In the name of efficiency, our society increasingly relies on data to guide all forms of decision making. This cost-effective, data-led decision making, particularly when guided by unsupervised analytical methods, is often assumed to be free of human bias. However, there is growing concern about the potential misuse of these methods to further oppress already marginalized populations. From hiring decisions, to predictive policing, to auto insurance premiums, poor black and brown populations have been shown to be disproportionately impacted across a wide variety of domains. Less is known however about the impact of these systems on sexual and gender minority (SGM) populations.

Human biases emerge in these systems through various mechanisms. First, data can only mirror the existing social world – therefore analytical techniques which utilize existing data to predict the future will inevitably replicate and often amplify existing biases. Furthermore, decisions about what data are collected and what questions are important enough to be asked are also shaped by societal biases. Finally, those learning, developing, and deploying data science techniques are rarely connected to the communities most harmed by these practices. What results are data systems which function in ways that not only replicate but amplify existing biases and disproportionately hurt the least powerful populations.
Meet the Speakers

Yeshimabeit Milner (she/her) is the Founder & Executive Director of Data for Black Lives. She has worked since she was 17 behind the scenes as a movement builder, technologist and data scientist on a number of campaigns. She started Data for Black Lives because for too long she straddled the worlds of data and organizing and was determined to break down the silos to harness the power of data to make change in the lives of Black people. In two years, Data for Black Lives has raised over $2 million, hosted two sold out conferences at the MIT Media Lab and has changed the conversation around big data & technology across the US and globally.

As the founder of Data for Black Lives, her work has received much acclaim. Yeshimabeit is an Echoing Green Black Male Achievement Fellow and joins the founders of Black Lives Matter and Occupy Wall Street in the distinguished inaugural class of Roddenberry Foundation Fellows. Yeshimabeit has a BA from Brown University and serves on the board of the historic Highlander Center for Research & Education.

Michelle Birkett, Ph.D. (she/her) is an assistant professor in the Department of Medical Social Sciences at Northwestern University and directs the CONNECT Complex Systems and Health Disparities Research Program within the Institute for Sexual and Gender Minority Health and Wellbeing. Dr. Birkett’s research uses network and quantitative methodologies to understand the social contextual influence of stigma on the health and wellbeing of marginalized populations, and in particular, sexual and gender minority youth. She is committed to conducting research that leads to social change at multiple levels of society to eliminate health disparities. Dr. Birkett has led multiple NIH-funded projects. She is the recipient of a NIH Career Development Award focused on understanding network, multilevel, and contextual influences on racial disparities in HIV within young men who have sex with men (K08 DA037825). She also directs Network Canvas (R01 DA042711; Dual PIs: Birkett & Phillips), a software development project which seeks to simplify the collection and streamline the management of social data, thereby allowing health researchers to assess more nuanced associations between social contextual factors and disease.
Lauren Beach, J.D./Ph.D., is a Research Assistant Professor within the Department of Medical Social Sciences in the Feinberg School of Medicine. She is also Associate Director of the EDIT Program within the Institute for Sexual and Gender Minority Health and Wellbeing at Northwestern University. Dr. Beach is a sexual and gender minority health researcher who aspires to advance health equity through collaborative scholarship, community engagement, and advocacy while applying an intersectional social justice based lens. Dr. Beach completed her Ph.D. in Molecular, Cellular, Developmental Biology & Genetics in 2014. In December 2012, she received her law degree magna cum laude from the University of Minnesota Law School. Dr. Beach is supported by a K12 award from the Third Coast HIV-related Cardiovascular (CV) and Sleep Disorders K12 Career Development Program (K12HL143959). For her K12 project CADENCES HIV, she investigates social and biological mechanisms that contribute to heart failure in people living with HIV. Dr. Beach is a well-recognized LGBTQIA and bisexual community leader. Among other accolades, she has been named a Point Foundation scholar and one of Advocate Magazine’s 40 Under 40 LGBT activists in the United States.

