

Considerations on Identity and Bias in Health Data

Abel Kho MD, MS, FACMI

5/24/21



CHiP
I.AIM

Institute for Augmented
Intelligence in Medicine

Disclosures

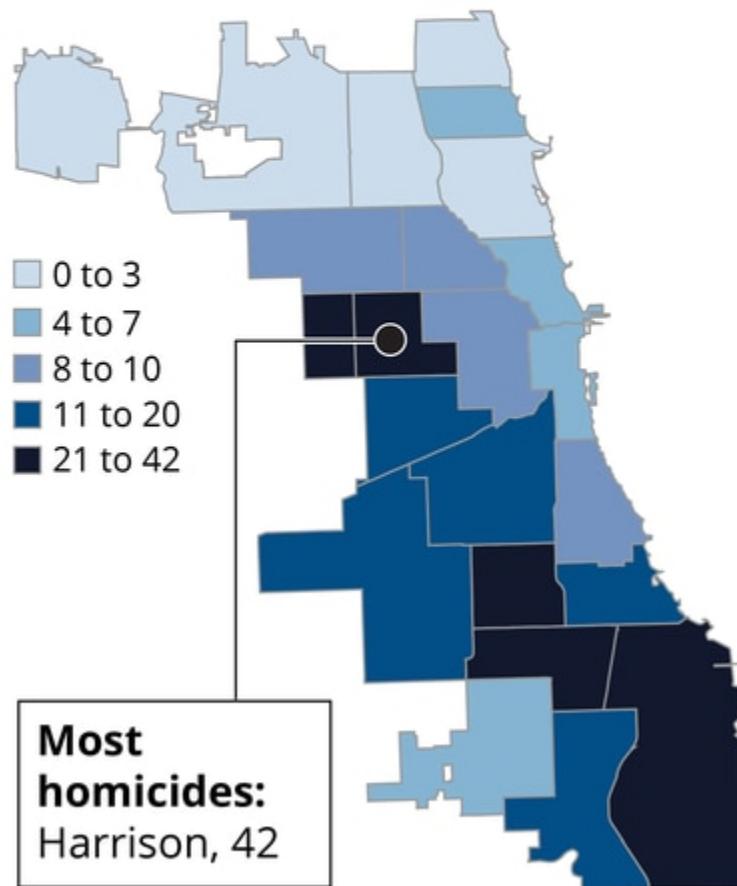
- I am Advisor and Equity holder in Datavant.



