affects day-to-day life functioning and increases risk of mental illness (e.g., depression, anxiety, etc.).
- Fragmented, under-resourced, under-educated, and underprepared health systems and healthcare providers contribute to delayed diagnosis.

Leveraging stories of cardiac amyloidosis patients of African ancestry or descent to support patient-derived data elements for efficient diagnosis and treatment

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## Rethinking Quality of Life Data Based Patient Experiences

- PROMIS<sup>®</sup>, PRO-CTCAE, and ATTR-QOL are PRO tools currently used to quantify amyloidosis patient-reported outcomes.
- Yet, non of these tools presently contain domains focused on:
  - Access to molecular testing
  - Access to non-health insurance following testing
  - Follow-up testing and/or care
  - Concern about late-stage diagnosis and poor symptom stabilization
  - Experiences navigating complex health systems that contribute to delayed diagnosis
- It is important for the actuarial science community to consider this real-world context, particularly where “quality of life” measures are considered and late-stage disease diagnoses and care are more likely due to structural inequities in the health system.

## Questions? Contact Me!



Email: [Rachele.hendricks.sturup@duke.edu](mailto:Rachele.hendricks.sturup@duke.edu)



# North Carolina Medicaid: Leveraging Actuarial Analysis to Advance Health Equity

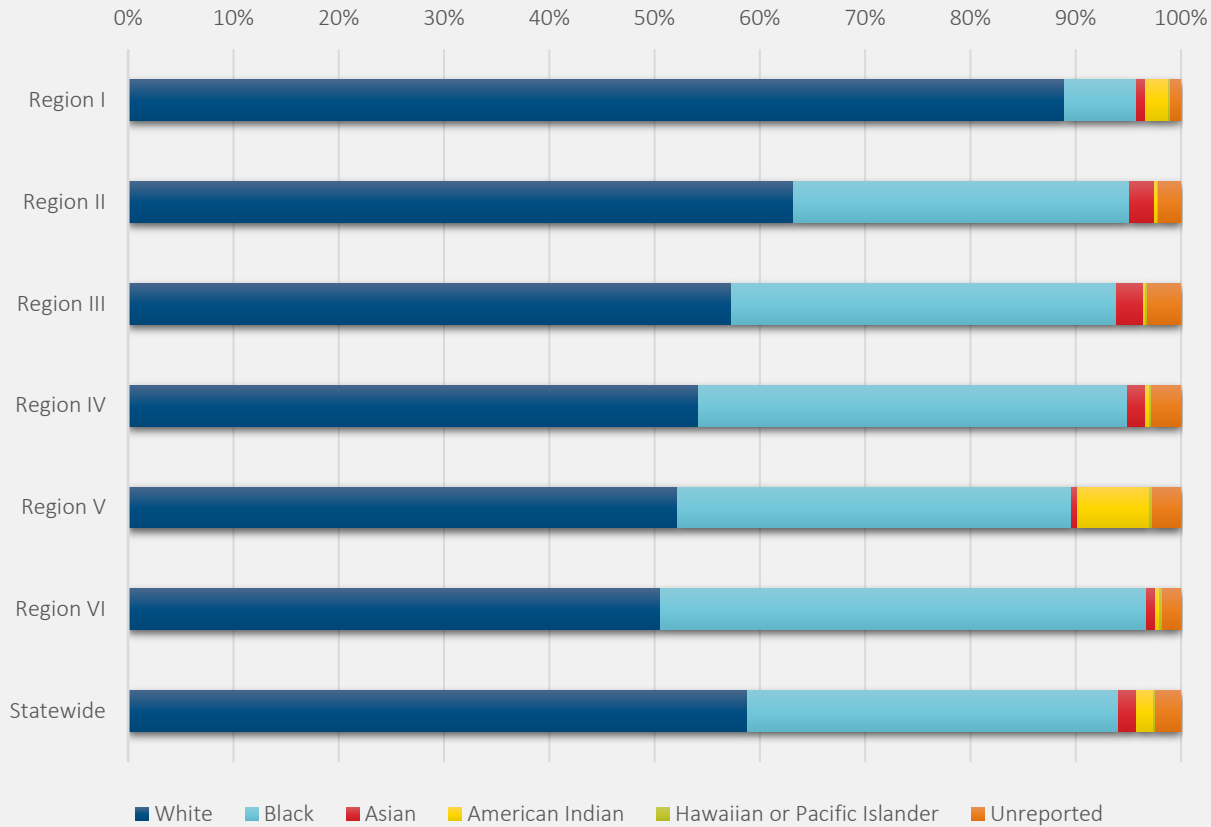
Julia Lerche; FSA, MAAA, MSPH

# Objectives of Analysis

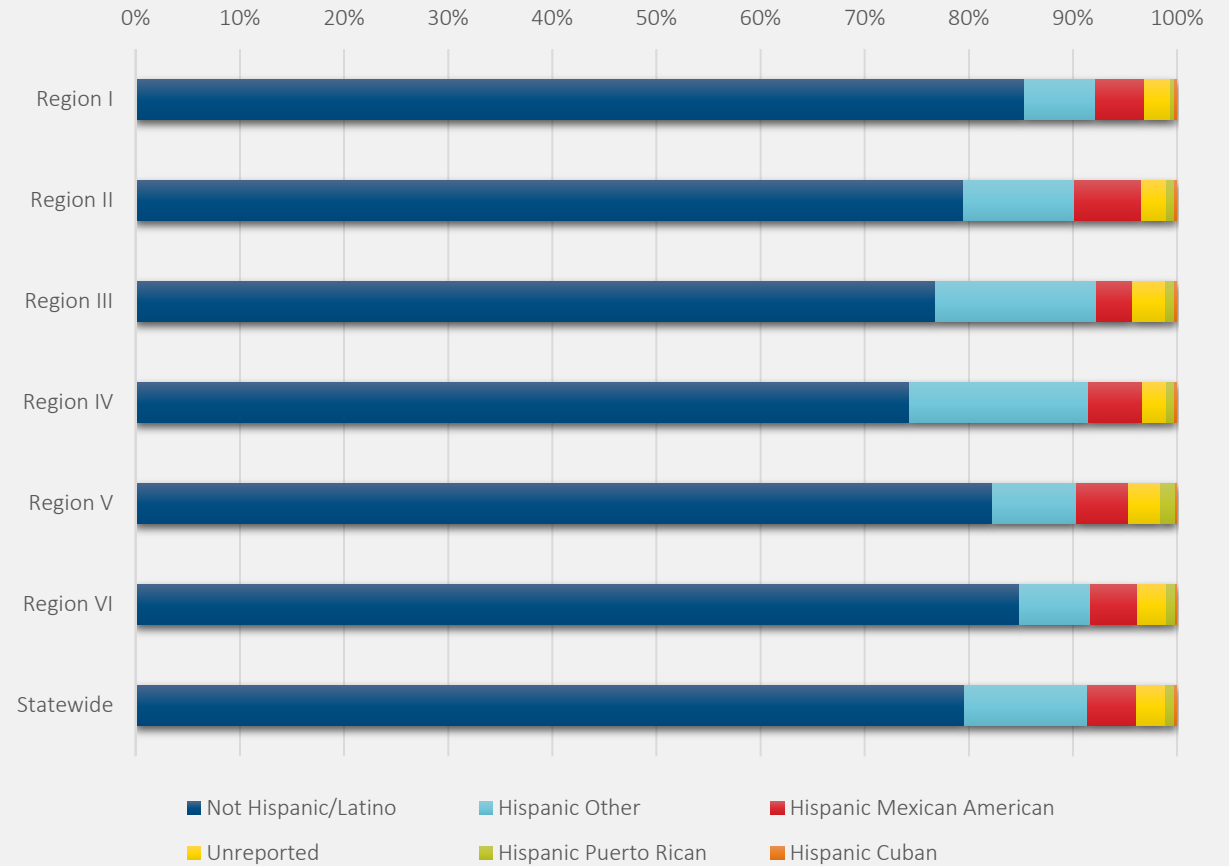
- Leverage actuarial tools to identify disparities and support data driven solutions.
  - Testing ability to leverage available data and analysis used for MCO risk adjustment model calibration to identify potential disparities
  - Initial pass to identify research questions for further analysis
    - Opportunities for deeper dive to validate drivers of disparities
    - Inform development of interventions for addressing inequities
- Assess impact of capitation rate setting and risk adjustment methodologies on health equity.
- Explore potential approaches to incorporating social risk factors in capitation rate setting and/or risk adjustment to ensure capitation payment methodology supports health equity goals
  - Review of risk adjustment model with equity lens and identify opportunities for improvement