Meet the Speakers

Gregory Phillips II, M.S., Ph.D., (he/him) is an assistant professor in the Department of Medical Social Sciences, and directs the research program in Evaluation, Data Integration, and Technical Assistance (EDIT) within ISGMH. His research focuses on understanding social-, sexual-, and network-level factors that drive the HIV epidemic among men who have sex with men (MSM), particularly among young MSM and Black MSM. He received his doctorate in Epidemiology from The George Washington University in 2012, and has spent the last decade working on HRSA-, CDC-, and NIH-funded projects focused on identifying behaviors associated with HIV infection and effective interventions to halt the spread of HIV among affected populations. He is currently the principal investigator (PI) of two NIH-funded R01 awards: an NIAAA-funded project assessing the role of alcohol disparities in HIV risk among sexual minority youth utilizing data from the CDC’s Youth Risk Behavior Survey (YRBS), and Network Canvas, a NIDA-funded project to develop a standalone software suite that will simplify the process of collecting complex network and geospatial data. Additionally, Dr. Phillips works on and collaborates with a variety of research projects related to program evaluation and use of diverse datasets to address health disparities among sexual and gender minority individuals.

Meet the Speakers

Lauren Beach, J.D./Ph.D., is a Research Assistant Professor within the Department of Medical Social Sciences in the Feinberg School of Medicine. She is also Associate Director of the EDIT Program within the Institute for Sexual and Gender Minority Health and Wellbeing at Northwestern University. Dr. Beach is a sexual and gender minority health researcher who aspires to advance health equity through collaborative scholarship, community engagement, and advocacy while applying an intersectional social justice based lens. Dr. Beach completed her Ph.D. in Molecular, Cellular, Developmental Biology & Genetics in 2014. In December 2012, she received her law degree magna cum laude from the University of Minnesota Law School. Dr. Beach is supported by a K12 award from the Third Coast HIV-related Cardiovascular (CV) and Sleep Disorders K12 Career Development Program (K12HL143959). For her K12 project CADENCES HIV, she investigates social and biological mechanisms that contribute to heart failure in people living with HIV. Dr. Beach is a well-recognized LGBTQIA and bisexual community leader. Among other accolades, she has been named a Point Foundation scholar and one of Advocate Magazine’s 40 Under 40 LGBT activists in the United States.
Agenda

- 11:00 - 11:15 - Registration
- 11:15 - 12:15 - Introduction and Orientation
- 12:15 - 12:30 - Break, Lunch
- 12:30 - 1:30 - Yeshimabeit Milner, Data for Black Lives
- 1:30 - 2:00 - Break, Check-in
- 2:00 - 3:00 - Shifting the conversation to Health Research in SGM populations
- 3:00 - 4:00 - How to promote the inclusion of diverse voices in big data and data science?
- 4:00 - 4:30 - Where do we go from here?
- 4:30 - 6:00 - Reception
Recognizing Emerging SGM Scholars

STUDENT GUESTS

Winners of the 2018 Data Science & SGM Health Equity Paper Competition

William Goedel
PhD candidate in Epidemiology, Brown University, School of Public Health

William’s paper, “Predictors of User Engagement with Facebook Posts Generated by a National Sample of LGBTQ Community Centers in the United States” couples his work as a social epidemiologist with his interest in the health of the LGBTQ community.

Austin Eklund
PhD candidate in Counseling Psychology, University at Albany, State University of New York

Austin’s paper, “Individual and Structural Predictors of HIV Testing among Latinx MSM: Substance Use as a Moderating Factor” explores the relationship between substance abuse and HIV testing among Latinx men who have sex with men.

Andrew Young Choi
PhD candidate in Counseling, Clinical, and School Psychology at the University of California, Santa Barbara

Andrew’s paper, “Syndemic Behavioral Risk among Bisexual Adolescents: A Latent Class Analysis” studies the interconnected factors that contribute to the gross health disparities experienced by bisexual youth in comparison to monosexual youth.