Homicides through June 21



By police district

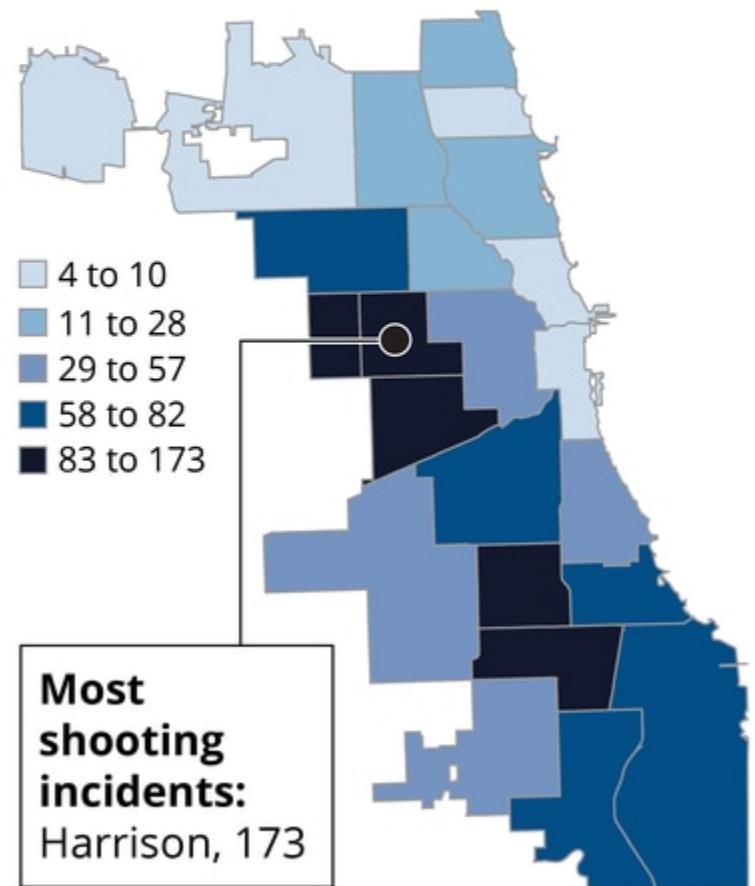


SOURCE: Chicago Police Department

