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CTSA Program Steering Committee

May 22, 2023

2:30 – 3:30 ET

CTSA Clinical & Translational Science Awards Program

NIH National Center for Advancing Translational Sciences

Agenda May 22, 2022

Time	Topic	Speaker(s)
2:30 – 2:35	Welcome Follow-up on EHR/RWD discussion*	Michael Kurilla, Duane Mitchell & Joni Rutter
2:35 – 2:55	Pod Feedback	Erica Rosemond
2:55 – 3:30	Crowd Sourced Agenda Topic: SDoH Report Out	Melissa Haendel & Anita Walden

Implementing a Vision for Data-Driven Clinical Research: A CTSA Enterprise

- **Opportunity:**
  - To build a clinical research data and Human+AI structure that will enable researchers to gain insights, information, and analytics to improve patient and public health.
    - Support clinical decision-making
    - Enhance the design and operations of clinical trials
    - Enable more definitive clinical trials
    - Honing the generation and impact of RWD/RWE
    - Expand community engagement opportunities
    - Drive needed scientific insights for better healthcare
    - Provide the CTSAs an edge for training savvy next gen scientists on RWD and Human+AI
    - Enable consent platform at scale

Call for the creation of a Steering Committee Task Force
Members: Arleen Brown, Muredach Reilly, Melissa Haendel, Steve Reis, Karen Johnston, Tesheia Johnson

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Pod Feedback

Erica Rosemond

Date Received: **March 2, 2023**

Pod Lead: **Karen Johnston, University of Virginia**

Pod Membership: **New York School of Medicine, Yale, Georgetown, VCU, UMass**

Pod Meeting Summary Report:

1. Discussed "crowd source" topic requests to be shared with the Steering Committee. Pod members to bring ideas to our next meeting.
2. Discussed update on spring ACTS meeting including the UL1 in-person PI networking meeting.
3. Early planning for fall 2023 CTSA meeting - shared potential dates as presented to SC.
   CCOS leadership (Kerry James and Stephan Bour) attended meeting for brief update about the CCOS transition.
4. Discussed website transition. Pod members expressed desire to see website mock-ups and Stephan offered to send working version after NCATS meeting this week. CCOS explained that there will be public website and private portal for CTSA hubs. Login information still in development - this is area of concern for the pod members.

Question:

What is the process for transitioning a completed Working Group to an Enterprise Committee or other permanently supported team for the network?

Date Received: April 25, 2023

Pod Lead: Karen Johnston, University of Virginia

Pod Membership: New York School of Medicine, Yale, Georgetown, VCU, UMass

Summary Report:

East Coast pod hosted the N3C leadership team for updates and discussion. N3C gave a brief overview of N3C platform and commonly asked questions. Discussion included requests for information about projects and participants at each site and how to access the site scorecard. One important message was how the team science approach is required to optimally utilize the N3C platform. Numerous people gave examples of the roles required to use the resource (example - clinician champion, data scientist, data technician, etc). One suggestion was to host webinars to share the lifecycle of N3C specific projects (tell the stories) to help users understand the team science approach which maximizes success. Pod members shared that participation in N3C continues to require site resources (varying levels) for mapping not only the primary hospitals but also growing community hospitals, FQHCs, and additional hospitals which may become part of the primary site network. Group discussed need for a funding source for sustainability of site efforts (possibly NCATS funding, NIH Common Fund, and /or other foundation/federal resources). Finally, we discussed how we might bring skills/resources related to large datasets to our trainees across the consortium (K and T Scholars).

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Date Received: March 16, 2023

Pod Lead: Randy Urban, UTMB Health

Pod Membership: Michigan , Emory, Miami , University of Kansas, University of Arkansas

Steering Committee Meeting Summaries

- Slides were distributed with Pod Meeting Agenda email . Items presented included Clinical Trials Management Ecosystem Maturity Model, the N3C and the National Clinical Cohort Collaborative pilot expansion beyond COVID. Pod discussed challenges of balancing roles among informatics team to support national initiatives as well as local research and service needs. Similarly, how will NCATS funding be balanced for centralized functions vs hub-specific functions.
- Some users find centralized data resources challenging to use.

Pod Presentations

- Topic ideas were collected from the hubs (see below). • The Georgia CTSA volunteered to present on their regional conference in May. Other topics/dates were tentative. The UTMB Galveston hub will send out a signup form so there will be a schedule and hubs can invite members who are relevant to particular discussions. • Another option is for hubs to use their presentation time to discuss a challenge.

Open Discussion

- Challenges of responding to NCATS or NIH queries with short deadlines (sometimes 48 hours). Conversely, long waiting periods for prior approval requests.
- Hubs discussed experiences with recent or planned External Advisory Committee meetings, including different approaches to presentation length and number, EAC breakout groups tasked with addressing specific issues, use of scribes during meeting to provide notes to EAC.

Updates from Pod Members

- Michigan – New award cycle started yesterday, team is already launching several efforts including large Clinical and Translational Science project (Element E). Needed to provide education on Clinical and Translational Science to potential pilot applicants. o Discussion around cultural shift at hub institutions as the hubs move from Clinical and Translational Research support to Clinical and Translational Science. Also, challenges among researchers who typically use pilot funds to generate pilot data for an R01 or other NIH application-- Clinical and Translational Science projects don't lend themselves to this
- Miami – Received a good score on renewal application, likely to be funded. Starting the strategize about transitioning to new FOA structure.
- Georgia/Emory – EAC meeting is tomorrow. Hub is also reformatting their leadership council meeting. RPPR coming up soon.
- Kansas – Recently had their EAC, and just completed a research symposium. Scheduled two events together so EAC members could present at the symposium. Also working on RPPR. Have started to educate institution on need to shift from cores and functions to structure of new FOA.
- Galveston – Continuing to work with partners and planning out the proposal for the new FOA. Finding ways to balance diverse needs of different partners which include undergraduate schools and a large private healthcare system. Undergraduate campuses may not be able to have K12 Scholars, but their participation is important to increase diversity of translational workforce.

Date Received: March 16, 2023
Pod Lead: Randy Urban, UTMB Health
Pod Membership: Michigan , Emory, Miami , University of Kansas, University of Arkansas

Crowdsourced Hub Presentation Topics for Future Pod Meetings

- Strengths and weaknesses in reviews for recent grant applications (U, K, T, R, etc)
- Successes and barriers to clinical trials improvements
- Feedback on the DEIA framework and next steps
- Fostering cross CTSA collaborations
- What is the role for informatics in the new CTSA world?
- How do other hubs structure CQI reporting internally, and what systems are they using to track performance improvement?
- How are other hubs disseminating evidence of their own performance improvement?
- What specific CTS topics are we likely to see our colleagues working to show they are driving improvement in?
- How do you construct your EAB/EAC and meetings? (Crowd Sourced Topic 7/24)
- Pilots and CTR vs CTS

Date Received: **April 28, 2023**

Pod Lead: **Muredach Reilly, Columbia**

Pod Membership: Harvard, Einstein, Wash U, Rochester, Children's

Summary Report: Notes:

• Pod notes plan meetings in Nov 2023 and Spring 2024
• We welcomed Mike Bell (Washington National) and did a round of introductions
• Mimi Kim and Marla Keller led the CTSA PI meeting
• The Pod noted dates for the fall meeting 2023 and the spring 2024 meeting as well as discussion on CCOS transitions

Idea Sharing Feedback:

• Discussed and will reflect upon CTSA PI meeting with NCATS and Joni Rutter on 4/20, 3 major topics - EHR utilization, clinicaltrials.gov, multisite studies
• Discussed Dr. Rutter's nascent vision for NCATS/CTSA Program informatics strategies/goals. The pod discussed the need to improve phenotypes at local levels, eg use of computable phenotypes, and enhanced
training for teams of investigators to use such real world data sets
• Suggestion for NCATS funding mechanisms (eg CCIA) for specific collaborative projects using real world data
• Discussed the list the CTSA SC is prioritizing for consideration for CTSA consortium work. Our Pod strongly encourages emphasis on physician-scientist/clinician scientist pipelines

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Crowd Sourced Agenda Topic: SDoH Report Out

Melissa Haendel & Anita Walden

National Center for Advancing Translational Sciences

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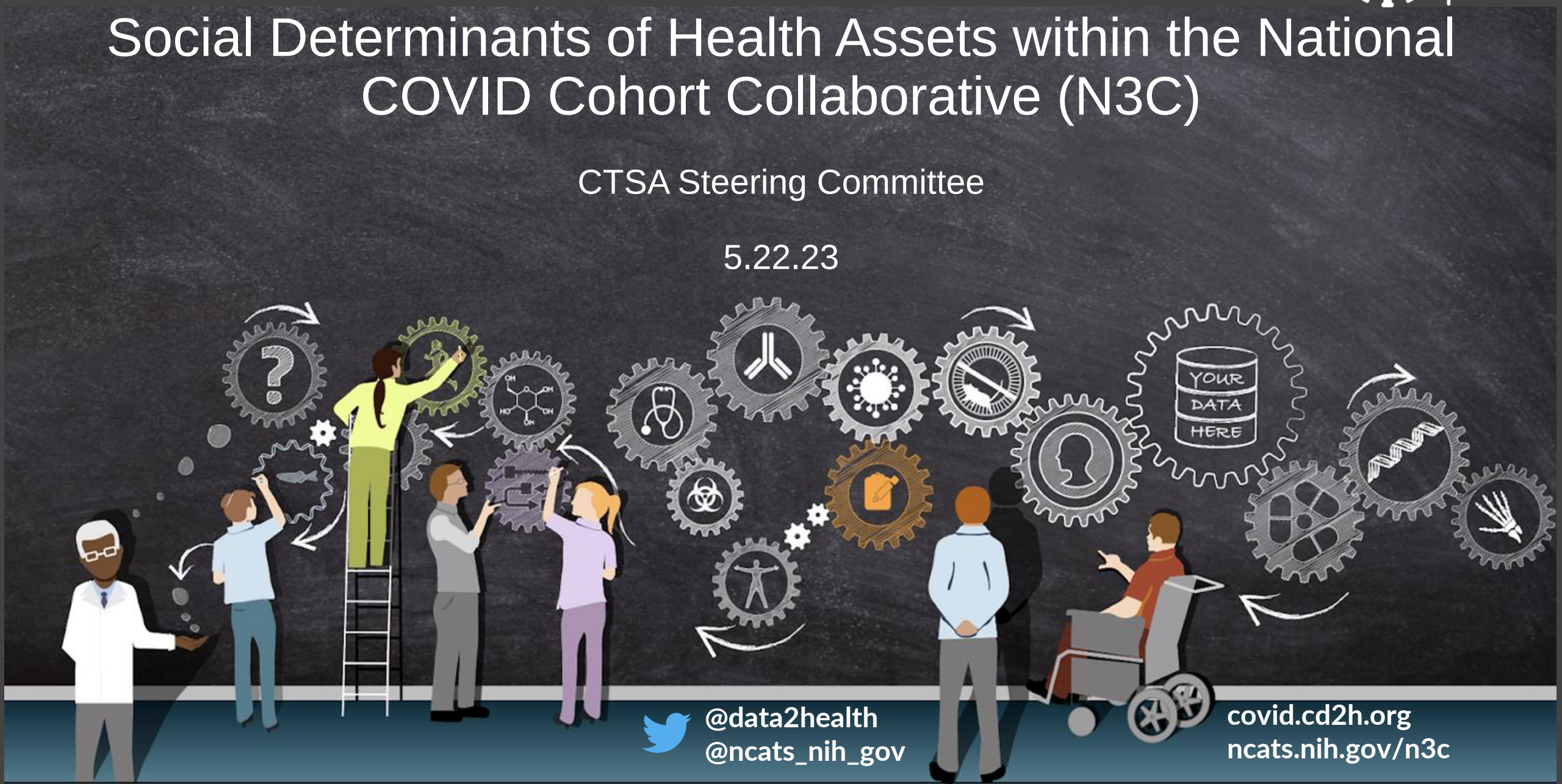
National COVID Cohort Collaborative

Social Determinants of Health Assets within the National COVID Cohort Collaborative (N3C)