CALL FOR SUBMISSIONS

Data Science & SGM Health Equity Paper Competition

The call for the 2019 Data Science & SGM Health Equity Paper Competition will be announced the week of July 22, 2019.

Three winners will receive a $500 prize, an invitation to present their work at ISGMH, & the opportunity to be featured in ISGMH publications. Follow us on Twitter to learn about submission details and deadline!
Ground Rules

1. Be mindful in your participation
Be a conscious observer of your own power in this conversation. Do not abuse that power.

2. Make space
We want this conversation to include as many voices as possible. Take the space you need to participate, but make space for others as well.

3. Respect lived experiences
The lived experiences of people in this room matter. Discussing bias and discrimination can be triggering and we are committed to engaging in discussion that is respectful and affirming.

Thank you for your participation and cooperation!
ABOLISH BIG DATA

I learned very early in life that zipcodes is destiny. I will never forget my first year of middle school when our Assistant Principal took the stage to welcome us to the next three years of k-12 education, but also the rest of our lives.

“We are in the era of Zero Tolerance,” his words exactly, spoken loudly over the speakers in our assembly room. “One strike and you are out, you mess up, and there are no second chances.” I can still remember the silence that fell over the room of energetic eleven and twelve year olds, not sure what to expect out of middle school, but so happy to finally be out of elementary school. We had been waiting for this moment, to be big kids, to choose electives and have a rotating schedule.

His words struck something deep within me, and though there were stretches of my childhood I don’t remember, I have made myself forget, I remember this day clearly. I remember locking eyes with other children from my elementary school, searching their glances, wondering if the sudden fear I felt they also shared. They looked back at me. This was when we would all learn to police ourselves to avoid over-policing. This was when we would learn to navigate the world in our Blackness and youngness in a way to avoid being a problem. It was then that we would learn that to be us would mean to be in trouble. We had done nothing wrong.

It was not until high school as a youth organizer that I would learn about the the Crack Baby Myth, a study with only 23 participants that would come to influence a regime of policy, practices and culture that would shape our experiences in that auditorium and beyond. It was not until I was in college that I would have the data literacy to understand tracking, how and why the very children I grew up with that lived close to the school on a census tract spanning a few blocks, were automatically enrolled in alternative education classes, marked by a label in the same way the late Devah Pager wrote about the mark of a criminal record. Many of these children would later become incarcerated themselves. I think about that, how if it wasn’t for the courageous advocacy on behalf of my mother, who spoke English and worked at home, that there would be no Data for Black Lives, and even more, there is a chance I would not even be alive.

Big data is more than a collection of technologies, a vast amount of information and different types of it. It is more than a revolution in measurement and prediction. It has become a philosophy, an ideological regime, about how decisions are made and who makes them. It has given legitimacy to a new form of social and political control that has taken the digital artifacts of our existence and found new ways to use it against us.

Big Data is not new. It is not as novel or revolutionary as we worship it to be. It is apart of a long and pervasive historical legacy and technological timeline of scientific oppression, aggressive public policy and the most influential political and economic system that has and continues to shape this country’s economy, chattel slavery. Algorithms and other Big Data technologies are the engines that have facilitated the evolution of chattel slavery into the the Prison Industrial Complex, the militarization of schoolyards and borders alike, and the incarceration of the futures of millions of Americans of all races into peonage, modern day debt slavery. Just because something is a new technology doesn’t make it innovative.

This essay is a call to action, but also a personal testimony about why we need to abolish big data. This is not a call to end all use of data, quite the opposite. It is an opportunity for us all to apply the organizing methods and approaches of the primordial social reform movement of this country, the abolition of slavery, and the most significant movement of our generation, the abolition of prisons, to address the leviathan that is the Big Data Industrial Complex.

