

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

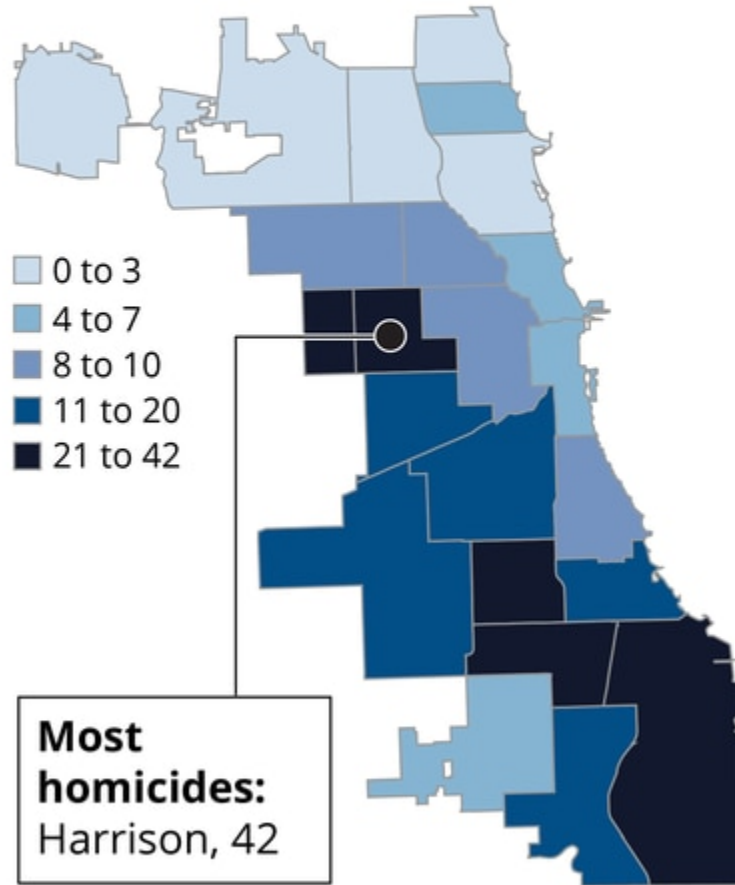
- I am Advisor and Equity holder in Datavant.