CTSA Steering Committee

5.22.23



@data2health
@ncats_nih_gov

covid.cd2h.org
ncats.nih.gov/n3c

National COVID Cohort Collaborative

The Impact of Social Determinants of Health

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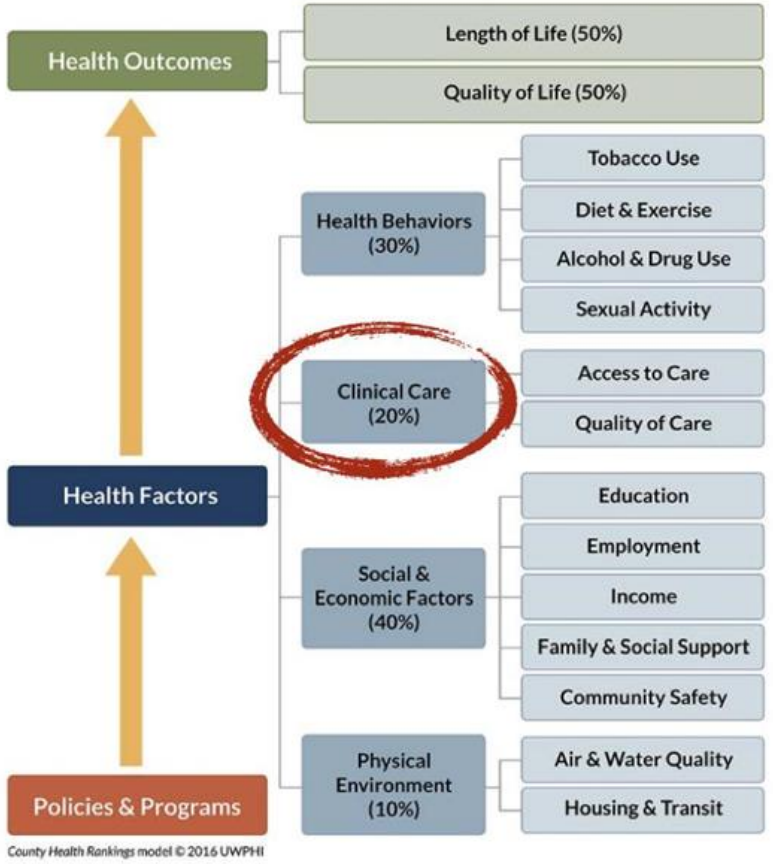
ACHIEVING HEALTH & MENTAL HEALTH EQUITY AT EVERY LEVEL

Transforming the conditions in which people are BORN, GROW, LIVE, WORK and AGE for optimal health, mental health & well-being.

Let's Get Healthy California



National Academy of Sciences

Courtesy of Dr. Juan Espinoza

National COVID Cohort Collaborative

Measures of Social Determinants of Health (SDOH)

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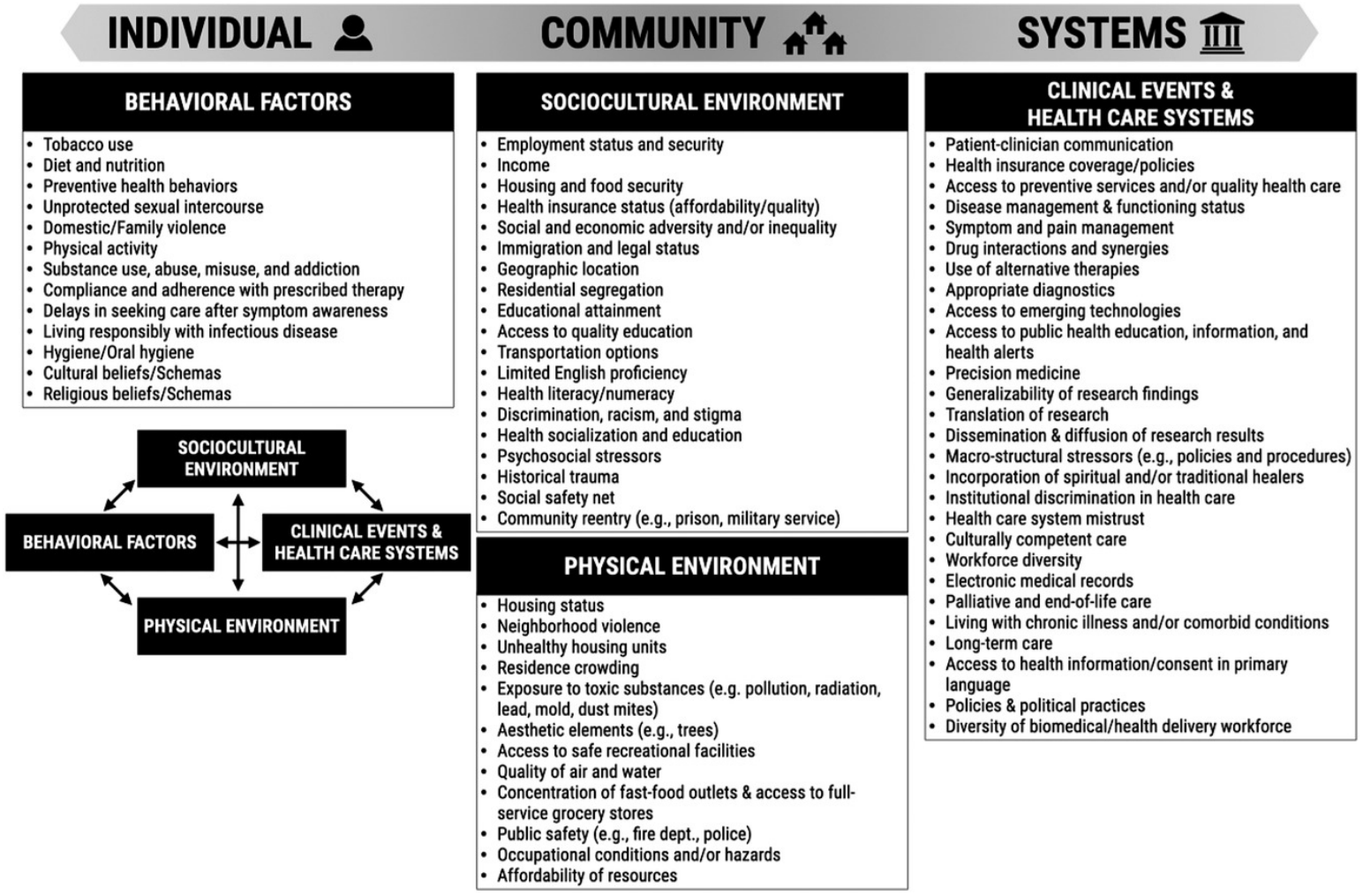


Measuring SDoH requires integration of individual, population, and system levels

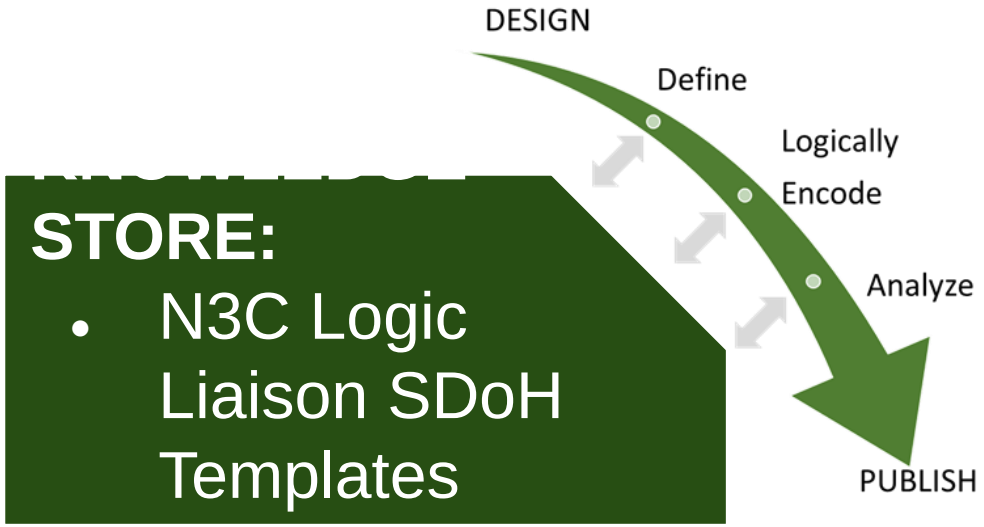
"Social Determinants of Health Factors for Gene–Environment COVID-19 Research: Challenges and Opportunities," published in *Advanced Genetics. 2022*

SDoH Domain team and resources in N3C

Charisse Madlock-Brown, PhD, MLS
University of Tennessee Health Science Center

Jimmy Phuong, MSPH, PhD
University of Washington

Adam Wilcox, PhD
University of Washington

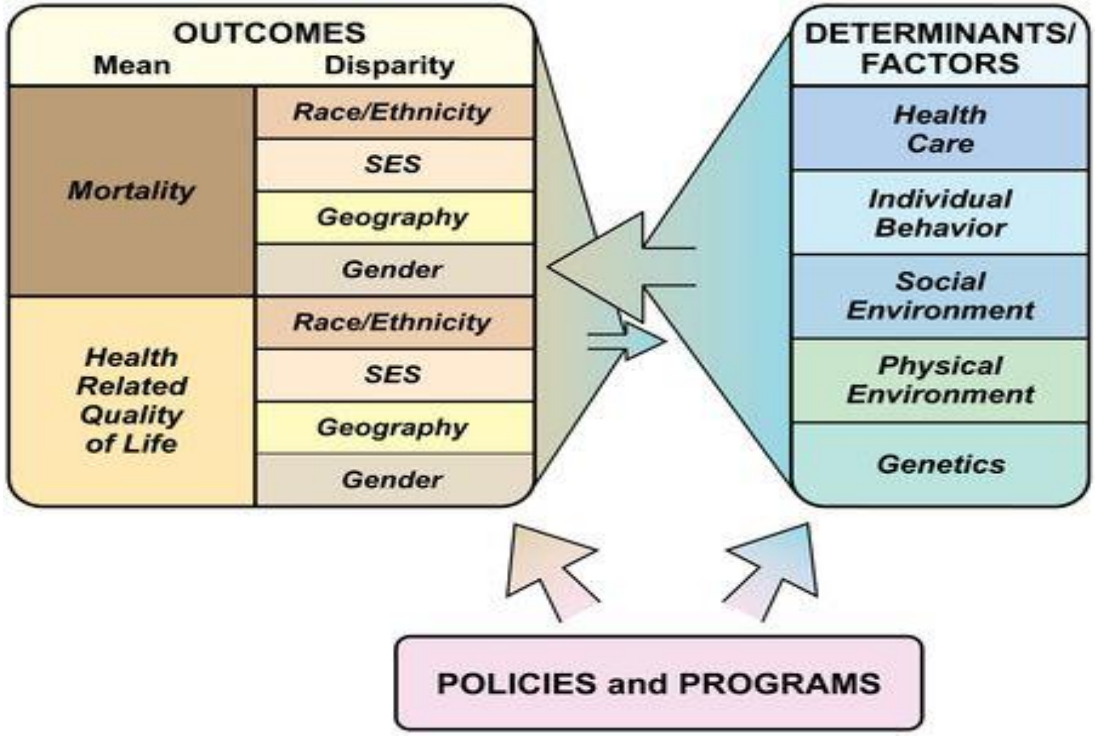


DATA DISCOVERY ENGINE

SDoH N3C Domain Team Activities

Domain teamwork:

- Community level COVID-19 outcomes related to **community-level SDoH**
- **Data engineering** Efforts to improve patient-level SDoH integration
- How **disadvantaged groups** are disproportionately affected by COVID-19
- SDoH in the time of COVID



The N3C dataset and Enclave has provided a unique opportunity to study and improve data infrastructure for SDoH