This is a call to action to reject the concentration of Big Data into the hands of a few, to challenge the structures that allow it to be wielded as a weapon of immense political influence. It is a call to action on behalf of the Data for Black Lives movement for us to reckon with the reality of the future to come, a future where data is destiny.

Data is power. Big Data is fascism. To Abolish Big Data would mean to put data in the hands of the people who need it the most.

This call to action is an open door for all to come in, sit and listen. It is a new opportunity to pick up our tools, our own skills and experiences and toil beside each other. We have a lot to abolish, but there is also so much to build. And we are ready.

Welcome to Data for Black Lives II.
TOWARDS ABOLITION

Abolition is a process, not an end goal. It is the rejection of prisons as the “answer” to the most pressing social problems. For too long prisons has been the response to mental trauma and illness, addiction and poverty. They have become the answer as international trade agreements and the decline of industry have made it clear that there is no role for young Black men and women in the global economy. Prisons have become public housing where policies and political will fail. Increasingly, they have become the “answer” to the disappearance of jobs due to automation, a culture of incarceration that is normalized on Netflix as much as it is accepted by those who argue for work-around solutions masked as reform.

How do we imagine a world without prisons when that is all we know? How did our ancestors imagine freedom, and fight for it, while still in chains? The process of Abolition begins in our minds—in our organizations, our academic institutions. It is a new way of understanding the world. And if there is any venue that allows for the imagination to result in exponential change, it is technology. The opportunity we have with data to abolish and reimagine and recreate new structures of knowledge production, new forms of decision making and new ways of relating to each other are infinite.

"Abolitionist steps are about gaining ground in the constant effort to radically transform society. They are about chipping away at oppressive institutions rather than helping them live longer. They are about pushing critical consciousness, gaining more resources, building larger coalitions, and developing more skills for future campaigns. They are about making the ultimate goal of abolition more possible”

-Critical Resistance Handbook

Yeshimabiet Milner,
Yeshimabiet Milner
Executive Director - Data for Black Lives

Yeshimabiet Milner,
Yeshimabiet Milner
Executive Director - Data for Black Lives
Key Recommendations from #MoreThanCode

The #MoreThanCode report was produced by the Tech for Social Justice Project (http://t4sj.co), co-led by Research Action Design (RAD) and the Open Technology Institute at New America (OTI), together with research partners Upturn, Media Mobilizing Project, Coworker.org, Hack the Hood, May First/People Link, Palante Technology Cooperative, Vulpine Blue, and The Engine Room. NetGain, the Ford Foundation, Mozilla, Code For America, and OTI funded and advised the project.

1. Nothing About Us Without Us
   Adopt co-design methods and concrete community accountability mechanisms

2. From Silver Bullets to Useful Tools
   Change the narrative, lead with values, and recognize multiple frames and terms across the ecosystem

3. #RealDiversityNumbers
   Adopt proven strategies for diversity and inclusion

4. Developers, Developers, Developers?
   Recognize different roles and expertise in tech work, and support alternative pathways to participation

5. Coops, Collectives, and Networks, Oh My!
   Support alternative models beyond startups, government offices, and incorporated nonprofits

#MoreThanCode recommendations were compiled through Participatory Action Research. All research partner organizations worked together to develop the research questions, study design, data collection and analysis, conclusions, and recommendations. Participants were diverse in terms of gender identity, sexual orientation, race/ethnicity, educational background, sector (government, nonprofit, tech coop), urban/rural location, and other factors. 109 people were interviewed individually and 11 focus groups were conducted with 79 focus group participants. Please see:

Hashtags!
Please use on every tweet to help keep the conversation connected
#BiasInBigData

CONNECT’s social media account
Follow Us! Tag us! Live tweet the event!
Twitter: @CONNECT_ISGMH

Keeping the Conversation going through our Website
This website will host all of today’s resources, a video of the workshop, as well as update information to further progress the work that has been done today.

https://isgmh.northwestern.edu/bias-in-big-data/
Directed by Dr. Michelle Birkett, the CONNECT Complex Systems and Health Disparities Research Program, is focused around elucidating the complex mechanisms driving the health disparities of stigmatized populations, in particular gender and sexual minorities. CONNECT hopes to build research capacity in this area by strategically growing an interdisciplinary cadre of scholars addressing issues health disparities from a systems perspective.