# NC Medicaid Population Demographics by MCO Region

## NC Medicaid Population by Race



## NC Medicaid Population by Ethnicity



Population represents Standard Plan eligible beneficiaries based on 2019 data. Regions reflect Standard Plan capitation rating regions.

# Data Details and Limitations

## Data Sources

- **Demographic data:** NC Medicaid eligibility data, non-dual "Standard Plan" enrollees, excludes beneficiaries with IDD or severe behavioral health conditions, CY 2016 - 2019
- **Utilization metrics:** CY 2017 claims data
- **Condition prevalence and risk adjustment model comparisons:** CY 2016 data, CDPS+Rx with custom cost weights
- **Quality metrics and regression analysis:** CY 2019 data
- **Social Vulnerability Index and non-utilizer risk adjustment regression analysis:** CY 2019 data, CDPS+Rx with custom cost weights

## Data Notes & Limitations

- Included services: general acute care, including prescription drugs, transportation, and behavioral health. Limited HCBS waiver services.
- Considered age and disability distributions by race to understand potential influence on results; described differences but did not normalize for in all analyses
- Uses "older" data from prior to the Public Health Emergency
- Multi-race data not available
- Smaller populations for certain races and ethnicities limit conclusions
- Untested methodology, leads to more questions than answers at this stage
- Strong non-quantitative experience and perspective is needed to effectively interpret analyses

# Actual versus Predicted PMPM Costs

Compare actual to predicted cost, using CDPS+Rx and MRx risk scores to represent predicted costs. Reviewed by race, ethnicity, and region.

## Observations

- Risk scores and costs were significantly lower for Black beneficiaries than for White beneficiaries
  - Risk scores for Black population were 4 – 15% lower than the average
  - Black population had lower PMPM spend than average for all population cohorts (ranging from 8 – 18% lower)
- Normalizing for condition and demographic mix, average cost for Black population was lower than predicted in the risk adjustment models
  - Risk adjustment model showed mild over-prediction of the cost of Black population and mild under-prediction of White population
  - Dynamic is greatest for children; less for disabled population
- American Indians have highest PMPM cost; actual expenditures are above those predicted by the model (though some may be driven by IHS reimbursement levels)
- Asian population has lowest per capita spend and lowest spend relative to expected
- LatinX population has lower PMPM spend than average and lower actual PMPM spend than predicted
  - Dynamic is greatest in TANF adult population

## Summary Example

### Summary: PMPMs & Risk Scores by Rate Cell & Race

Rate Cell	Race	PMPM Relativity	Relative Risk Scores		Actual / Predicted Costs	
			CDPS+Rx	MRx	CDPS+Rx	MRx
TANF Adult	White	Green	Green	Green	Green	Green
TANF Adult	Black	Red	Red	Red	Red	Red
TANF Adult	Asian	Red	Red	Red	Red	Red
TANF Adult	American Indian	Green	Green	Green	Green	Green
TANF Adult	Hawaiian or Pacific Islander	Red	Red	Red	Red	Red
TANF Adult	Unreported	Red	Red	Red	Red	Red
<b>TANF Adult</b>	<b>All Race</b>	Green	Green	Green	Green	Green
TANF Child	White	Green	Green	Green	Green	Green
TANF Child	Black	Red	Red	Red	Red	Red
TANF Child	Asian	Red	Red	Red	Red	Red
TANF Child	American Indian	Green	Green	Green	Green	Green
TANF Child	Hawaiian or Pacific Islander	Red	Red	Red	Red	Red
TANF Child	Unreported	Red	Red	Red	Red	Red
<b>TANF Child</b>	<b>All Race</b>	Green	Green	Green	Green	Green
ABD	White	Green	Green	Green	Green	Green
ABD	Black	Red	Red	Red	Red	Red
ABD	Asian	Red	Red	Red	Red	Red
ABD	American Indian	Green	Green	Green	Green	Green
ABD	Hawaiian or Pacific Islander	Red	Red	Red	Red	Red
ABD	Unreported	Red	Red	Red	Red	Red
<b>ABD</b>	<b>All Race</b>	Green	Green	Green	Green	Green