Shooting incidents through June 21



By police district



CHICAGO TRIBUNE

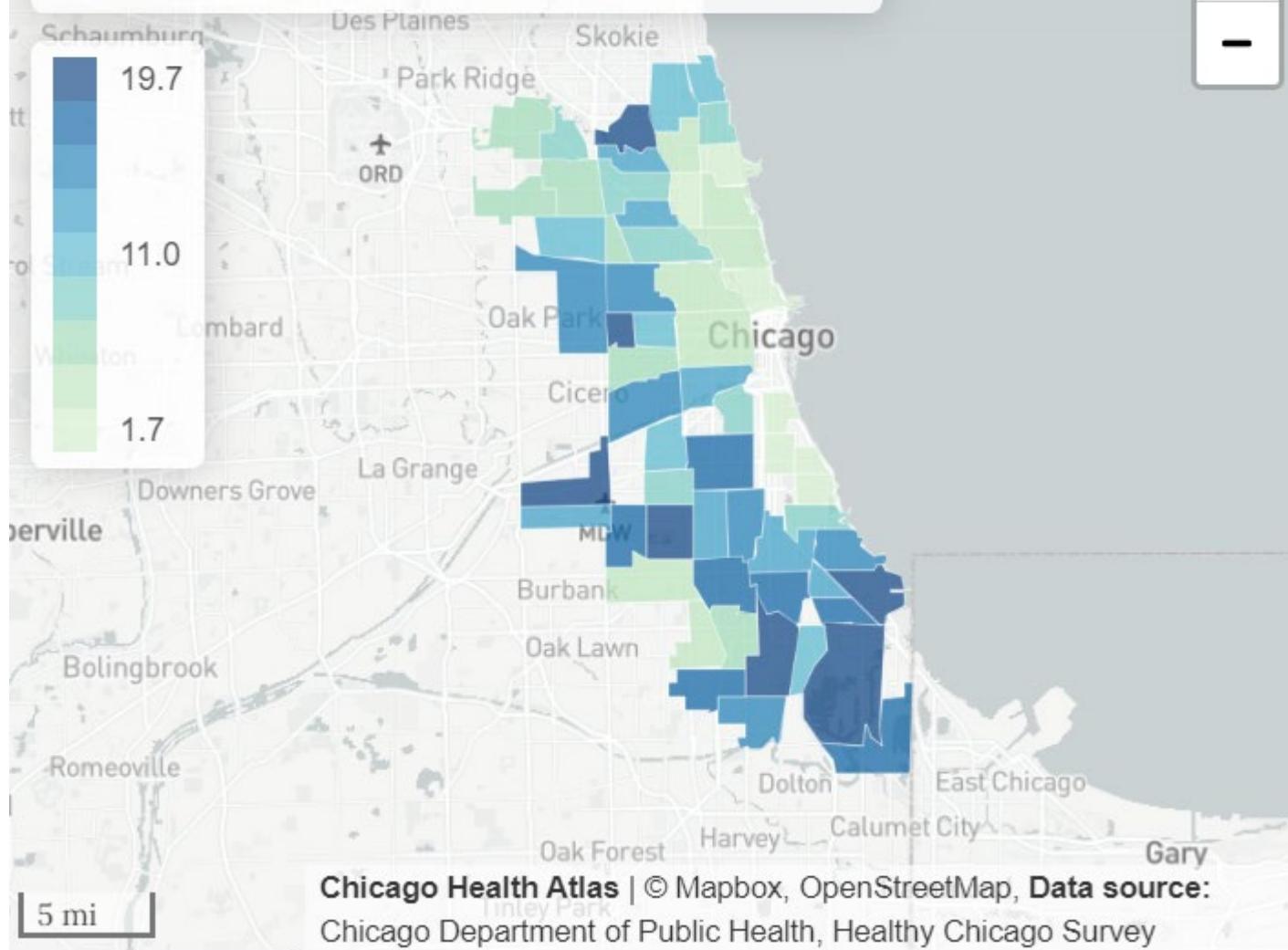