National COVID Cohort Collaborative

Modifying Screening Tools for Improved Response Rates

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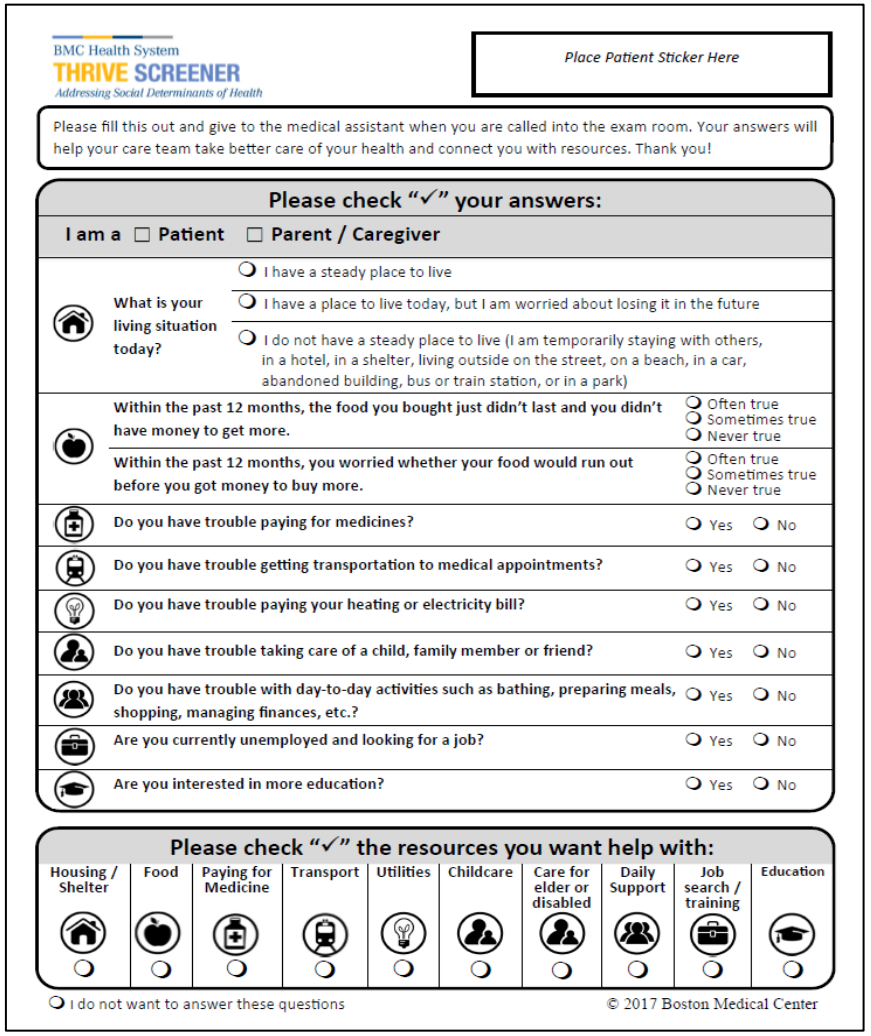
- Controlled vocabulary availability
- Semantic representation
- Database mapping
- Harmonized transformations
- Data collection completeness



BMC Health System
THRIVE SCREENER
Addressing Social Determinants of Health

Place Patient Sticker Here

Please fill this out and give to the medical assistant when you are called into the exam room. Your answers will help your care team take better care of your health and connect you with resources. Thank you!

Please check "✓" your answers:

I am a ☐ Patient ☐ Parent / Caregiver

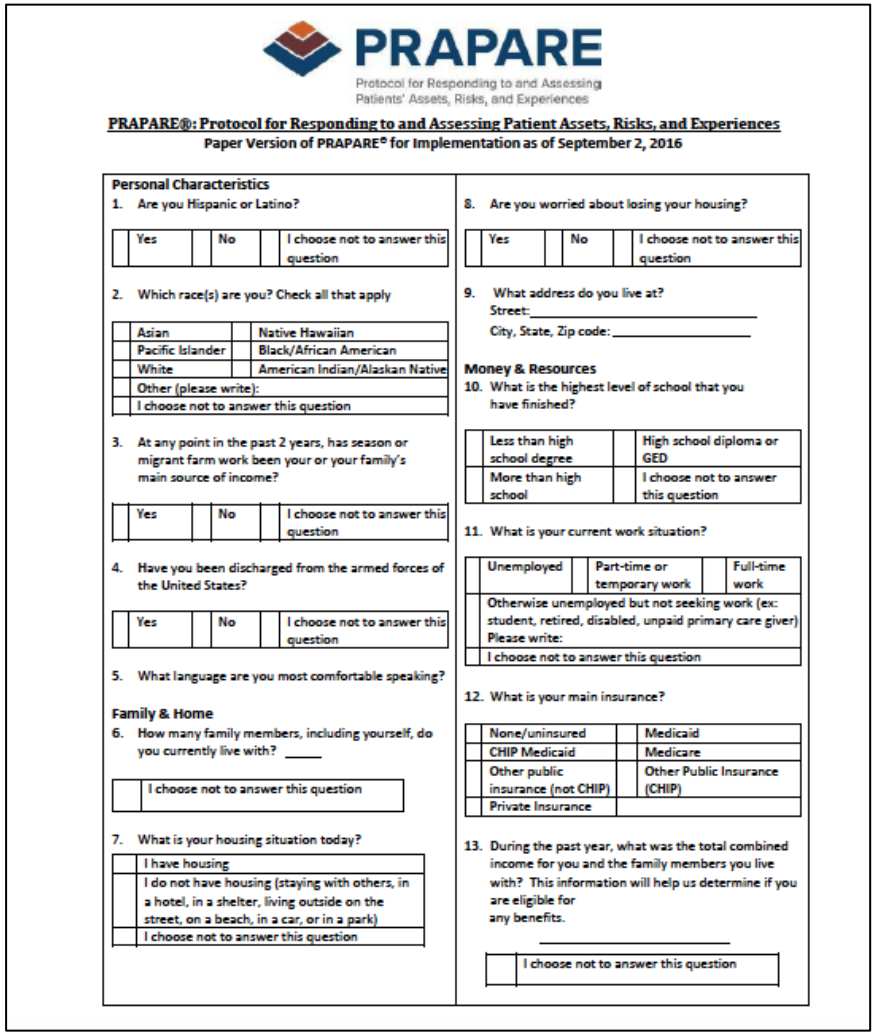
What is your living situation today?	❍ I have a steady place to live ❍ I have a place to live today, but I am worried about losing it in the future ❍ I do not have a steady place to live (I am temporarily staying with others, in a hotel, in a shelter, living outside on the street, on a beach, in a car, abandoned building, bus or train station, or in a park)	
Within the past 12 months, the food you bought just didn't last and you didn't have money to get more.		❍ Often true ❍ Sometimes true ❍ Never true
Within the past 12 months, you worried whether your food would run out before you got money to buy more.		❍ Often true ❍ Sometimes true ❍ Never true
Do you have trouble paying for medicines?		❍ Yes ❍ No
Do you have trouble getting transportation to medical appointments?		❍ Yes ❍ No
Do you have trouble paying your heating or electricity bill?		❍ Yes ❍ No
Do you have trouble taking care of a child, family member or friend?		❍ Yes ❍ No
Do you have trouble with day-to-day activities such as bathing, preparing meals, shopping, managing finances, etc.?		❍ Yes ❍ No
Are you currently unemployed and looking for a job?		❍ Yes ❍ No
Are you interested in more education?		❍ Yes ❍ No

Please check "✓" the resources you want help with:

Housing / Shelter	Food	Paying for Medicine	Transport	Utilities	Childcare	Care for elder or disabled	Daily Support	Job search / training	Education
❍	❍	❍	❍	❍	❍	❍	❍	❍	❍

❍ I do not want to answer these questions

© 2017 Boston Medical Center



PRAPARE
Protocol for Responding to and Assessing Patients' Assets, Risks, and Experiences

PRAPARE®: Protocol for Responding to and Assessing Patient Assets, Risks, and Experiences
Paper Version of PRAPARE® for Implementation as of September 2, 2016

Personal Characteristics

1. Are you Hispanic or Latino?
   Yes | No | I choose not to answer this question
2. Which race(s) are you? Check all that apply
   Asian | Native Hawaiian
   Pacific Islander | Black/African American
   White | American Indian/Alaskan Native
   Other (please write):
   I choose not to answer this question
3. At any point in the past 2 years, has season or migrant farm work been your or your family's main source of income?
   Yes | No | I choose not to answer this question
4. Have you been discharged from the armed forces of the United States?
   Yes | No | I choose not to answer this question
5. What language are you most comfortable speaking?

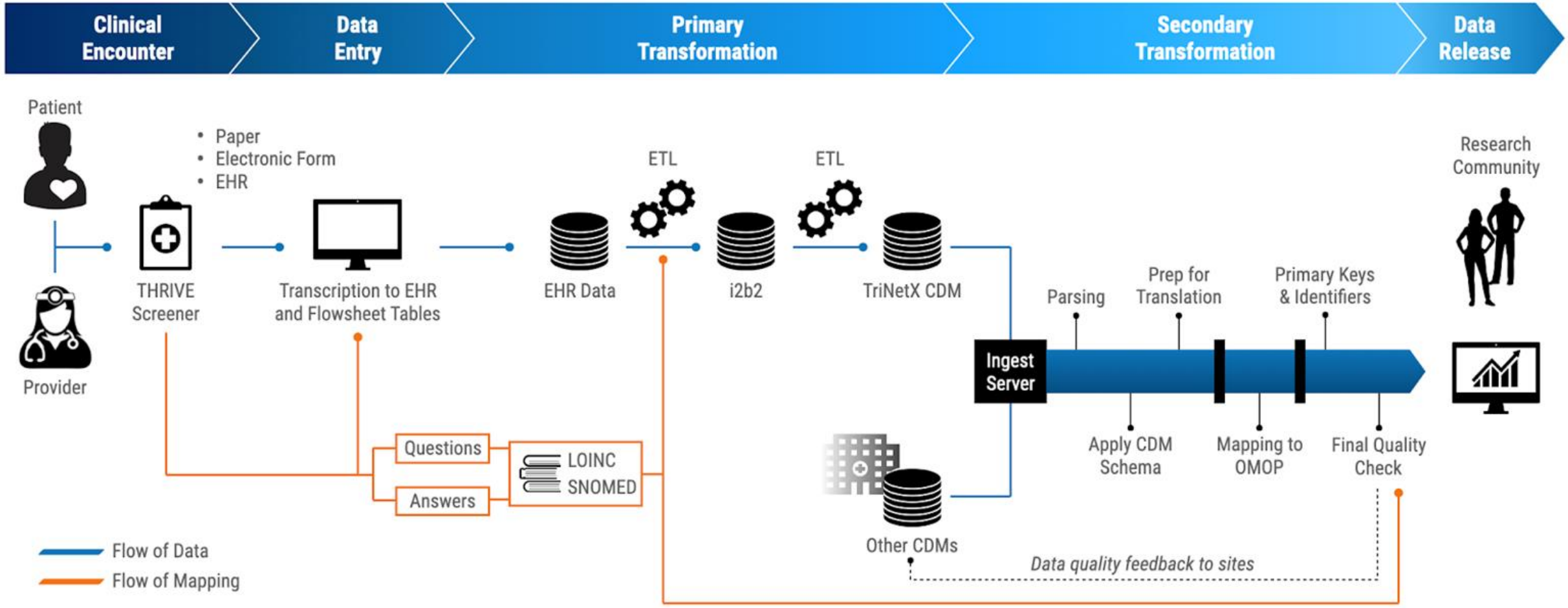
Family & Home

6. How many family members, including yourself, do you currently live with? ____
   I choose not to answer this question
7. What is your housing situation today?
   I have housing
   I do not have housing (staying with others, in a hotel, in a shelter, living outside on the street, on a beach, in a car, or in a park)
   I choose not to answer this question
8. Are you worried about losing your housing?
   Yes | No | I choose not to answer this question
9. What address do you live at?
   Street:_____
   City, State, Zip code:_____