Homicides through June 21



By police district

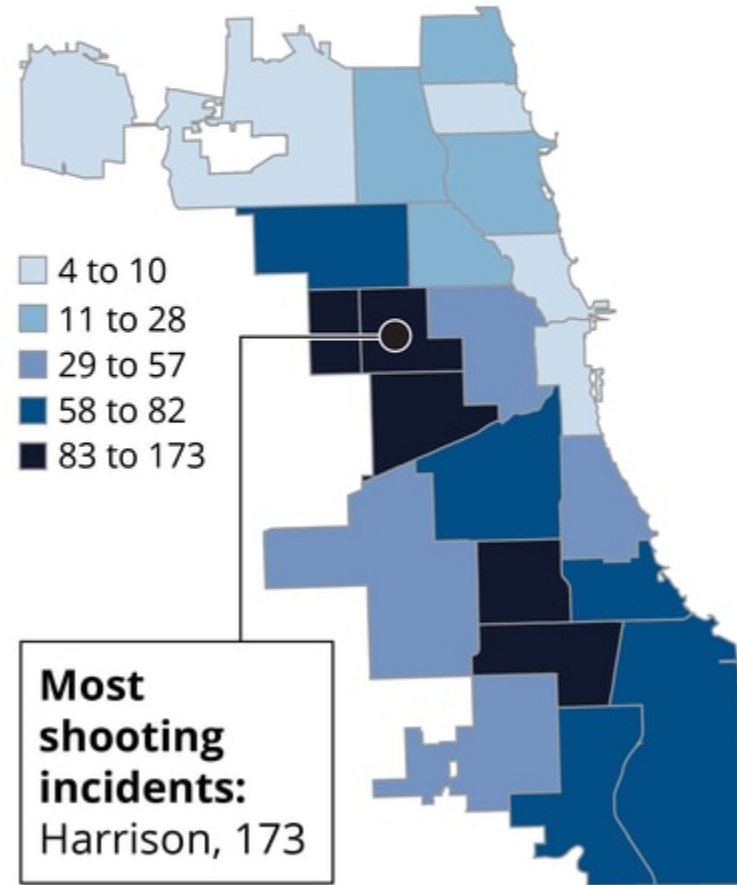


SOURCE: Chicago Police Department

Shooting incidents through June 21



By police district



CHICAGO TRIBUNE

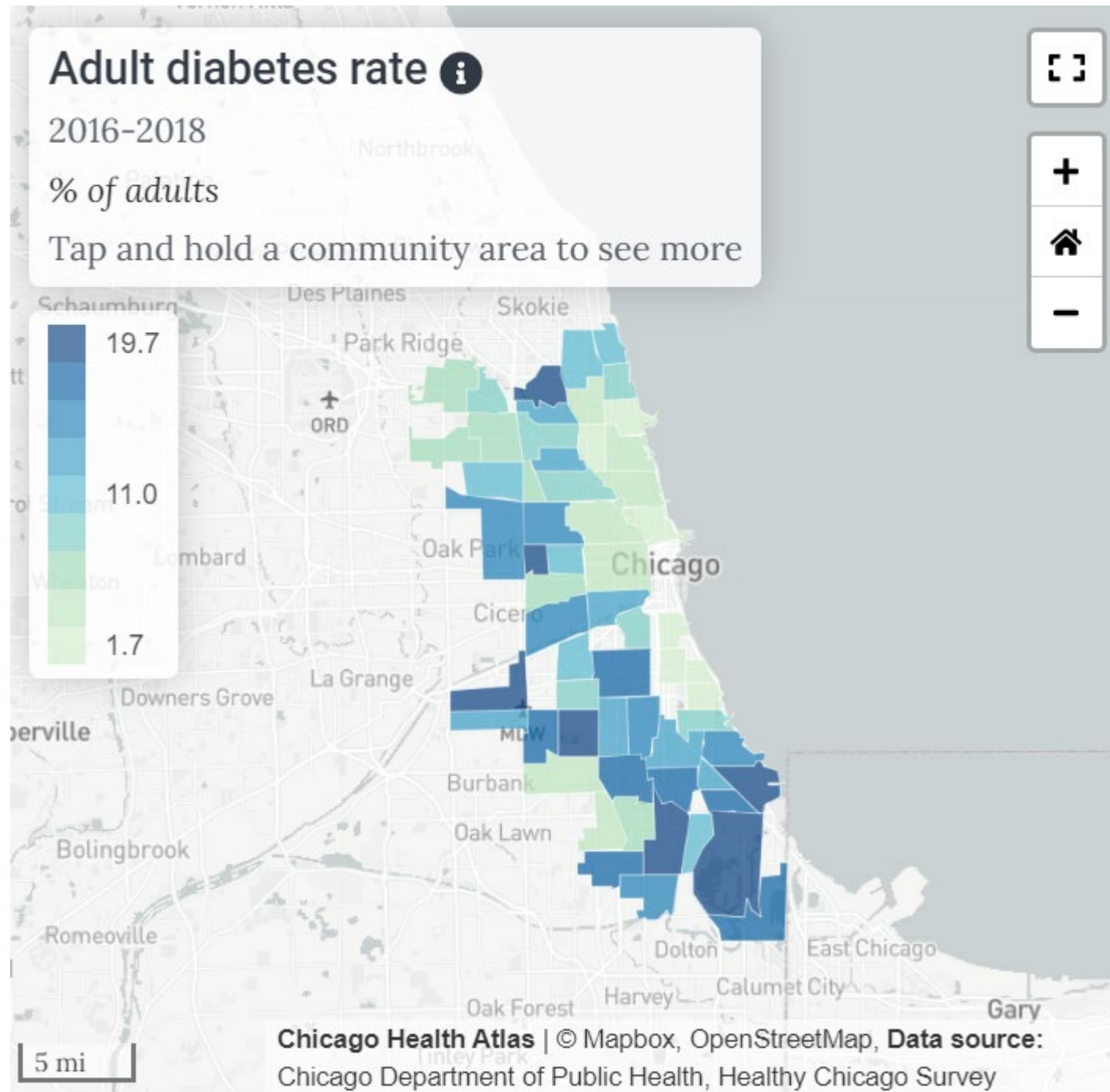
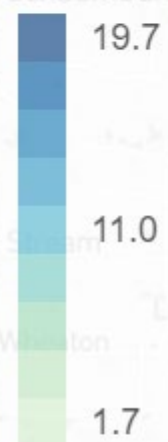


