Bias in Big Data

2019 Workshop

White Paper

Northwestern | Institute for Sexual and Gender Minority Health and Wellbeing

CONNECT Complex Systems and Health Disparities Research Program

About Bias in Big Data

The Bias in Big Data 2019 workshop was organized by the CONNECT Complex Systems and Health Disparities Research Program at the Institute for Sexual and Gender Minority Health and Wellbeing at Northwestern University. Yeshimabeit Milner of Data for Black Lives was the keynote speaker. The content of this white paper reflects the work of Yeshimabeit Milner and Jamelle Watson-Daniels of Data for Black Lives, and Kate Banner, Lauren Beach, Michelle Birkett, Cate Durudogan, Dylan Felt, Camille Galles, Patrick Janulis, and Gregory Phillips II of Northwestern University, as well as the discussion and input from workshop attendees, including written feedback from John Fahrenbach, Lauren Beard, Kelsey Campbell, William Goedel, and Nicole Pierce. The workshop sought to stimulate intersectional discussion about the role of bias in big data and to explore, in particular, how bias in data and data science impacts the health of sexual and gender minority populations. The workshop was also intended as a space for academic researchers and data scientists to become engaged with the data justice movement led by Data for Black Lives. The workshop was hosted in Chicago and livestreamed to ensure broad and inclusive participation at no charge.

About Data for Black Lives

Data for Black Lives is a movement of activists, organizers, and mathematicians committed to the mission of using data science to create concrete and measurable change in the lives of Black people.

The third annual Data for Black Lives conference will be held December 11-13, 2020, at MIT Media Lab in Cambridge, MA.

About CONNECT Research Program

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 of health disparities from a systems perspective.

Suggested citation

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About the publication of this white paper

A version of this paper was originally published in February 2020, but then retracted and modified in order to better incorporate the perspectives of several authors and event attendees. We now republish this work in July 2020. Within those five months, the structural inequities and racism that regularly kill Black people in this country have been on stark display in the forms of the SARS-CoV-2 pandemic and the pandemic of police brutality. While neither infectious disease inequities nor police violence are anything new – what may be novel is the growing access to and wielding of data and technology in order to elevate previously disregarded truths, stripping away all plausible deniability. Data is power, who wields that power matters, and each of us can do our part to create lasting change and bring about an end to white supremacy.

We join the millions across the nation in condemning the murders of George Floyd, Breonna Taylor, and Tony McDade by police, and the killing of countless Black individuals by centuries of white supremacist violence. We echo the calls of Black leaders for the abolition of and divestment from police departments in favor of greater investment in Black communities and Black lives. We unequivocally stand in solidarity with the Black community and allies who are fighting against the multitude of harms caused by racist violence, and we commit ourselves to deconstructing and disrupting the normalization of anti-blackness, particularly within white majority spaces, that perpetuate systematic inequities.

To uplift those at the forefront of this movement, we encourage all readers to consider how you can best take action in support of Black lives, whether it be through protest, donation, mutual aid, or other vital actions. At a minimum, we urge those of you with means to donate to groups like Data for Black Lives, Black Lives Matter, as well as a Minnesota-based youth-led response to the murder of George Floyd. We also urge you to educate yourself on these issues by reviewing resources like Dismantling Anti-Black Bias by AORTA Coop and Primer On How and What We Teach Youth about Racism and Xenophobia Across Family, School, Peer, Community, and Media Contexts by Dr. Debbie Rivas-Drake and Ms. Bernardette Pinnetta.

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Overview

The Bias in Big Data 2019 workshop was organized by the CONNECT Complex Systems and Health Disparities Research Program at the Institute for Sexual and Gender Minority Health and Wellbeing at Northwestern University, with further support by the Health Equity Hub of the Northwestern Department of Medical Social Sciences, the Northwestern Institute on Complex Systems, and the Northwestern Center for Health Equity Transformation.

The workshop was organized to bring awareness to the bias that inevitably shapes all big datasets and scientific research processes, and which can create danger and harm to Black, Indigenous and people of color (BIPOC), people who identify as sexual and gender minorities (SGM), and people who live at the intersection of BIPOC and SGM identities. Additionally, the workshop was organized to bring awareness to the importance of collecting accurate and holistic data about the health of sexual and gender minority groups, and to connect academics and data scientists with the growing data justice movement.