Money & Resources

10. What is the highest level of school that you have finished?
    Less than high school degree | High school diploma or GED
    More than high school | I choose not to answer this question
11. What is your current work situation?
    Unemployed | Part-time or temporary work | Full-time work
    Otherwise unemployed but not seeking work (ex: student, retired, disabled, unpaid primary care giver) Please write:
    I choose not to answer this question
12. What is your main insurance?
    None/uninsured | Medicaid
    CHIP Medicaid | Medicare
    Other public insurance (not CHIP) | Other Public Insurance (CHIP)
    Private Insurance
13. During the past year, what was the total combined income for you and the family members you live with? This information will help us determine if you are eligible for any benefits.
    _____
    I choose not to answer this question

Incorporating SDoH into the N3C

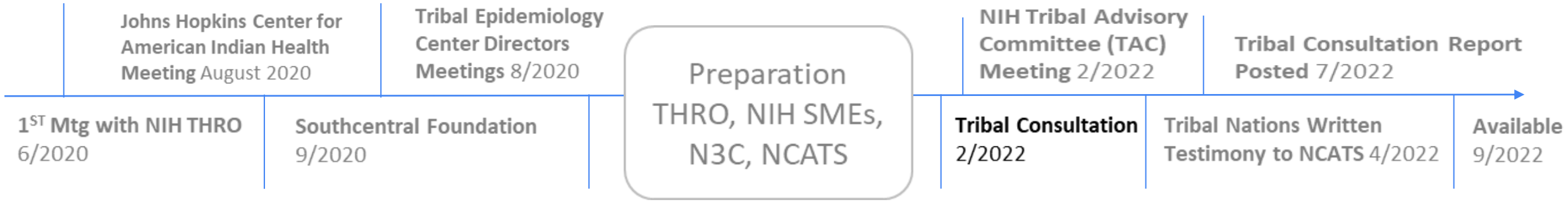


Courtesy of Dr. Juan Espinoza

American Indian and Alaska Native Data Management

- Coordination with the NIH Tribal Council over ~18 months and based on their input, data availability for this cohort has grown over time in N3C.
- Conservative measures were initially put in place to protect identification of this sensitive population; As of September 2022, AI/AN race data is available for over 100K AI/AN patients
- Similarly, ZIP codes representing rural populations predominantly with AI/AN-identifying individuals were initially removed all together, but now are provided limited to the first three digits.
- These changes were only made based on decisions made after tribal consultation

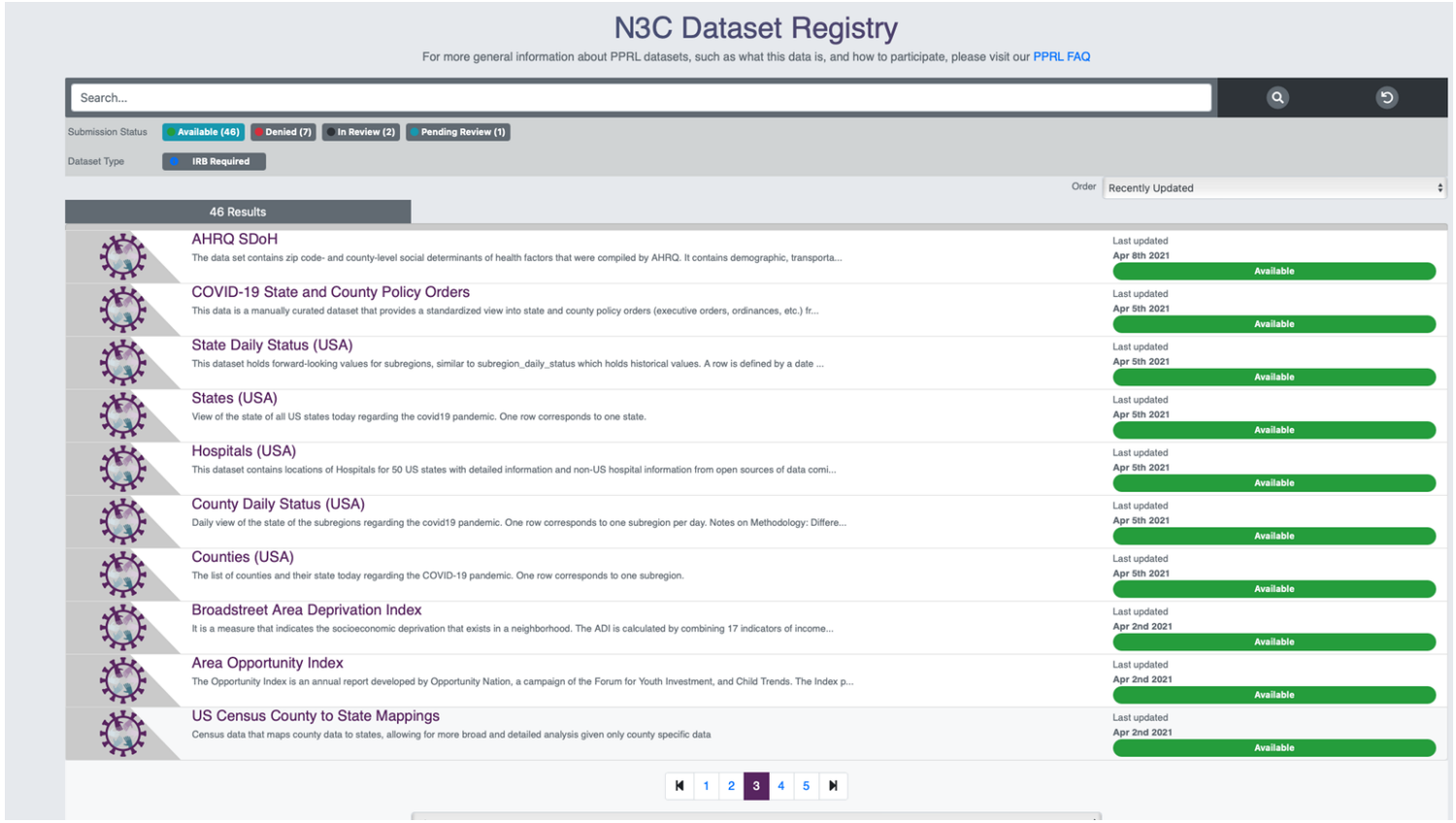
American Indian/Alaska Native Tribal Consultation timeline



Make AI / AN Data Visible → **Managing ZIP Codes** → **Changes to N3C Code of Conduct**

https://ncats.nih.gov/n3c/about/tribal-consultation

Data Integrations within the N3C



https://discovery.biothings.io/dataset?guide=/guide/n3c/dataset

➤ **SDoH relevant datasets integrated into N3C:**

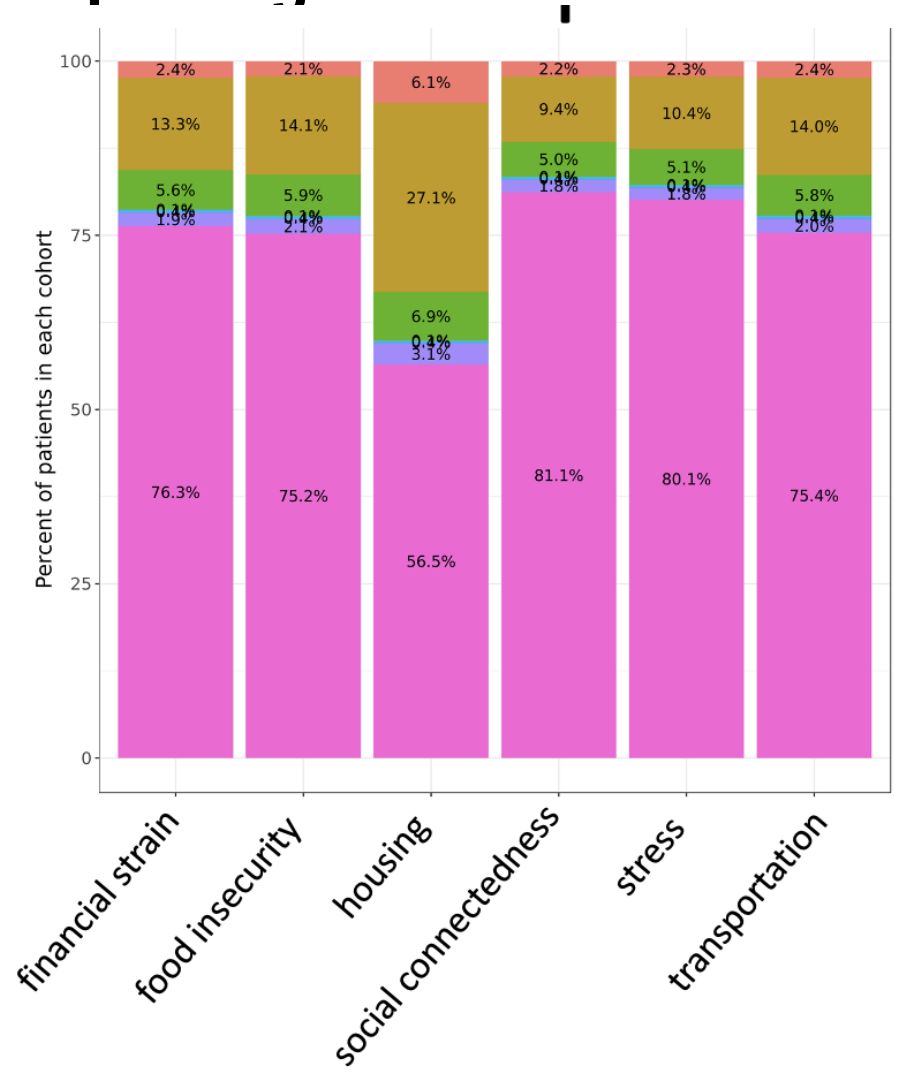
61 External Datasets have been added to the Enclave

➤ **SDoH Data Enhancements submitted by sites:**

financial
food
social
stress
housing
transportation

Making Patient-level SDoH Research Ready

Exploring



Data quality efforts:

- Each question has between <1% and 8% answers missing
- Identifying bias in who is asked an SDoH question

Transforming the data for research:

- Mapping variables to Health People 2030 and SIREN to align with standard categories
- Categorizing responses to identify the presence of a risk, need, or instability

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Geographically linking SDoH geocoded data

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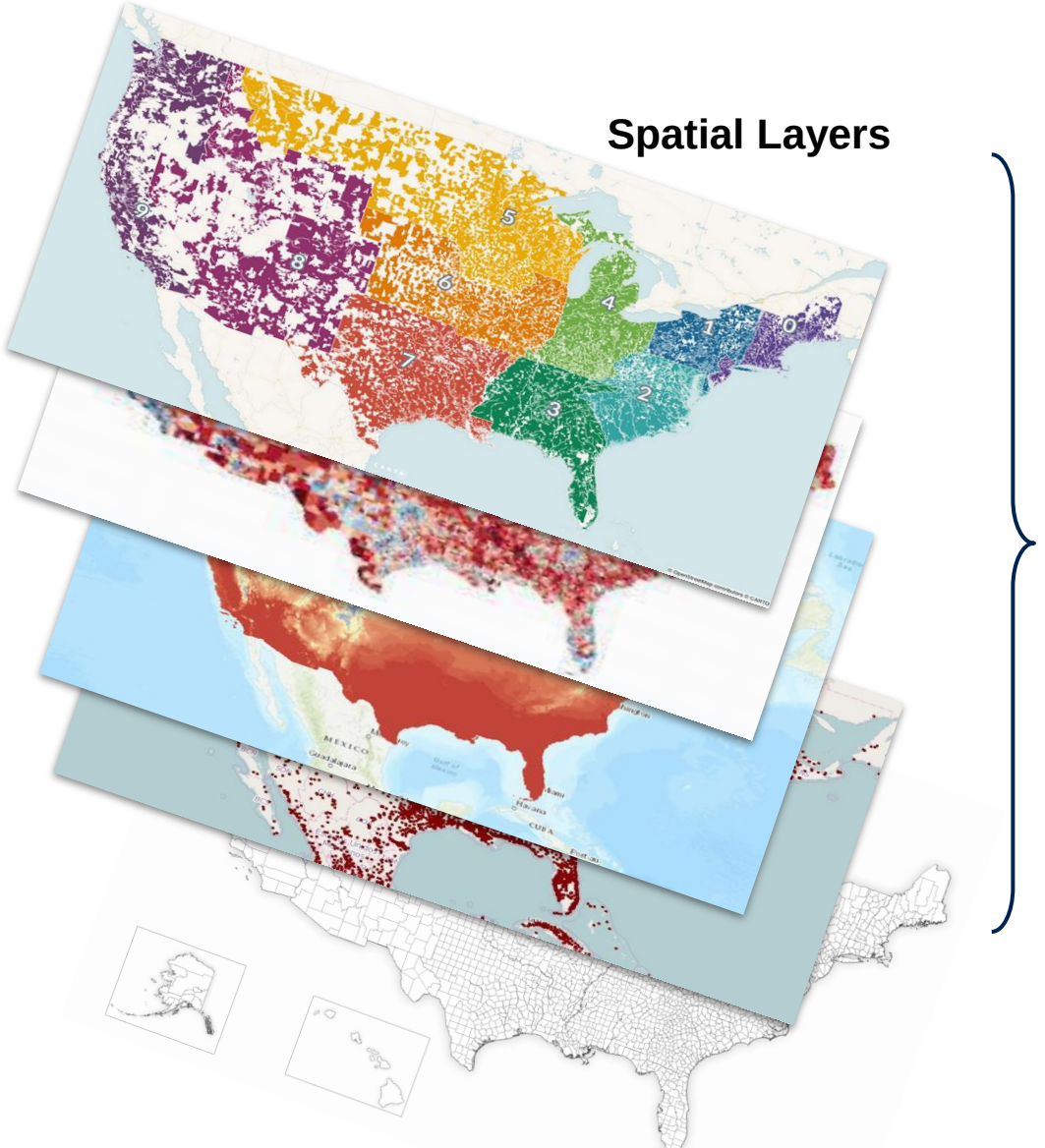
Initial Geocoding