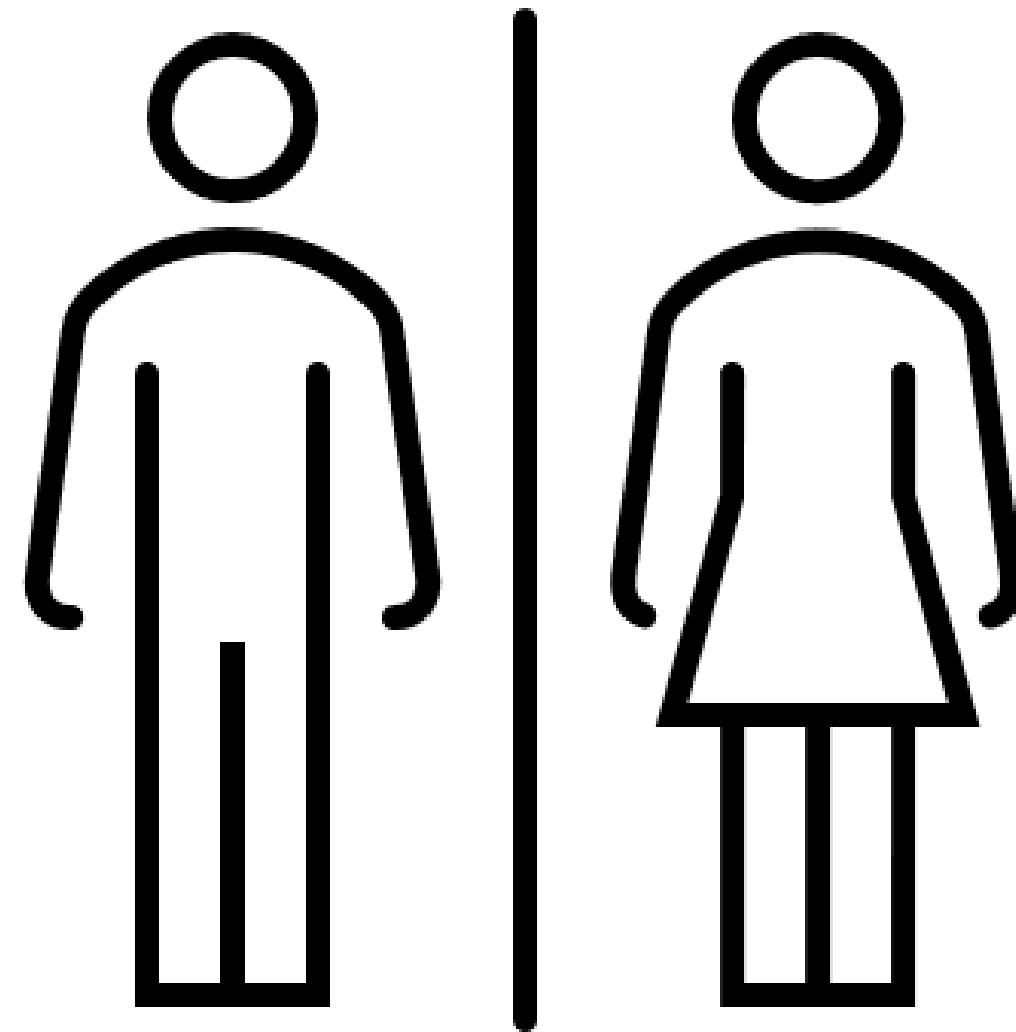
Adult diabetes rate

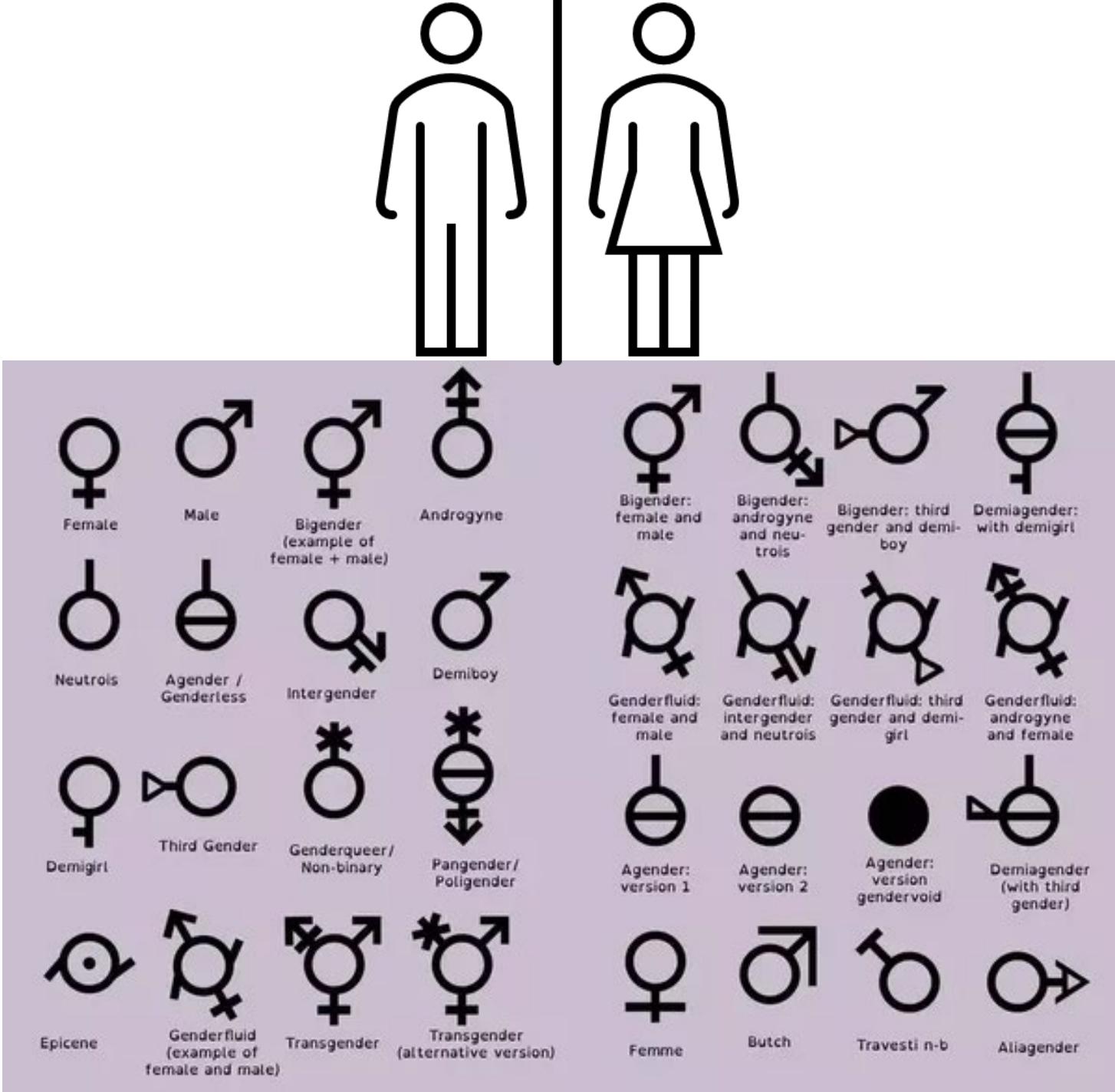