Following the workshop, CONNECT and Data for Black Lives collaborated to create an accessible summary of workshop presentations and discussions, along with recommendations suggested by speakers and workshop attendees. This is a living recollection for both the people that were present for the discussion and those who want to learn and do more to challenge bias in big data and data science. While documents like this have the ability to solidify statements, they cannot communicate the energy, the enthusiasm, or the urgency for action that was very real throughout the workshop. We urge readers of this paper to amplify and support the movement that Black-led data justice organizations and other organizations representing marginalized communities are leading, as opposed to seeking to take a leadership role in this work. There's no need to reinvent the wheel! At the end of this paper, we've listed several organizations to connect with as a jumping off point.

Ultimately, our goal is to provide an accurate summary of the workshop, allow for greater understanding of how data can harm historically marginalized people, and to inspire readers to amplify and follow the work and recommendations of Data for Black Lives and other community-led expert organizations who are on the front lines of data justice work.

Summary

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, from hiring decisions to predictive policing, poor Black and Brown populations have been shown to be disproportionately impacted across a wide variety of domains.[1, 2] Less is known, however, about the impact of these systems on sexual and gender minority (SGM) populations and those at the intersection of these experiences.

Finding solutions to these problems is immensely complex, and requires the input of a wide range of stakeholders. But spaces like these are rare. Therefore, the Bias in Big Data 2019 Workshop was conceived as a space to bring together diverse stakeholders across various sectors to discuss solutions. Approximately 50 in-person and 800 online participants attended the half-day meeting, representing public health, community organizations, data scientists in the private sector, and academics from over 20 universities. The agenda of the event is included below along with links to the videos of the workshop's lectures and discussions.

Below, we articulate six themes that emerged from conversations over the course of the workshop. Within each theme, broad needs are listed to illuminate guiding questions and current effects on historically marginalized populations. Themes were derived from lectures and discussions led by Yeshimabeit Milner, Gregory Phillips II, Lauren Beach, Austin Ecklund, and Michelle Birkett. Please see the event agenda on the following page, including links to recordings.

I. Bias is inherent.
II. Data is power.
III. Data representation can be dangerous.
IV. Silos are everywhere.
V. Priorities shape solutions.
VI. There is a need for ethical standards.

Following these themes, we have outlined suggestions grounded in our experiences as researchers, advocates, and community members that can be taken up by broad groups of stakeholders, including data scientists, policy makers, community members, academics, students, and funders.

The included suggestions build on existing work and advocacy led by SGM individuals and BIPOC. Most recommendations can be simplified as such: listen to Black people, Indigenous people, people of color, and sexual and gender minority people, and amplify their work and calls to action. If you hold a privileged identity, or occupy a space of power in your organization, we encourage you to explore strategies to yield and share your power with data justice leaders from marginalized communities.

Agenda of the 2019 Bias in Big Data Workshop

Michelle Birkett, Northwestern University

Oriented attendees to the structure and goals of the workshop. Conducted an activity exploring how bias enters research. Watch here.

Yeshimabeit Milner, Data for Black Lives

Discussed the deep history of data bias and examined how it is enmeshed in the foundation of our lives. Provided an example of a collective call to action and the beginning steps of protest and accountability towards big data abusers. Watch here.

Gregory Phillips II, Northwestern University

"Gaps, Challenges, and Opportunities in SGM Data"
Discussed how SGM inclusion in data systems reveals health disparities. Watch here.

Lauren Beach, Northwestern University

"Ethical Considerations of Conducting Research Utilizing Big Data on SGM Populations"
Evaluated the current ethical conditions and variations within data integration and analysis and introduced the need for ethical standardization. Watch here.

Austin Eklund, SUNY: University at Albany

Addressed how identity and personal experience matter and influence us doing this work. Watch here.

Wrap-up and Audience conversation

Watch here.

Theme I: Bias is inherant.

Race is not a risk factor.
Racism is.

LGBTQ identity is not a risk factor. Homophobia and transphobia are.

-Yeshimabeit Milner
Data for Black Lives

Bias is inherent.