- Participant Addresses → Points / Latitude Longitude Location
- Supplementary Environmental Data → Raster / Grid
- Environmental Justice Index (EJI) → Census Tract
- Supplementary SDoH → ZIP Code / County
- Supplemental Social & Health Vulnerability Data → Census Spatial Layers

Geographic Linkage Spatial Layer Integration

Spatial Layers



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Improving SEDoH data Centrally for Both Hub and Network Use

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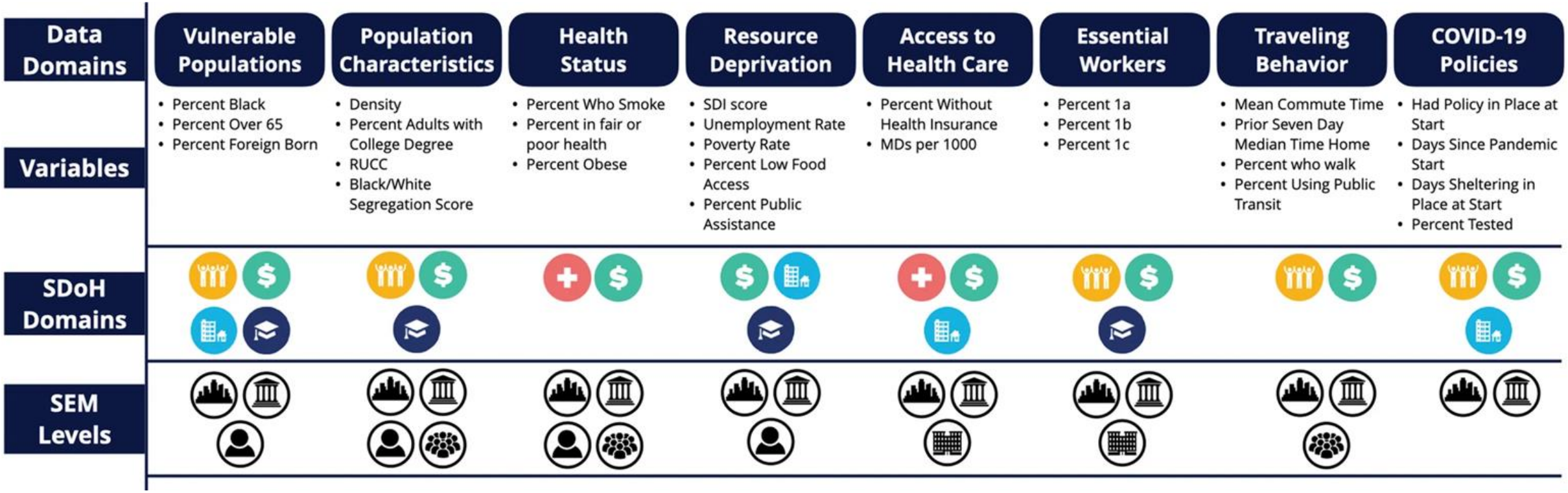
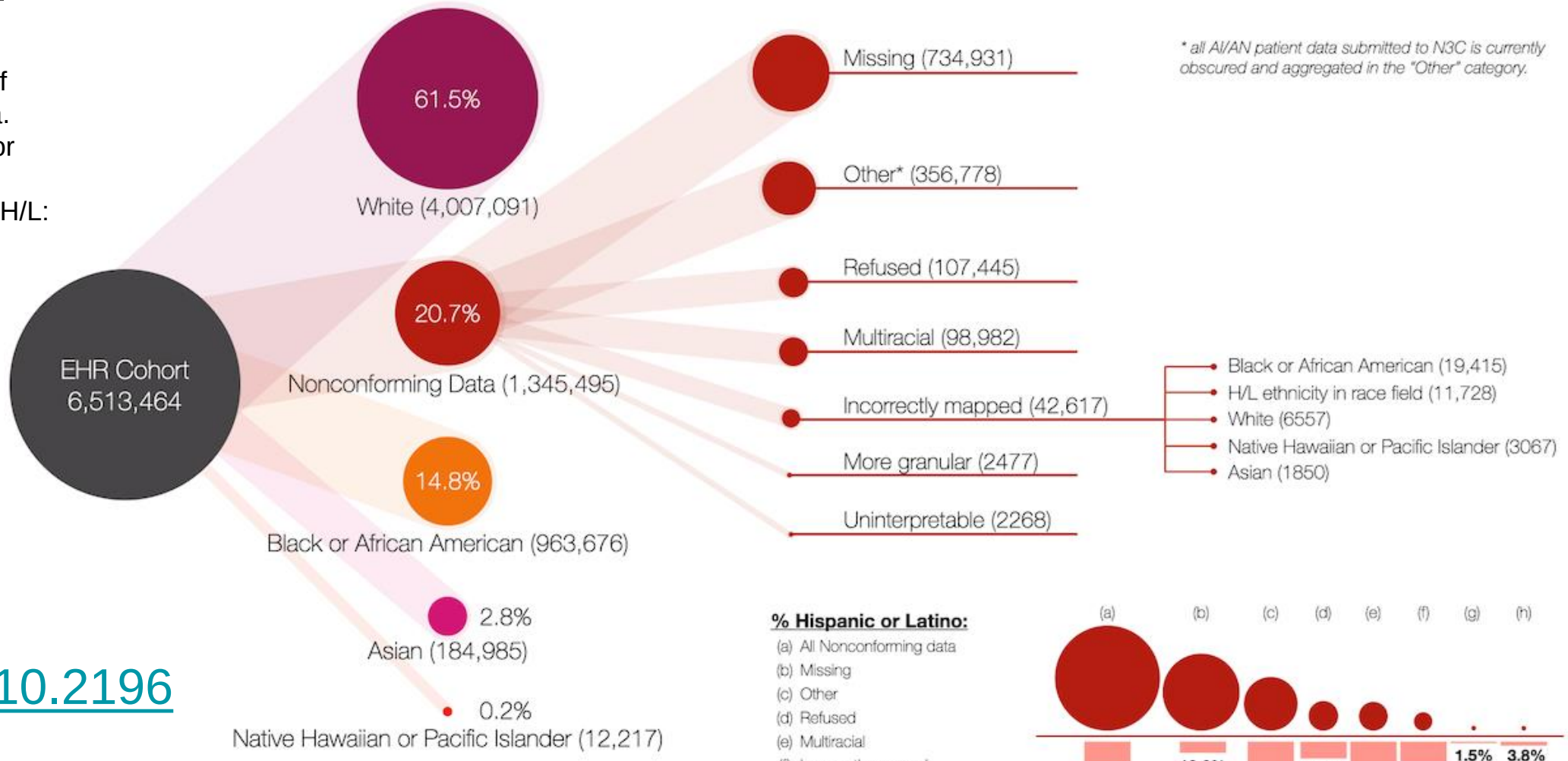


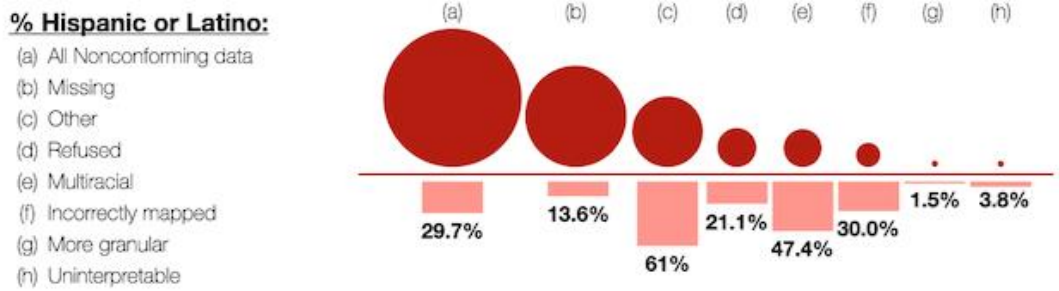
Integrating numerous data sources for supporting local and national analytics is required

Variability in Reporting of Race/Ethnicity Patient Data in the N3C

Weighted tree diagram of nonconforming race data. AI/AN: American Indian or Alaska Native; EHR: electronic health record; H/L: Hispanic/Latino; N3C: National COVID Cohort Collaborative



Cook et al: https://doi.org/10.2196/39235



N3C has afforded a unique opportunity to evaluate variability in SDoH data: its messy and we can all work together to improve!

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SDoH in PASC RECOVER: EHR COHORT

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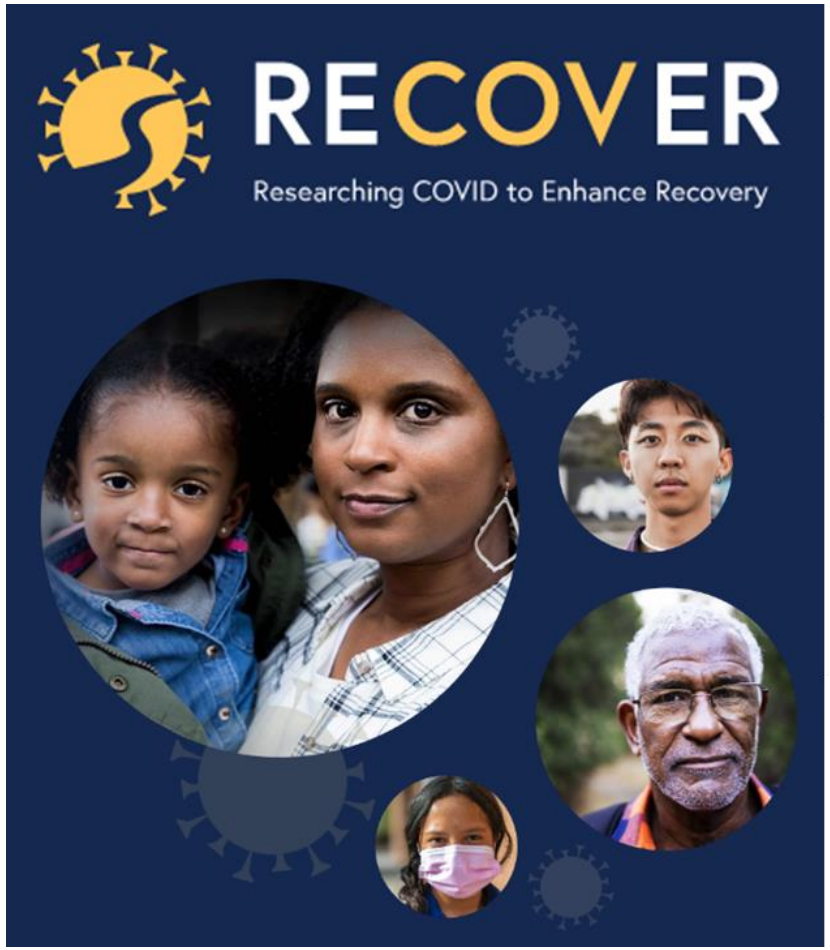