Why Complex Systems and Health Disparities?
Understanding the drivers of health disparities within populations is extremely complex – particularly within stigmatized populations, such as sexual and gender minorities. Health disparities have been suggested to occur because of intersecting individual, relational, and environmental processes caused by stigma, but little is known about the exact pathways. A complicating factor is that these pathways are often difficult to measure due to nonlinear relationships as well as time-delayed effects. Therefore it has been suggested that a systems science perspective must be used.

The term “systems science” refers here to a perspective in which the problem space is conceptualized as a system of interrelated component parts (i.e., the “big picture”). A systems science approach to health disparities is a major paradigm shift from focusing on one specific pathway toward focusing on how the entire system fits together to produce health disparities in a particular population.

This work requires a shift away from traditional statistical association analyses toward complex modeling approaches that can account for this complexity. These approaches include simulation modeling, learning and network analysis. However, new analytic techniques alone are unlikely to yield high impact findings. This innovative approach requires transdisciplinary collaborations between health researchers, with in-depth knowledge of the population and systems under investigation, and investigators at the forefront of innovative data collection and analytic techniques. For example, health disparities often manifest via multiple negative health outcomes such as the syndemic health burden of HIV, drug use, violence, and mental health problems faced by young men who have sex with men (YMSM). Accordingly, system-level approaches are required to accurately model, understand, and alter these interconnected health disparities.
About Our Sponsors

The Center for Health Equity Transformation (CHET) is about moving beyond a single story in achieving and maintaining health and healthcare delivery. This center serves as a hub within Institute for Public Health and Medicine and Lurie Cancer Center to convene, incubate, create and catalyze innovative clinical care approaches, research, education and training that will optimize health for all.

https://www.feinberg.northwestern.edu/sites/chet/about/message.html

The Northwestern Institute on Complex Systems (NICO) was founded in 2004 with the goals of uncovering fundamental principles that govern complex systems in science, technology, and human behavior and applying these principles to solve societally relevant problems through the analysis, design, and control of complex systems.

https://www.nico.northwestern.edu/about/

Northwestern University’s Data Science Initiative has its origin in a Lawrence B. Dumas Domain Dinner titled “The Possibilities of Big Data” that took place in May 2013. This was one of the best attended Domain Dinners in the two decade history of the Program. Due to such widespread interest across disciplines and an increasing number of established faculty wanting to participate, the Office of Research funded the Data Science Initiative in the Summer of 2015.

https://datascience.northwestern.edu/about
The action-oriented mission of the Health Equity Hub within the Department of Medical Social Sciences (MSS) is to combat inequities in health experienced by specific populations by conducting research to understand how, where, why and for whom they arise and then design and test interventions to address those factors.

Our work utilizes social and behavioral science methods together with biomedical science and implementation science to study the multilevel systems and contextual factors that influence the health of individuals and groups.

https://www.mss.northwestern.edu/research/health-equity/index.html

The Institute for Sexual and Gender Minority Health and Wellbeing (ISGMH) was founded in 2015 and is the first university-wide institute in the country focused exclusively on research to improve the health of the sexual and gender minority (SGM) community. They are a leader in research that fosters understanding of the development and experiences of SGM individuals and improves the health and wellbeing of the SGM community.

https://isgmh.northwestern.edu/about/

Special Thanks to Our Organizing Team

Kate Banner  Michelle Birkett  Dylan Felt  Gregory Phillips
Lauren Beach  Cate Durudogan  Patrick Janulis  Shannon Sotomayor