# Condition Prevalence and Service Utilization

Compare condition prevalence, using CDPS+Rx to identify and group conditions. Compare service utilization variations. Reviewed by race, ethnicity, and region.

## Observations

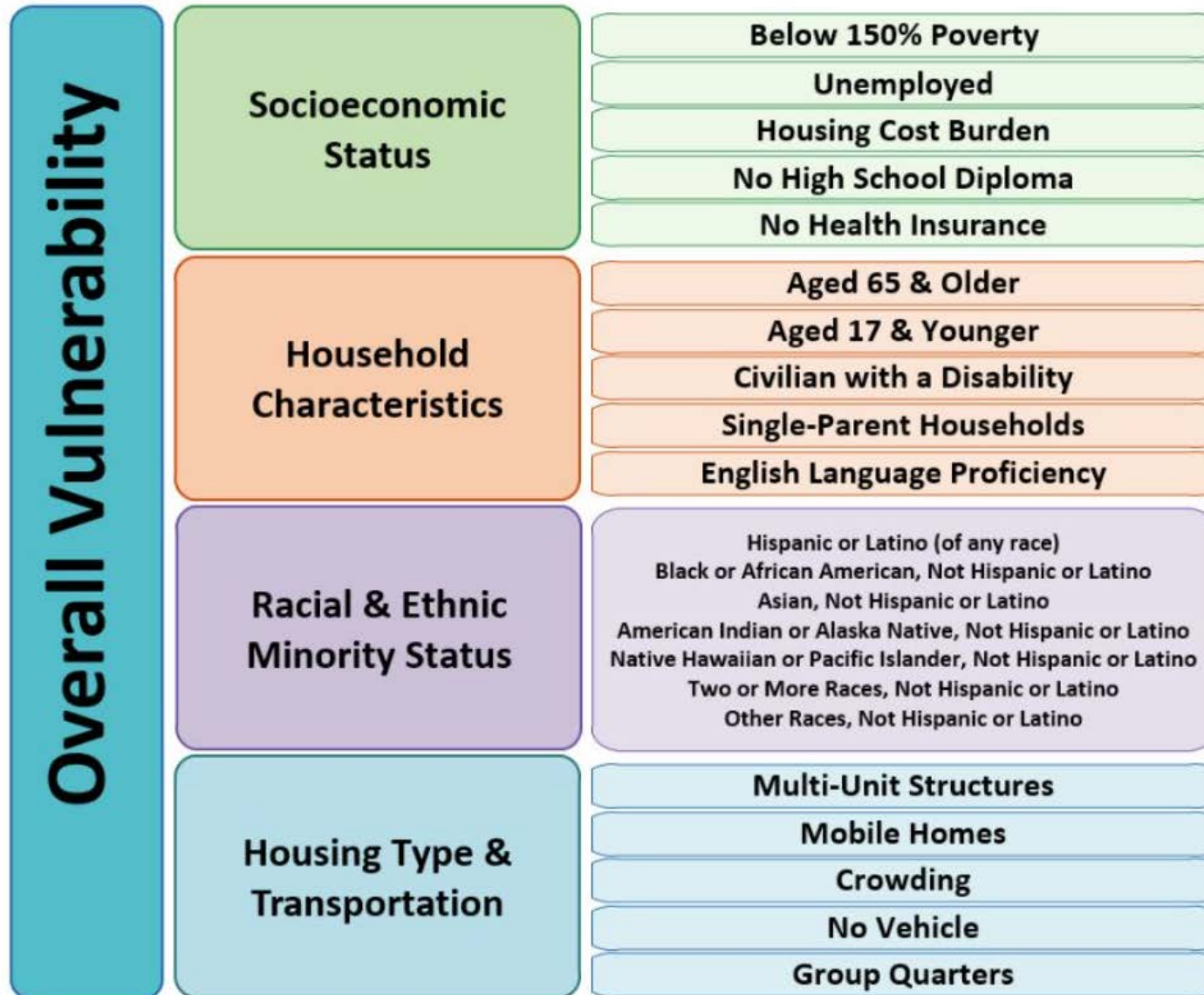
- Prevalence not as expected compared to other data sources
  - Diabetes prevalence in risk adjustment similar across all races; other population studies indicate higher incidence of diabetes among Black population
- Psychiatric prevalence notably higher for White members than other races, and especially low for Asian members
- Notable bias toward preventive care in White members, as compared to Black members
  - Similar patterns in each of non-disabled adults, non-disabled children, and disabled population
  - White population much higher Rx
  - White population higher Outpatient/Physician
  - Black population higher Emergency Room and Inpatient
- LatinX populations showed lower Rx, ER, primary/specialty care physician use. Higher IP and OP (non-disabled adults, disabled populations). Also higher Physician – FQHC, Other Clinic, Family Planning, Therapies