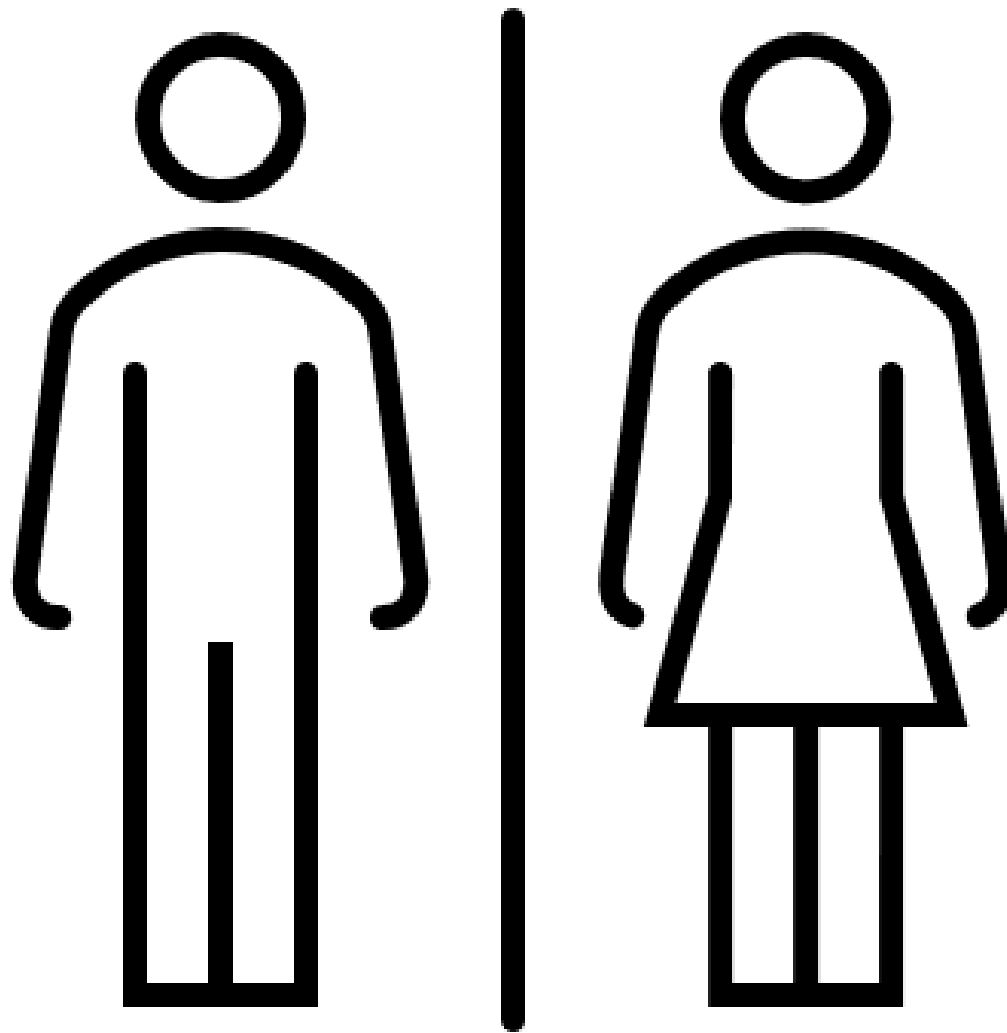
Adult diabetes rate