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pcornet®
The National Patient-Centered Clinical Research Network

PEDSnet
A Pediatric Learning Health System

National COVID Cohort Collaborative

RECOVER Query: PASC and Social Vulnerability Index

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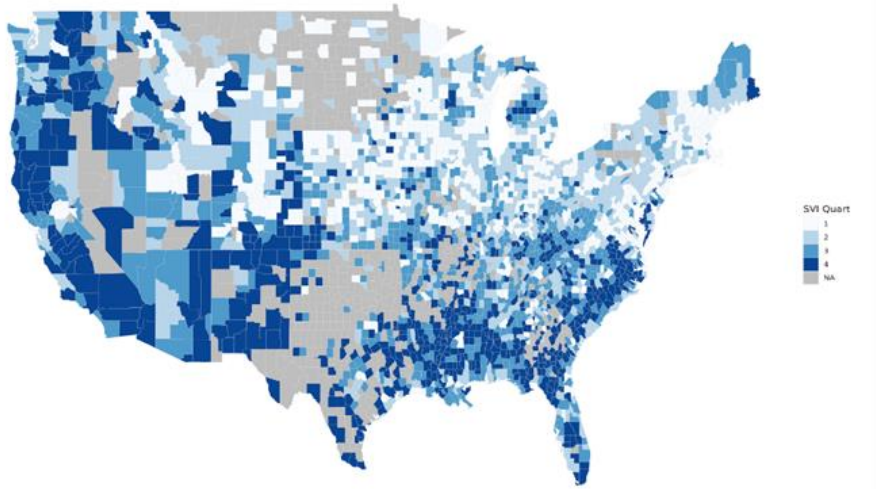
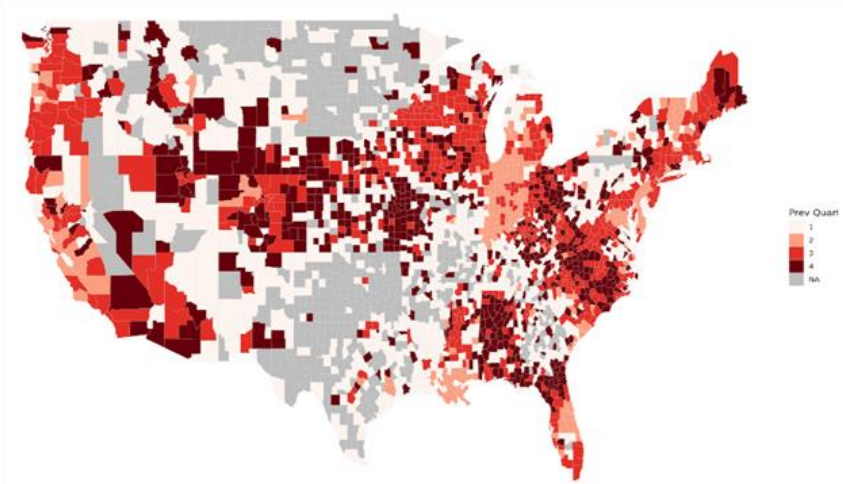
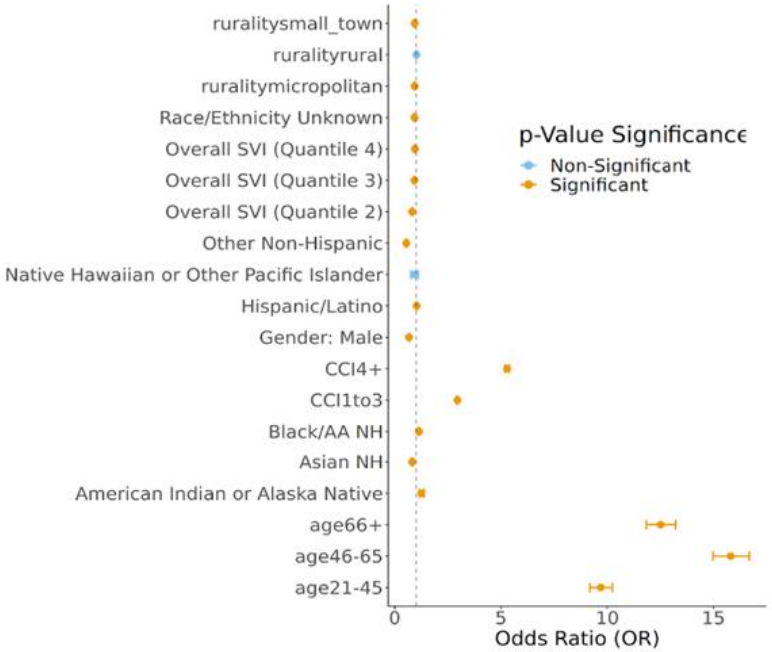
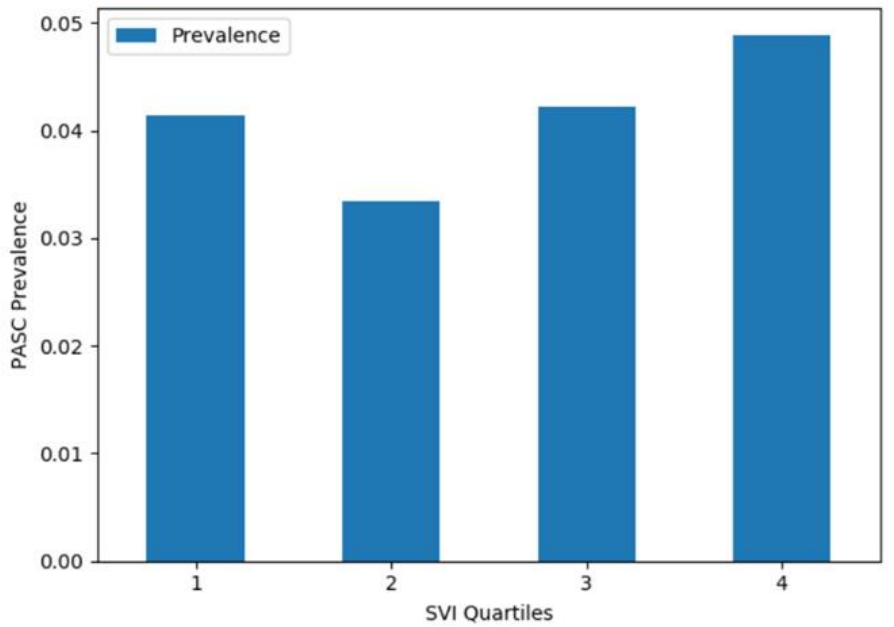