## Summary Example

CDPS+Rx Major Category	Difference in % of Members Compared to the All Population					
	White	Black	Asian	American Indian	Hawaiian or Pacific Islander	Unreported
Age 15 to 24 Male						
Age 15 to 24 Female						
Age 25 to 44 Male						
Age 25 to 44 Female						
Age 45 to 64 Male						
Age 45 to 64 Female						
Age 65+						
Cardiovascular						
Psychiatric						
Skeletal						
Central Nervous System						
Pulmonary						
Gastrointestinal						
Diabetes						
Skin						
Renal						
Substance Abuse						
Cancer						
Developmental Disability						
Genital						
Metabolic						
Eye						
Cerebrovascular						
Infectious						
Hematological						

COS	White	Black	Asian	American Indian	Hawaiian or Pacific Islander	Unreported	All Population
Normalized Utilization Relative to All Population							
Prescribed Drugs							
Inpatient Hospital							
Outpatient Hospital							
Emergency Room							
Physician - Primary Care							
Physician - Specialty							
Physician							
Other Acute Care							
LTSS HCBS							
Transportation							
Other BH Services							
All COS							

# Social Vulnerability Index (SVI) Background



[CDC/ATSDR Social Vulnerability Index \(CDC/ATSDR SVI\)](#)

# Social Vulnerability Index & Non-Utilizer Regression Analysis

Evaluate additional risk adjustment model variables that may help mitigate inequities. Utilize the predictive ability of the risk adjustment model to identify statistically significant patterns. Evaluated by adding variables to existing CDPS+Rx model.

## Approach

### Social Vulnerability Index (SVI)

- Developed by the CDC, national, publicly available geographic-based index measuring social vulnerability.
- The CDC defined social vulnerability as “the demographic and socioeconomic factors that adversely affect communities that encounter hazards and other community-level stressors.”
- Includes four major themes:
  - Socioeconomic Status
  - Household Composition
  - Race/Ethnicity/Language
  - Housing/Transportation

### Non-Utilizer

- Identified members without any claims data in the defined period
- Designed to encourage health plans to engage members in proactive, preventive care

## Findings & Results

### Social Vulnerability Index (SVI)

- Focused on scenarios with good statistical significance
- Some scenarios of negative cost correlation as social vulnerability increases:
  - Race/ethnicity/language: TANF Child
  - Housing/transportation: TANF Child
- Some scenarios of positive cost correlation as social vulnerability increases:
  - Race/ethnicity/language: ABD
  - Socioeconomic status: TANF Child
- Due to observed lower costs with increased social vulnerability, implementing in risk adjustment would have an adverse impact