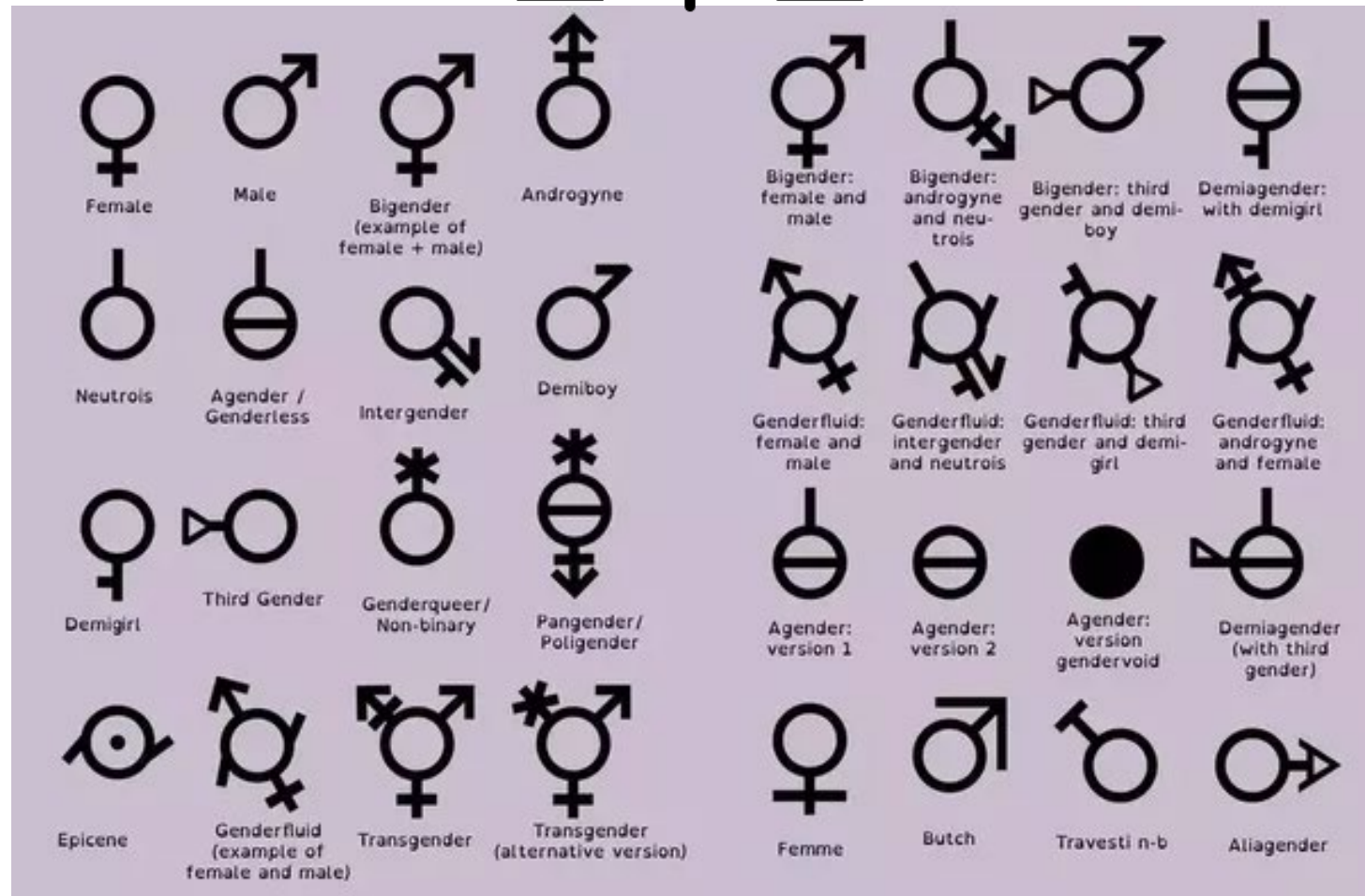
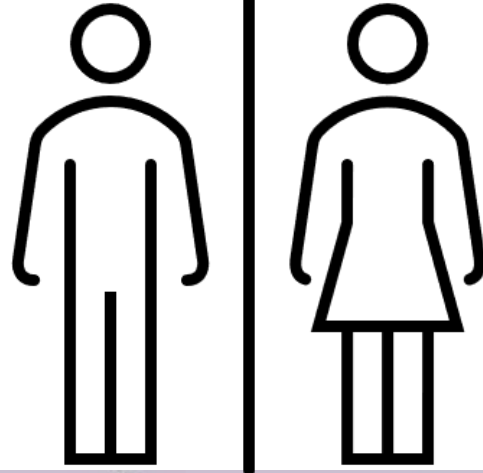
2016-2018