2016-2018

% of adults

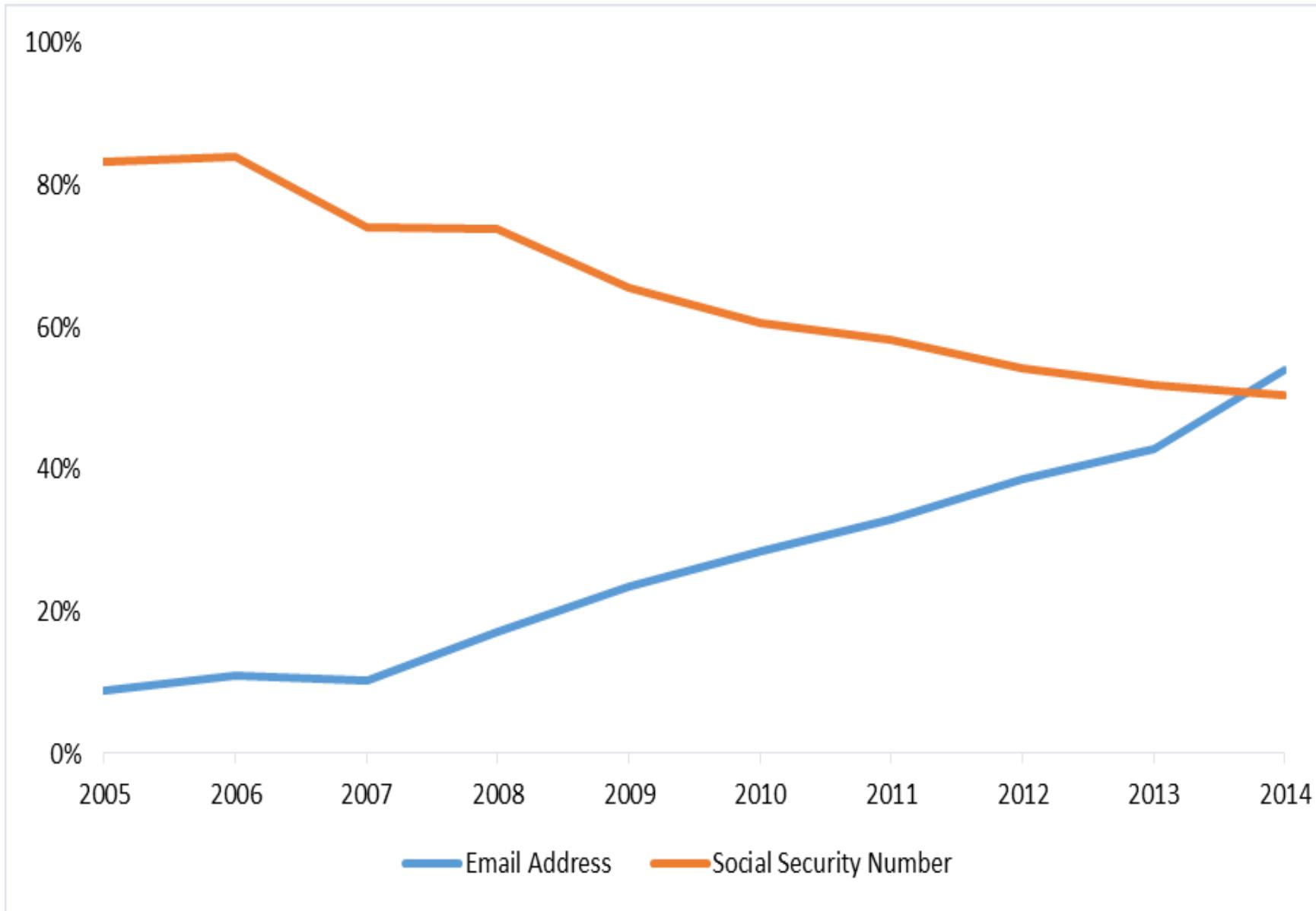
Tap and hold a community area to see more