### Non-Utilizer

- Incorporated in the Standard Plan risk adjustment model
- Reduces reimbursement for members not receiving services, increases reimbursement for members receiving services
- Improves model prediction, specifically for certain segments of the population

# Additional Research & Publications

## Research with Similar Findings

Jacob Wallace, PhD (Yale)

- *Risk Adjustment And Promoting Health Equity In Population-Based Payment: Concepts And Evidence*
  - J Michael McWilliams; Gabe Weinreb; Lin Ding; Chima D Ndumele; Jacob Wallace
  - Adding social risk factors to risk adjustment may be counterproductive
- Additional publications on related topics

Todd Gilmer, PhD & Richard Kronick, PhD (UCSD)

- *Updating the Chronic Illness and Disability Payment System*
  - Social Deprivation Index
  - Majority of variables did not reach statistical significance
  - Members living in higher social deprivation areas did not have consistently higher spend
  - Discussion of alternative approaches to addressing social deprivation impacts on health care spending

## Other Research

Massachusetts Medicaid

- *Social Determinants of Health in Managed Care Payment Formulas*
  - Arlene S. Ash, PhD; Eric O. Mick, ScD; Randall P. Ellis, PhD; Catarina I. Kiefe, PhD, MD; Jeroan J. Allison, MD, MS; and Melissa A. Clark, PhD
  - Geographic-based indicators and other social indicators
  - Found an approach to incorporate social determinants of health variables into the risk adjustment model that eliminates or significantly reduces underpayments for several vulnerable populations

# Questions to Inform Next Steps

- What were drivers of lower PMPM costs for Black, Asian and LatinX populations compared to average?
  - Were there significant differences in service utilization or types of services being utilized?
- Why were risk scores for Black, Asian and Latinx populations so much lower than the average?
  - Was condition prevalence being captured as expected?
  - What were the drivers of potential undercoding and/or underutilization of marginalized populations (especially primary care use) and how can it be addressed?
  - Was 12 month study period resulting in inequitable condition flagging?
  - How does access to care intersect with risk adjustment?
  - How does enrollment churn intersect with risk adjustment methodologies?
- What are broader implications for risk adjustment?
  - At MCO level?
  - When used for alternative payment approaches at provider level?

# Appendix

## SVI Regression Analysis

- Methodology:
  - Score assigned based on residential address at the county level. SAS geocoding also used to map at census tract level.
  - Explored variables as continuous, categorical, aggregate, themes
  - Grouped SVI scores into quartiles (lowest became the intercept)
  - Utilized P-value and Variance Inflation Factors to validate and interpret statistical results
  - P-Value is a measure of the statistical significance of variables in the regression model. The smaller P-Values represents stronger significance and the larger P-Values represents little to no significance.
  - Variance inflation factor (VIF) is a measure of multi-collinearity which is a statistical characteristic among predictors in a linear regression in which the contribution of the predictors to the dependent variable cannot be determined because the two predictors are highly correlated to one another. A VIF greater than 10 may imply the variable is highly correlated.

## Non-Utilizer Regression Analysis

- Non-utilizer is defined consistent with the NC-specific metric added to the CDPS+Rx model, which is defined by not having any claims data except potentially the following categories of services:
  - Excluded Services (e.g. Dental and LEA/Children's Developmental Services Agency [CDSA]), DME, Lab/X-ray, optical, eyeglass fitting, Dental (Limited), Family Planning Services, NEMT, Other Practitioner.

## References:

- [Updating the Chronic Illness and Disability Payment System - PMC \(nih.gov\)](#)
- [Risk Adjustment And Promoting Health Equity In Population-Based Payment: Concepts And Evidence - PubMed \(nih.gov\)](#)
- [Jacob Wallace, PhD < Yale School of Public Health](#)
- [Social Determinants of Health in Managed Care Payment Formulas - PMC \(nih.gov\)](#)



# Q&A

# Thank You

For more information, please contact

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