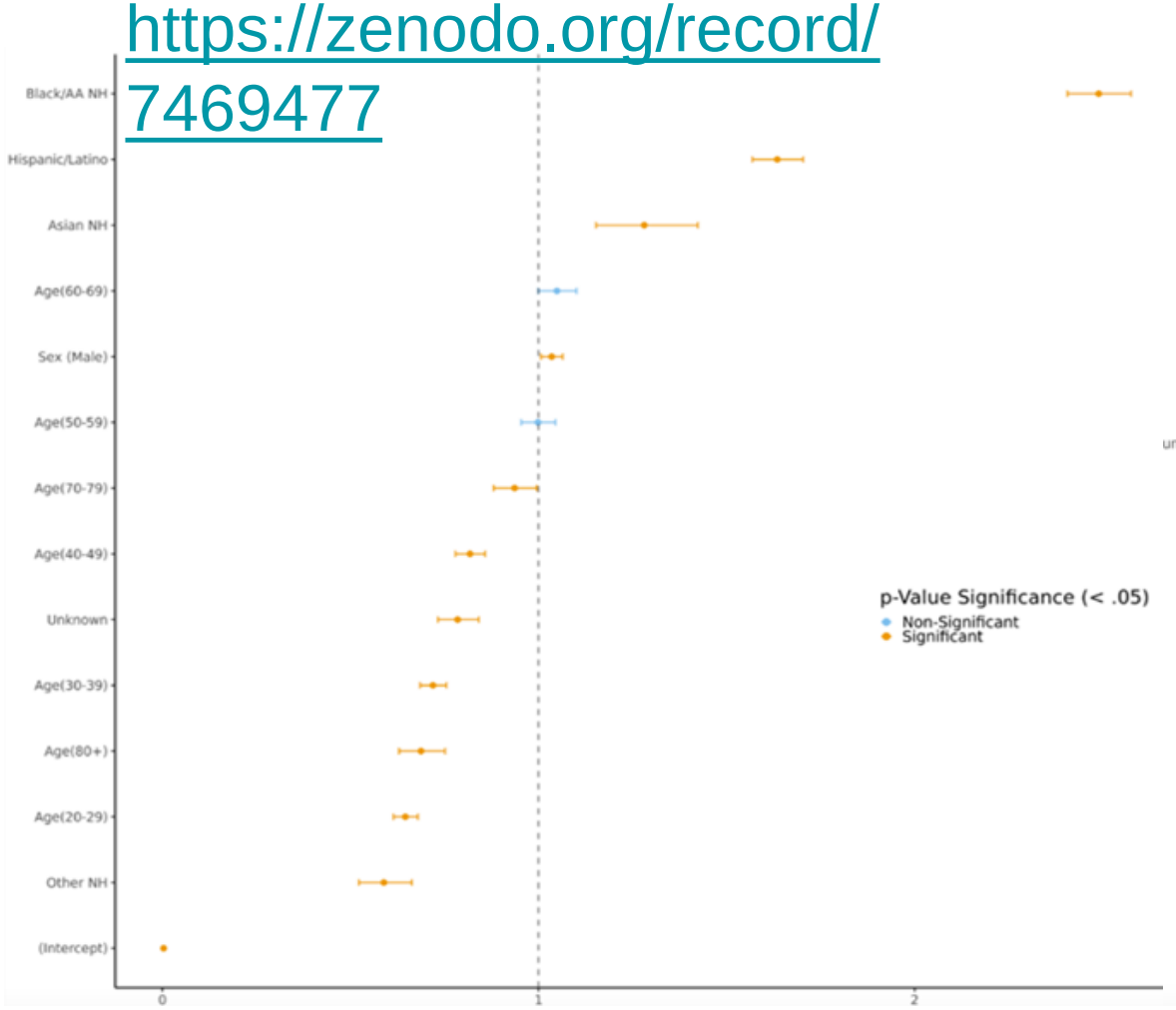


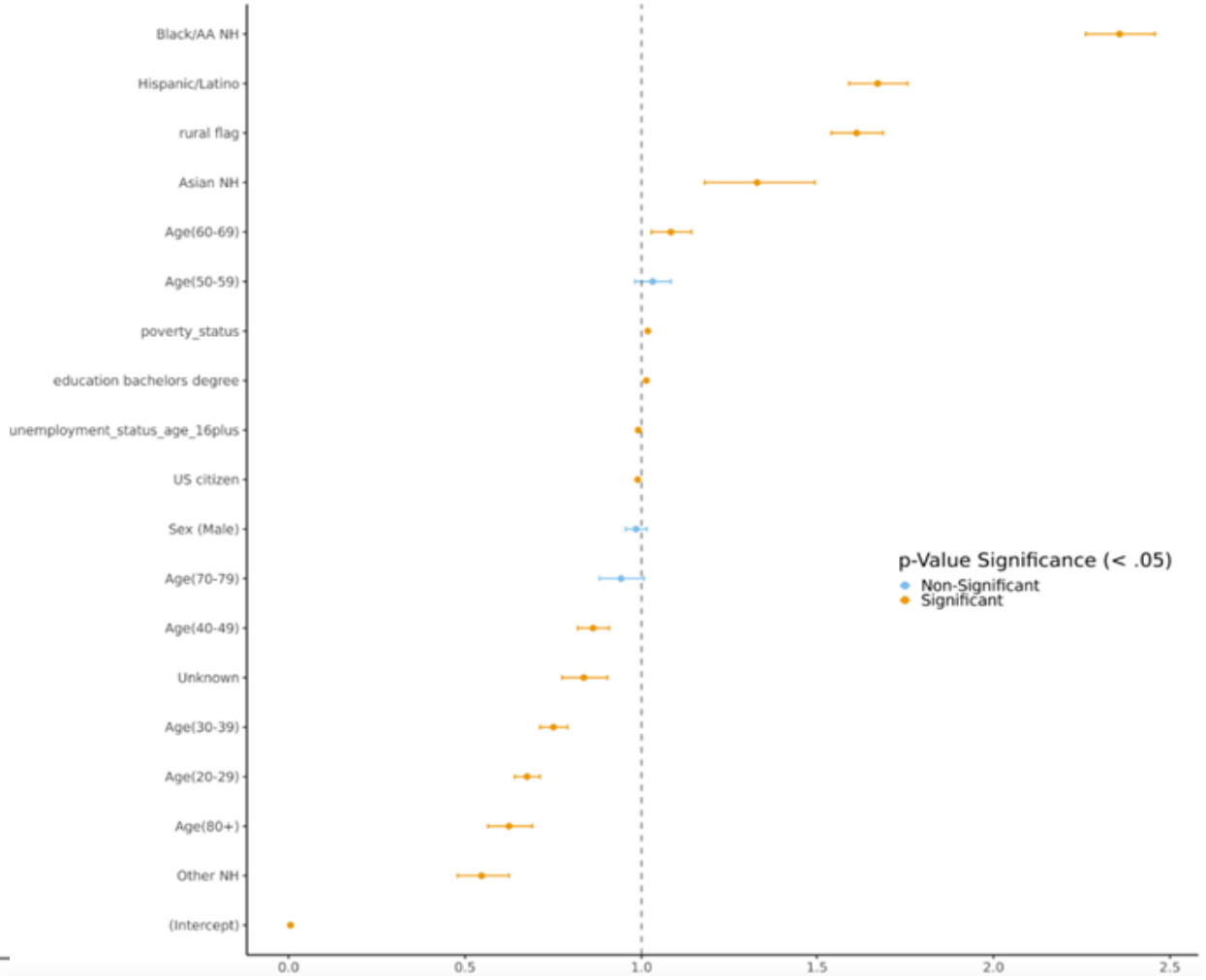




Senator Kaine's RECOVER Query: New Economic Instability

https://zenodo.org/record/7469477





Black/African American and Hispanic or Latino race/ethnicity values patients had consistently high odds ratio for new Economic Instability post-COVID. Controlling for area-level SDoH features did not reduce these apparent racial disparities.

iTHRIV CTSA: Example N3C Equity Projects and SDoH

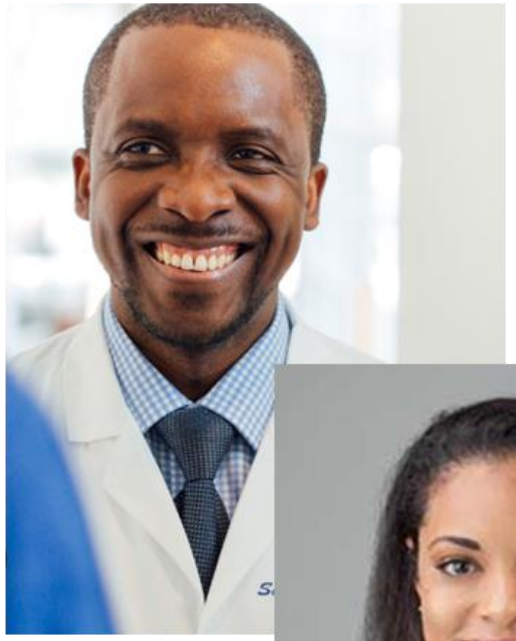
Using Machine Learning to Predict Racial and Ethnic Disparities in the Development of Myocardial Infarction and Pulmonary Thromboembolic Disease Post Acute COVID-19 Infection

Stroke and COVID Population: A Health Equity Analysis

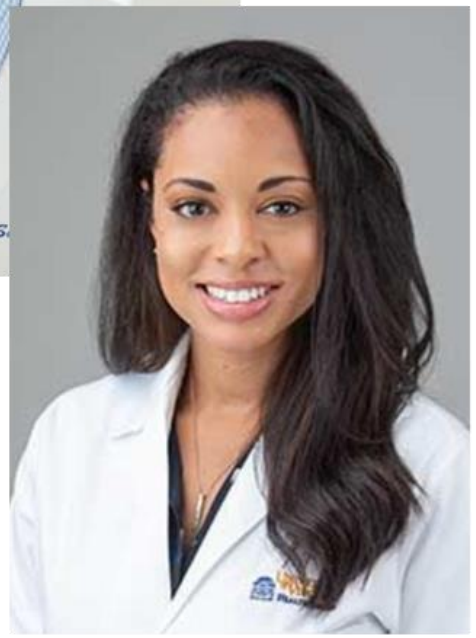
Racial and Ethnic Disparities in COVID-19 Hospitalizations and Treatment Allocation—Analysis of the N3C Database

Investigating the Impact of Temporal Labeling of Emergency Department Visits for COVID-19: Comparing Healthcare Disparities Analyses Using Comprehensive, Single-Site Data with National COVID Cohort Collaborative (N3C) Data

Dr. Sula Mazimba



integrated Translational Health Research Institute of Virginia



Dr. Ebony Hilton

National COVID Cohort Collaborative

SDoH and Racial Equity in Clinical Decision Making

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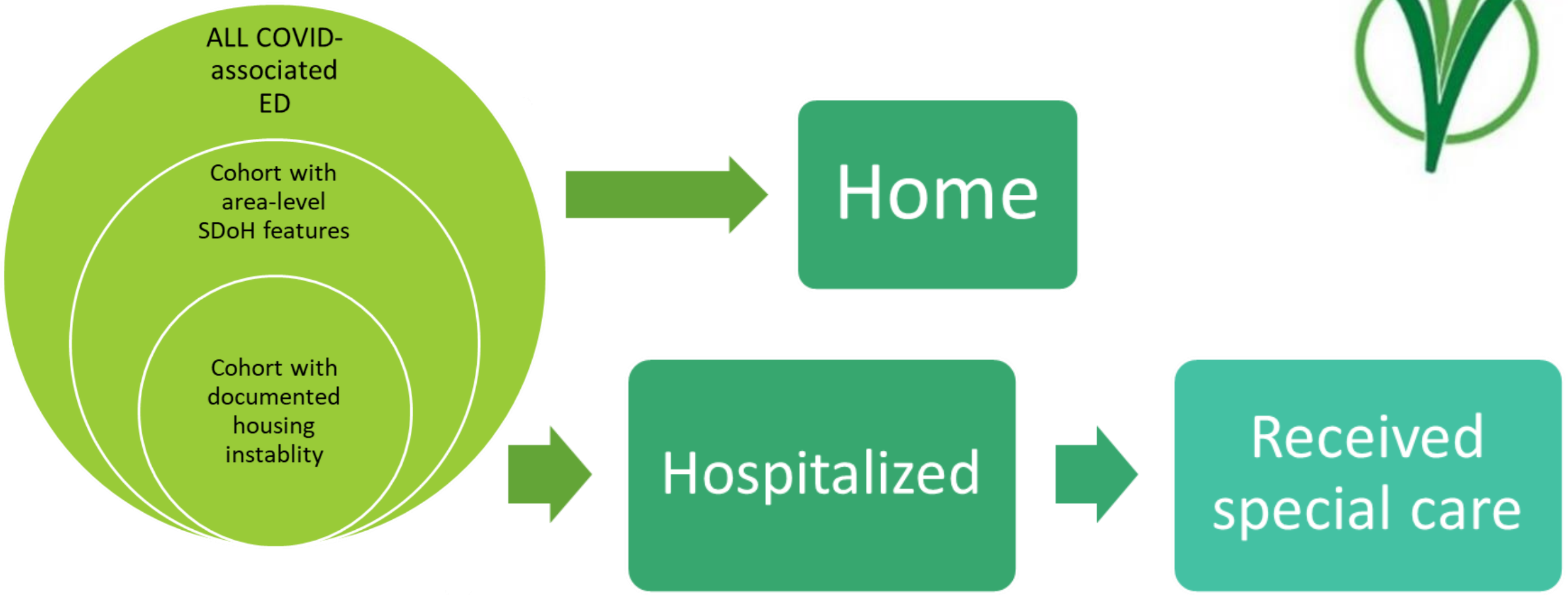

This study sought to examine racial and ethnic disparities around hospitalization decisions in the ED and inpatient treatment allocation. Features were added at the area code level. A sub-analysis was done on the subset of patients with documented housing instability.

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SDoH and Racial Equity in Clinical Decision Making

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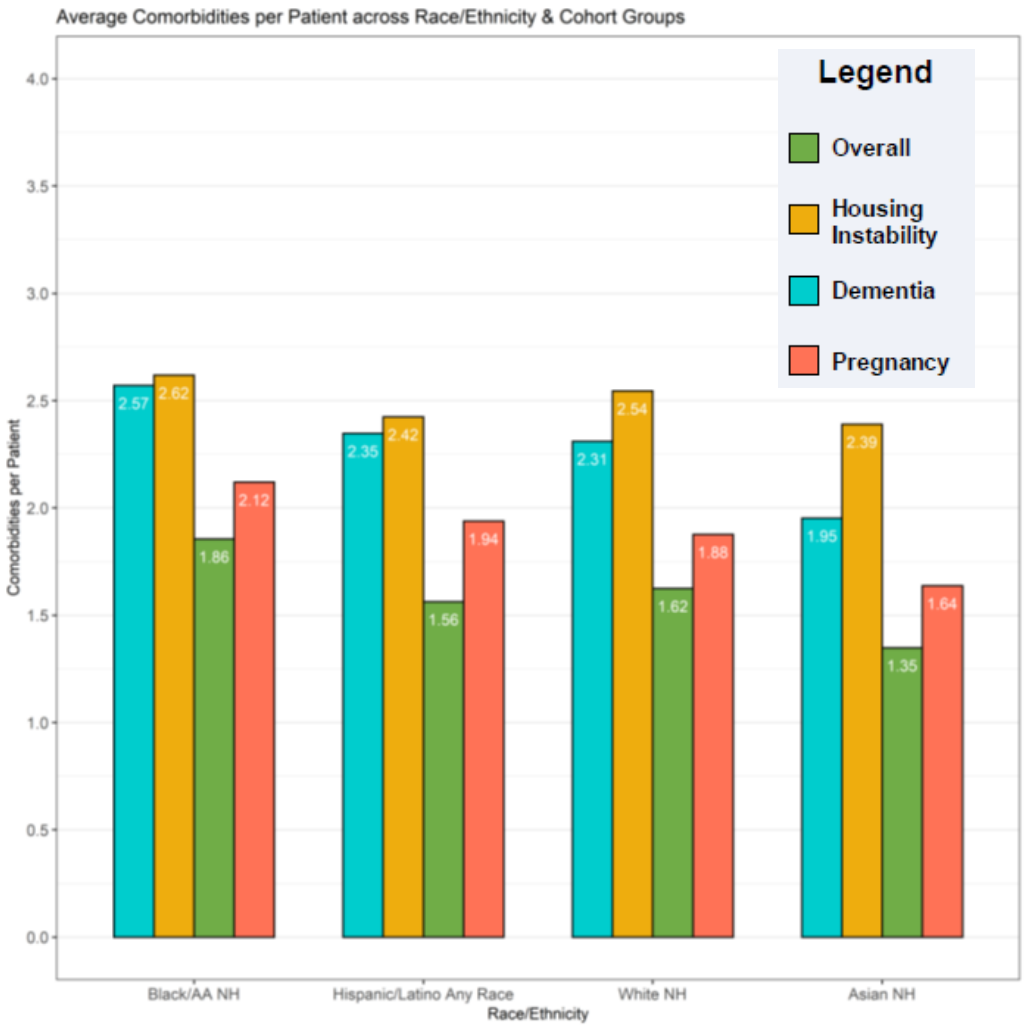