% of adults

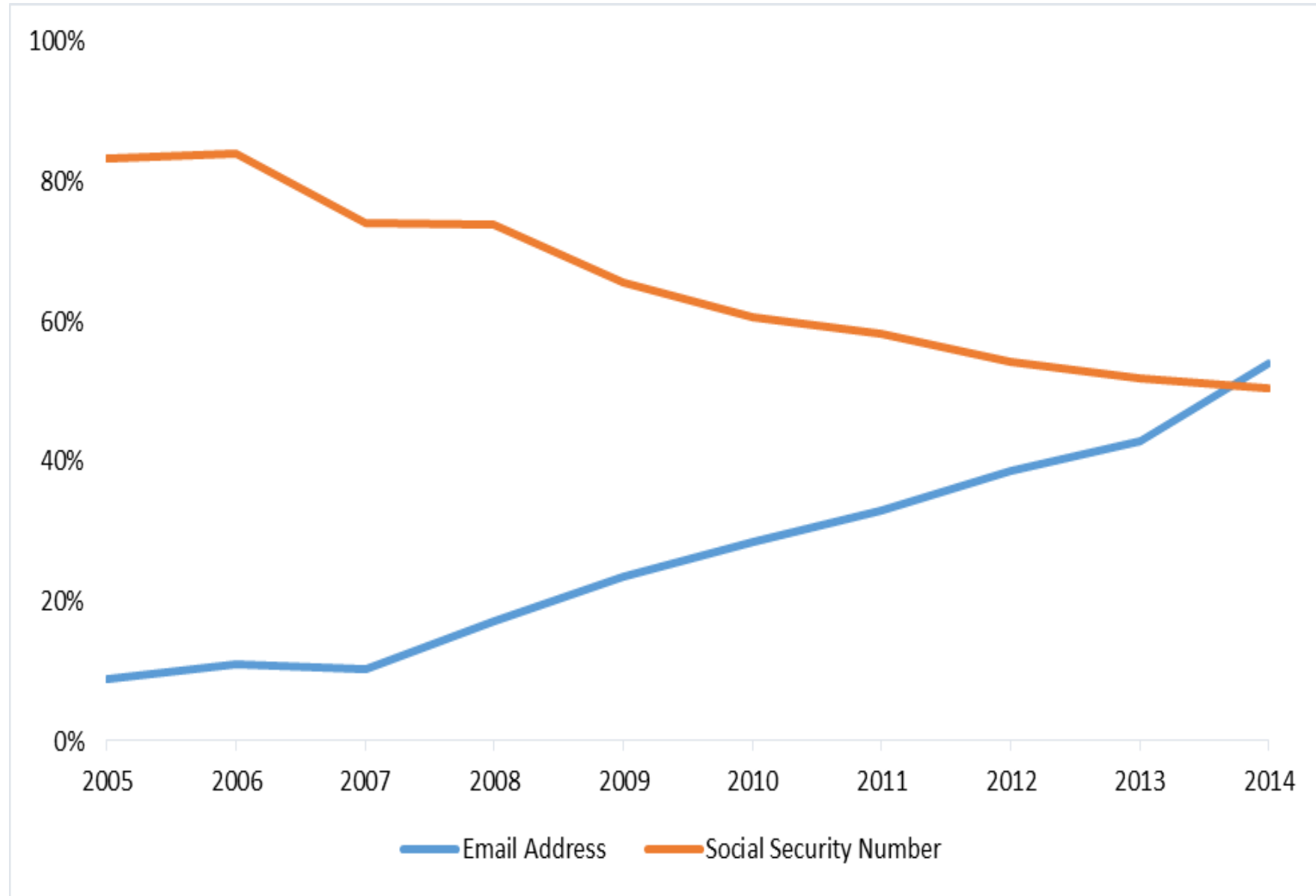
Tap and hold a community area to see more