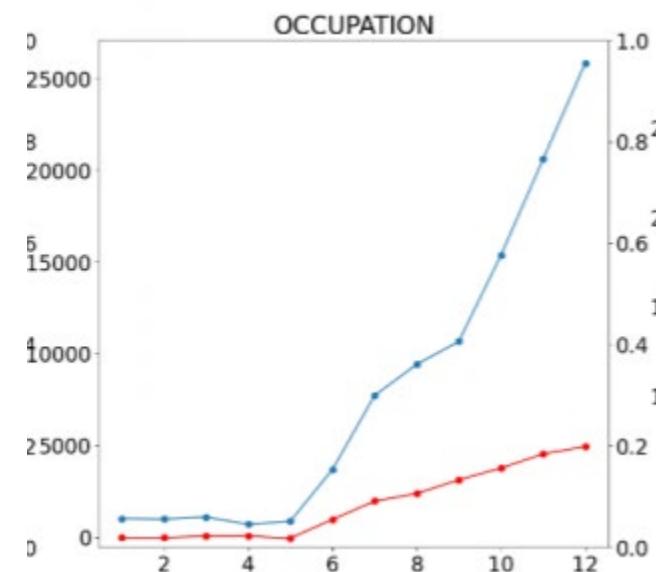
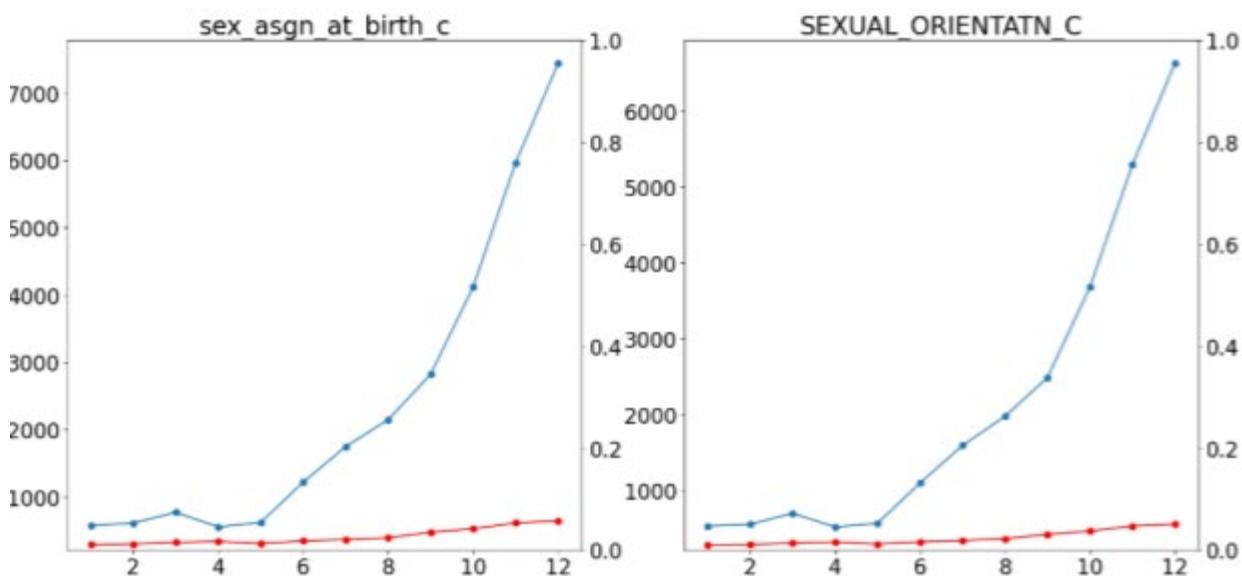
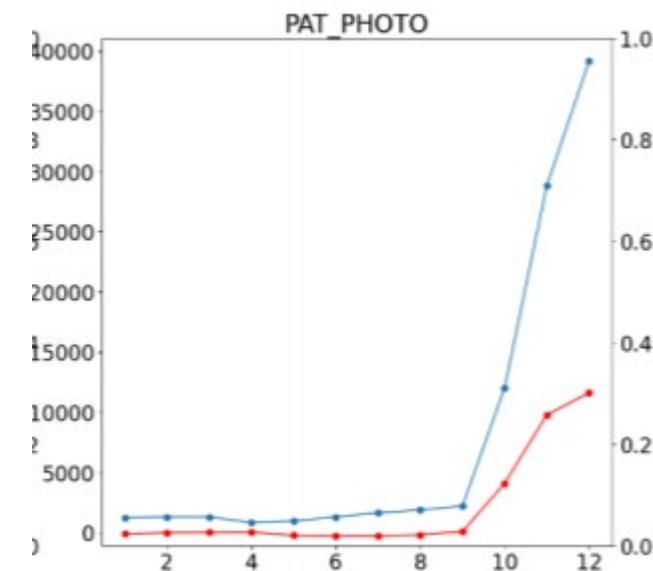
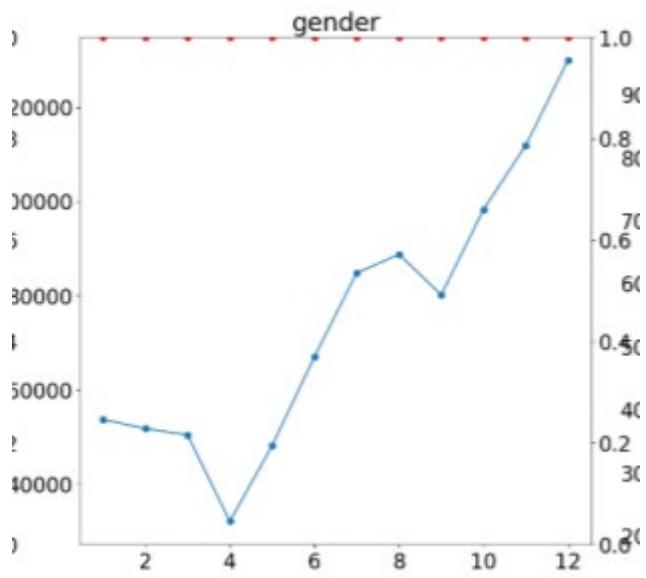