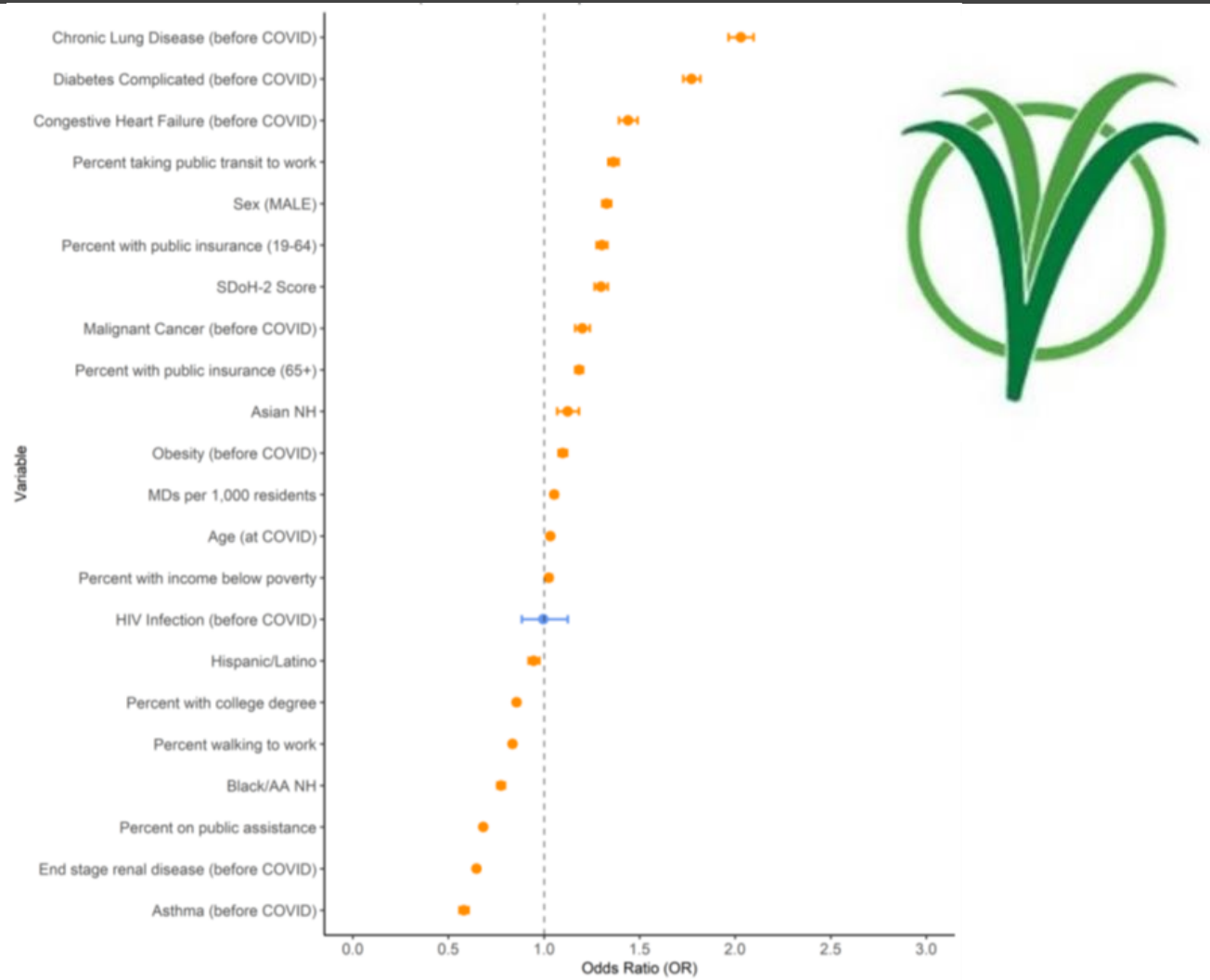

Racial and Ethnic disparities were evident in the analyses, with Black/African American patients having lower odds of hospitalization from the ED when controlling for comorbidities. This is despite the higher number of comorbidities charted for this demographic.

SDoH Research in Health Informatics: Growing the Workforce

The data and tools available in N3C have impacted many students already and enabled them to learn and contribute to the important and quickly evolving practices around incorporating SDoH features into research questions asked of observational health records.

Map SDoH Survey Instruments

If you intend to map SDoH Survey Instruments...

You might want to ask following maturity questions:

1. Does your site currently build in standard screening tools into your EHR? e.g.
    a. PRAPARE
    b. AHC-Tools
    c. BMC-THRIVE
    d. Comprehensive Universal Behavior Health Screen (CUBS)
    e. Food Security Survey (FSS)
    f. Hunger Vital Signs (HVS)
    g. WellRx
    h. Epic SDoH Module
2. Have you already mapped the questions and answers to controlled vocabulary?
3. Do you have a process to transform this information into your CDM?

Link up with the N3C SDoH domain team [https://covid.cd2h.org/domain-teams]

Thank you!

National Center for Advancing Translational Sciences

CTSA Clinical & Translational Science Awards Program

IDeA Institutional Development Award CTRnet Clinical & Translational Research Network

RECOVER Researching COVID to Enhance Recovery

An Initiative Funded by the National Institutes of Health

The National COVID Cohort Collaborative (N3C): Rationale, Design, Infrastructure, and Deployment

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Shaymaa Al-Shukri,[4,15] Adil Alaoui,[101] Ahmad Baghal,[15] Pamela D. Banning,[15,100] Edward M. Barbour,[8,15] Michael J. Becich,[15,52,101] Afshin Beheshti,[14] Gordon R. Bernard,[8,15] Sharmodeep Bhattacharyya,[100] Mark M. Bissell,[9,15] L. Ebony Boulware,[14,100] Samuel Bozzette,[100,101] Donald E. Brown,[101] John B. Buse,[14] Brian J. Bush,[8,101] Tiffany J. Callahan,[14,52] Thomas R. Campion,[8,15] Elena Casiraghi,[9,15] Ammar A. Chaudhry,[13,14] Guanhua Chen,[9] Anjun Chen,[13] Gari D. Clifford,[8,15] Megan P. Coffee,[14,100] Tom Conlin,[14] Connor Cook,[7,78] Keith A. Crandall,[9,14,101] Mariam Deacy,[78] Racquel R. Dietz,[78] Nicholas J. Dobbins,[8,9] Peter L. Elkin,[15,52,100] Peter J. Embi,[52,101] Julio C. Facelli,[8,15] Karamarie Fecho,[13] Xue Feng,[9] Randi E. Foraker,[8,13,15] Tamas S. Gal,[8,15] Linqiang Ge,[14] George Golovko,[15,101] Ramkiran Gouripeddi,[14,15] Casey S. Greene,[13,14] Sangeeta Gupta,[52,101] Ashish Gupta,[13,101] Janos G. Hajagos,[9,15] David A. Hanauer,[15,52] Jeremy Richard Harper,[9,14,52] Nomi L. Harris,[14] Paul A. Harris,[101] Mehadi R. Hassan,[9] Yongqun He,[15,52,100] Elaine L. Hill,[9,14] Maureen E. Hoatlin,[14] Kristi L. Holmes,[4,101] LaRon Hughes,[14] Randeep S. Jawa,[14] Guoqian Jiang,[14] Xia Jing,[7,14] Marcin P. Joachimiak,[8,15] Steven G. Johnson,[9,14,101] Rishikesan Kamaleswaran,[9,15,78] Thomas George Kannampallil,[15,101] Andrew S. Kanter,[15,52] Ramakanth Kavuluru,[9,13,14] Kamil Khanipov,[8,14] Hadi Kharrazi,[9,14] Dongkyu Kim,[15,52] Boyd M. Knosp,[8,15] Arunkumar Krishnan,[9] Tahsin Kurc,[9,15] Albert M. Lai,[101] Christophe G. Lambert,[52,101] Michael Larionov,[14] Stephen B. Lee,[1,14] Michael D. Lesh,[9] Olivier Lichtarge,[14] John Liu,[9] Sijia Liu,[8,9,101] Hongfang Liu,[9,15] Johanna J. Loomba,[1,15,78,101] Sandeep K. Mallipattu,[9,14,15] Chaitanya K. Mamillapalli,[14] Christopher E. Mason,[15] Jomol P. Mathew,[8,15,52] James C. McClay,[101] Julie A. McMurry,[1,4,7,9,13,14,78] Paras P. Mehta,[14] Ofer Mendelevitch,[9] Stephane Meystre,[8,14,15] Richard A. Moffitt,[9,13,15] Jason H. Moore,[8,9] Hiroki Morizono,[13,14,15,52] Christopher J. Mungall,[15,52] Monica C. Munoz-Torres,[7,10,78] Andrew J. Neumann,[78] Xia Ning,[14] Jennifer E. Nyland,[13,14] Lisa O'Keefe,[78] Anna O'Malley,[78] Shawn T. O'Neil,[78] Jihad S. Obeid,[10,14,15] Elizabeth L. Ogburn,[13] Jimmy Phuong,[9,15,52,100,101] Jose D Posada,[8,15] Prateek Prasanna,[14,52] Fred Prior,[9,14,15] Justin Prosser,[9,78] Amanda Lienau Purnell,[101] Ali Rahnavard,[9,52] Harish Ramadas,[9,52,78] Justin T. Reese,[9,10] Jennifer L. Robinson,[14,100] Daniel L. Rubin,[101] Cody D. Rutherford,[9,101] Eugene M. Sadhu,[8,15] Amit Saha,[9] Mary Morrison Saltz,[15,52,101] Thomas Schaffter,[78] Titus KL Schleyer,[14] Soko Setoguchi,[8,14,15] Nigam H. Shah,[8,14] Noha Sharafeldin,[14] Evan Sholle,[15,52] Jonathan C. Silverstein,[15,52,101] Anthony Solomonides,[101] Julian Solway,[14,101] Jing Su,[101] Vignesh Subbian,[9,52,101] Hyo Jung Tak,[15] Bradley W. Taylor,[9,14] Anne E. Thessen,[14,101] Jason A. Thomas,[15] Umit Topaloglu,[15,52] Deepak R. Unni,[8,9,15,52] Joshua T. Vogelstein,[14] Andréa M. Volz,[7] David A. Williams,[14,15] Kelli M. Wilson,[9,78] Clark B. Xu,[8,9,15] Hua Xu,[9,10,14] Yao Yan,[9,15,52] Elizabeth Zak,[8,15] Lanjing Zhang,[101] Chengda Zhang,[14] Jingyi Zheng,[14]

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Open science and team science at an unprecedented scale in clinical informatics!

National COVID Cohort Collaborative

Articles

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- Madlock-Brown et al. (2022) "Clinical, social, and policy factors in COVID-19 cases and deaths: methodological considerations for feature selection and modeling in county-level analyses"
- Phuong et al., (2022) "Social Determinants of Health Factors for Gene–Environment COVID-19 Research: Challenges and Opportunities"
- Phuong et al., (2022) "Advancing Interoperability of Patient-level Social Determinants of Health Data to Support COVID-19 Research"
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- Johanna Loomba, & Suchetha Sharma. (2022). New Economic Instability Post-COVID-19 Infection: A Year 1 Quarter 4 PASC RECOVER EHR-Based Query Report from N3C (21Dec2022). Zenodo. https://doi.org/10.5281/zenodo.7469477
- E. Cathey et al., "Using Machine Learning to Predict Development of Heart Failure, during Post-Acute COVID-19, by Race and Ethnicity," 2022 Systems and Information Engineering Design Symposium (SIEDS), Charlottesville, VA, USA, 2022, pp. 276-281, doi: 10.1109/SIEDS55548.2022.9799382.
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Next Steering Committee Meeting:

June 12, 2:30-3:30 PM ET

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