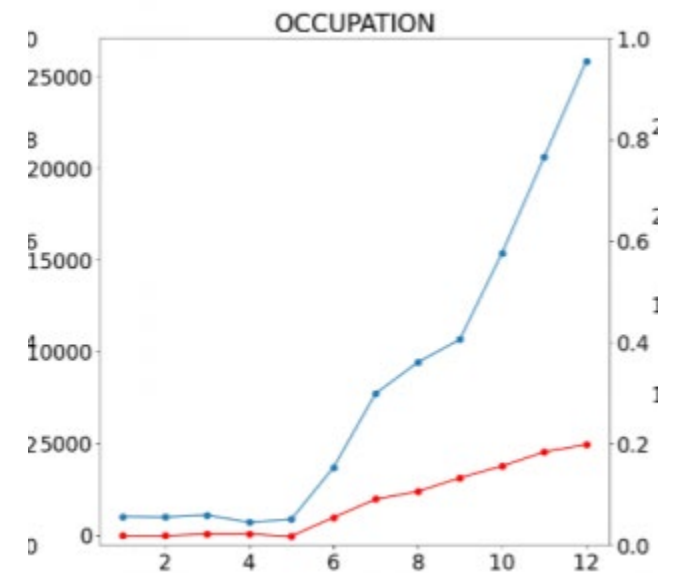
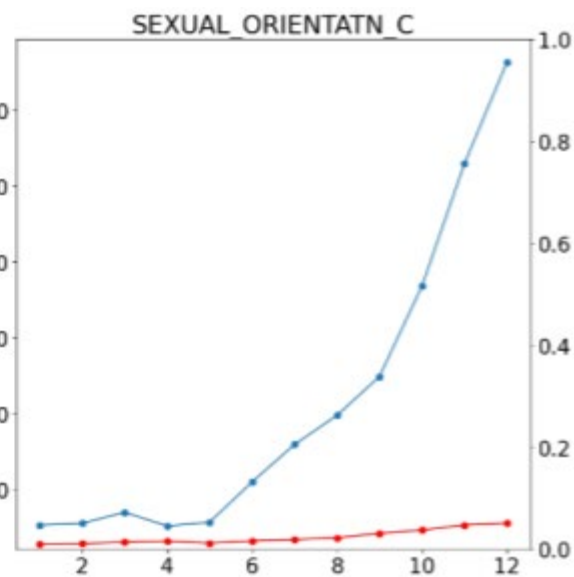
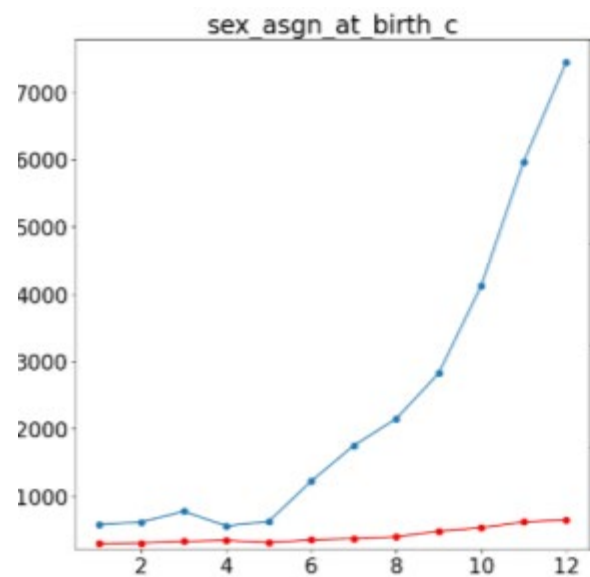
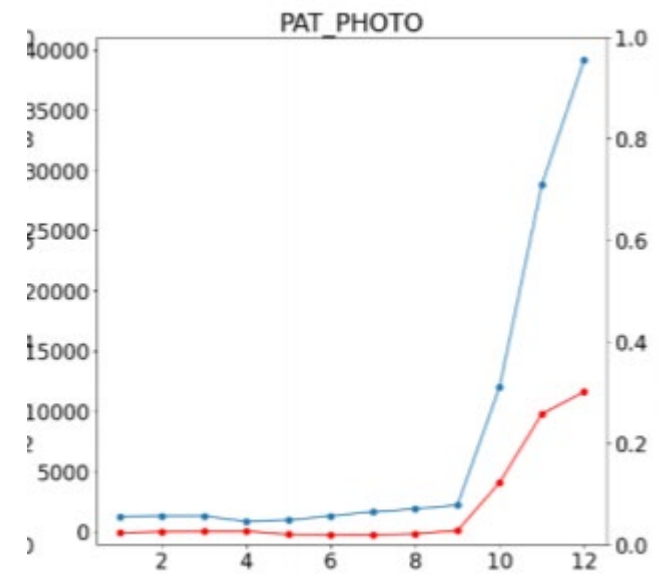
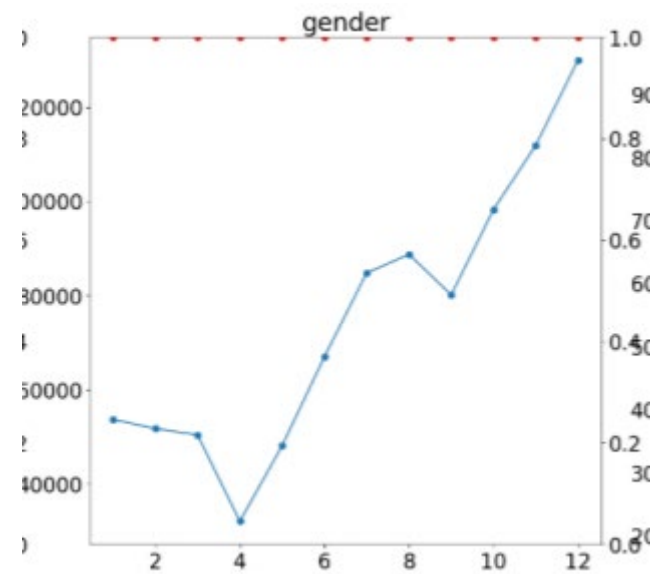