Data availability in EHR registrations





Individual Privacy
Community benefit
Better Treatments
Representativeness
Self-Identity



Big Brother
Research Insights
Who can afford treatment?
Bias (e.g. who is missing?)
Categories/labels

Some considerations

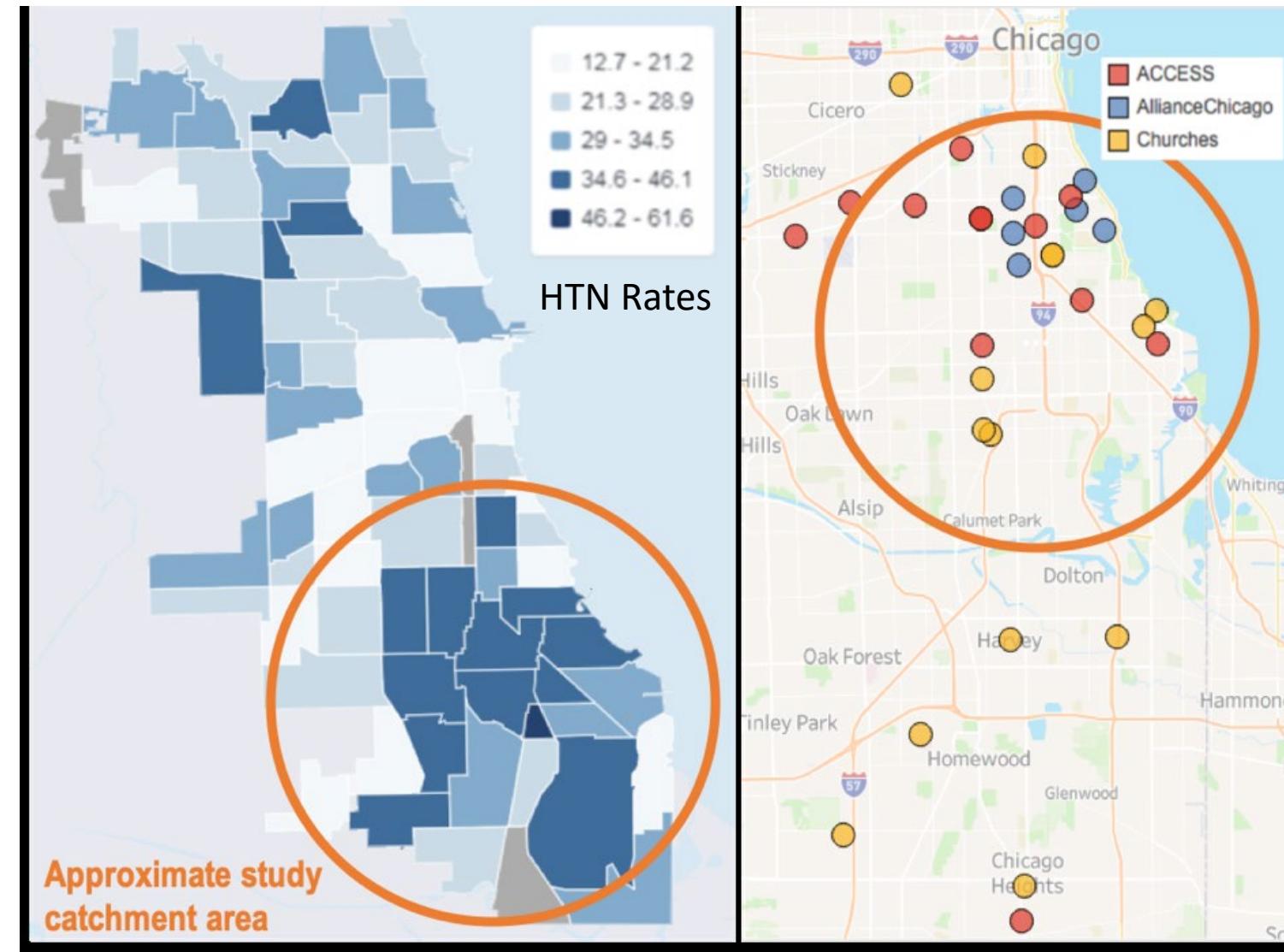
- Our data is biased and is constantly changing. Identity is changing too. Understand the when and how collected.
- Data hygiene is easier to manage (and can be policy driven) than data bias, which requires deeper engagement of at-risk/hidden populations.
- Data bias is not (solely) a technical issue. Engage people/populations/patients early and often.

Community Intervention to Reduce CardiovascuLar Disease in Chicago (CIRCL-Chicago)

Funder: NHLBI under the DECIPHeR mechanism:
1UG3HL154297-01

PIs: Abel Kho (Northwestern), JD Smith (University of Utah), Paris Davis (Pastors4PCOR)

Goal: Adapt an evidence-based hypertension intervention (Kaiser bundle) to under-resourced neighborhoods in the South Side of Chicago, leveraging a network of research-enabled churches (Pastors4PCOR) and local community health centers.



TRCDO Pastors4PCOR – A Community Partner



Housing Counseling Agency

Since 2010
2020 YTD:
COVID Pandemic
Emergency Housing (74) & Rental (608) Clients; Direct Support \$4.1 Million Hardest Hit Clients (168) Assistance \$5,880,000 Direct to Clients
Housing Counseling
Households
Assisted: 380; \$18M
• Staff – 6 Paid
• Funders
• Housing Action of Illinois
• HUD
• Illinois Hardest Hit
• Illinois Housing Development Authority
Foreclosure Prevention and Graduated Programs
• State Emergency Housing Funds Programs



CEDA/LIHEAP Energy Assistance

Since 2006
2020 YTD: \$1,300,000 Direct to Clients for Gas, Lights, Water
Tier 1 Level Site

- Clients
 - Served: 1,100
 - Assistance: AVG \$1,200
- Staff – 4 Paid
- Sites – 2
 - TRCDO (South)
 - Heritage (West)
- Funders & Partners:
 - CEDA Cook County
 - ComEd
 - COMCAST



Harvest for the World Food Pantry

Since 2002
2020 YTD:
+15,500 Families
\$376,000 Direct to Clients

- 2019 Clients - Served: 22,536
 - Assistance: \$200 Per Week per Family
- Volunteers – 12

Hunger Walk 2019

- 95 Walkers



Health Awareness and Healthcare Resources

Since 1999
2020 YTD:
Community Engagement
Community COVID Testing Onsite: 415 Flu Shots: 25

Pastors4PCOR

59 Trained IRB Health Research Ministry Ambassadors
22 P4P Trainers
Faith-Based Network: 55
Evidenced Based Work: 1 Manual 4 Publications

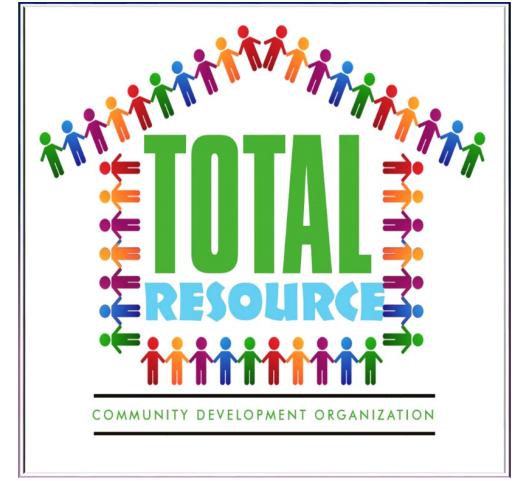
- Stipends: \$30K to RMAs
- Funders/Partners:
 - PCORI, NIH, NW ARCC, CCT ADAPTABLE, ACTS, Rush, U of Illinois & Chicago, Miami U, IIT, Advocate, CORE



Community Youth Programs

Since 2008
2020 YTD:
\$750 Stipend to 34 ASM Interns

- Clients
 - Served: 580 Youth since 2008
- Staff – 2.5 Paid
- Funders:
 - AfterSchool Matters Summer “Music Experience Program”



Community-driven research



Pastors4PCOR (P4P) Faith-Based Community Network

P4P Two-fold Community Engagement Approach

- Pastors4PCOR – Becoming Engagement Ready
- Stakeholder Projects – Engaging a Specific Study