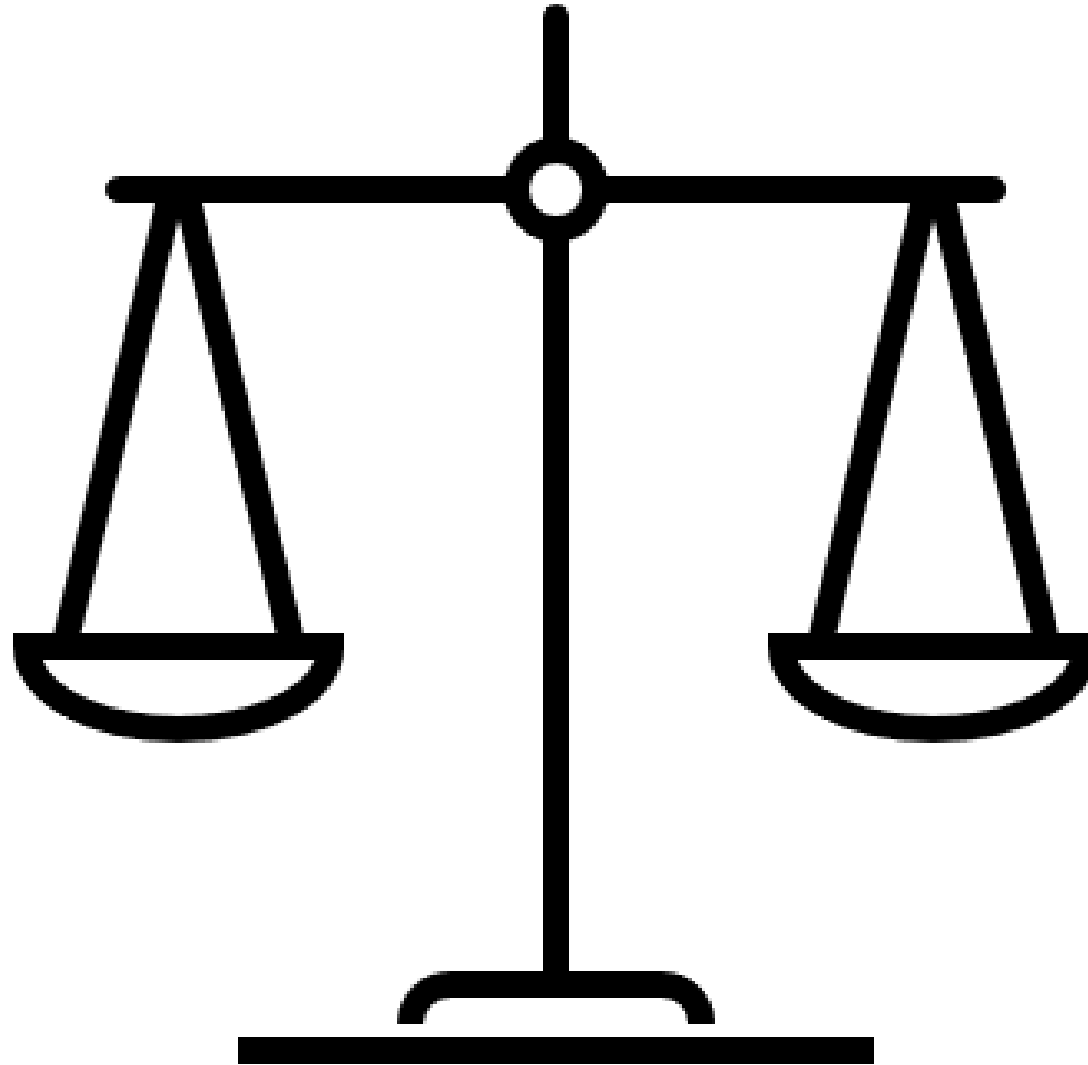
Data availability in EHR registrations



Culbertson et al, Applied Clinical Informatics 2017



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

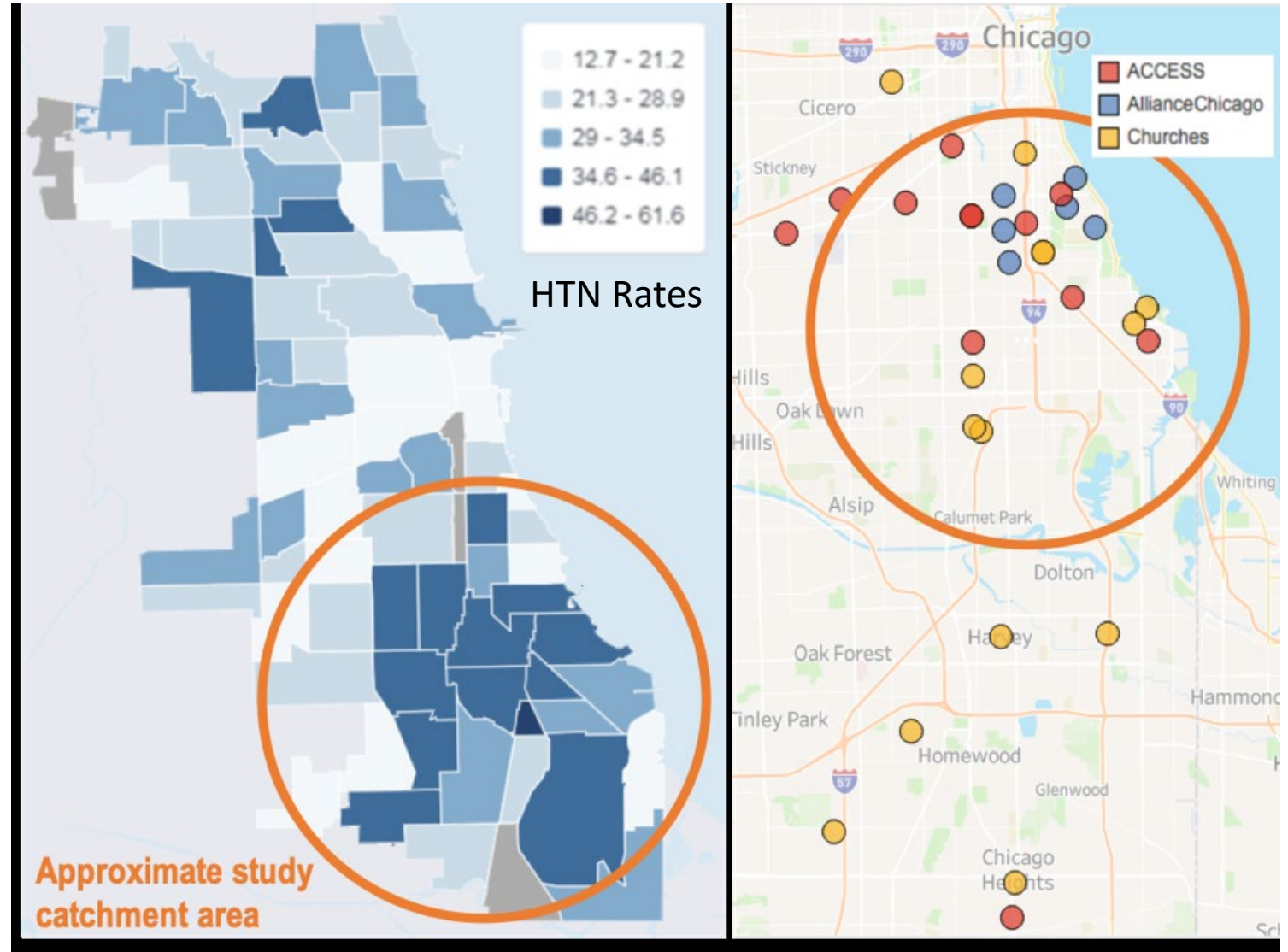
- Our data is biased and is constantly changing. Identity is changing too. Understand the when and how collected.
- Data hygiene is easier to manage (and can be policy driven) than data bias, which requires deeper engagement of at-risk/hidden populations.
- Data bias is not (solely) a technical issue.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

• Funders -

- Greater Chicago Food Depository
- Triedstone FGBC



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