- Bias is often solely associated with an individual's conscious or unconscious prejudices. In this work, bias also refers to the structural and systemic inequities present in the world which have disparate and discriminatory impacts and have been shaped by historical hierarchies of power.
- Bias can enter at any point in the research process. The following questions reveal opportunities for bias to enter a project:
    - Which research questions are deemed worthy of study? Who is able to ask the research questions? What methods are used to answer a research question? Why have they been chosen and what are the potential limitations of these methods?
    - Which constructs or variables are included in an analysis? Why, and how have they been defined, and which datasets will be utilized? How has data been removed or imputed during cleaning?Are results validated? How? Who benefits from the criteria used for validation?
    - To which communities will results be disseminated?
    - Who does the research benefit? In what ways?
- Data is often assumed to be free of bias, but data systems only mirror the existing social world**.** It can be easy to forget that humans determine what data is captured, create algorithms, assemble datasets, and build artificial intelligence – and that humans are inherently biased**.** Therefore, the analytical techniques which utilize existing data to predict the future will inevitably replicate and often amplify existing biases**.**
    - Common examples include utilizing population data, such as ZIP codes, to determine the risk of an individual. Although using a ZIP code in this way may appear "neutral” or unbiased, neighborhood populations reflect a history of income inequality, redlining, housing discrimination, and racial segregation. When ZIP codes are used as a proxy for individual risk in order to predict insurance premiums, Black communities are charged as much as 30 percent more than white counterparts.
    - While algorithmic fairness is beginning to be considered - these criteria and their adoption are very much in their infancy. What communities are being consulted in this work? How transparent are the criteria for fairness?

Broad Needs

- Researchers and consumers of research must critically interrogate why research questions are structured in particular ways. Who benefits? Who is left out? What are the priorities of this work? Does it prioritize justice or efficiency? Who is the most vulnerable in the research process, and who is most empowered to inform and conduct the given research?
- Data oligarchy, defined by Lauren Beach as “data in the hands of a few,” must be combatted through decentralizing the research process. Open science and open data should be promoted. Partnerships must be built that are mutually beneficial. Impacted populations must be centered at each step of the work.
- Recognize that personal identities and backgrounds will impact how work is conducted. History, values, and the role of power and privilege should always be checked. Challenge the assumption that scientific research and the scientists conducting it operate in a vacuum separate from societal factors. Acknowledge that race, sex, sexual orientation, gender, class, culture, and all identities impact and inform the scientific process and include this consideration in data-enabled work.

Theme II: Data is power.

Data is a form of protest when all other channels of advocacy are blocked.

- Yeshimabeit Milner

Data for Black Lives

Data is power.

- Data is an increasingly valuable commodity, and a growing number of sectors are using large datasets to guide their work. From determining insurance premiums[3] to Netflix recommendations[4], data's influence on our everyday lives continues to grow.
- Data and computational literacy are increasingly valuable skills. Those with access to data and knowledge of computational methodologies are able to shape the world in ways which can be used to further gain or remove power.
- As data become larger and more varied and approaches to data analysis become more complicated, oversight and transparency become more difficult. Data analysis techniques have become more complex while the explain-ability and accountability of the resulting systems is becoming alarmingly inaccessible. The combination of data systems being less broadly understood and algorithms becoming less transparent result in a growing concern about the lack of oversight and accountability for data collection, data privacy, data-enabled algorithmic development, and more.

Broad Needs

- Advocates must educate the public about the societal effects of concentrating data and the power of computational literacy into the hands of a few. Public education campaigns are needed to equip communities with the tools to contribute to algorithmic and data accountability efforts. It is critical that people are empowered to push back against the lack of explain-ability and accountability currently associated with data systems.
- Efforts to develop more inclusive, transparent, and fair data-enabled practices must include input and contributions of those most historically marginalized, as well as those across a wide variety of disciplines and sectors. Specifically, SGM individuals and BIPOC must be included in the design, development, analysis, dissemination and evaluation of data-enabled systems.
- Data must also be utilized for protest. Data-supported narratives are an important tool for demonstrating inequity and can be utilized to demand accountability.

Theme III: Data representation can be dangerous.

If we’re not asking the right questions, we’re not going to get the right data. This can often lead to the collapse of sexual and gender minority categories, erasing identities, and perpetuating false narratives.

- Gregory Phillips II

Northwestern University

Data representation can be dangerous.

- While data has the power to elevate the truth, vulnerable and marginalized communities are disproportionately hurt by data and data systems.[5] For example:
  - Algorithms used to determine car insurance premiums charge Black people as much as 30 percent more than their white counterparts.
  - Software used by police to predict recidivism is biased towards Black people.
  - Data integration practices can out SGM individuals.
  - "Risk score" healthcare algorithms underestimate the risk of Black patients compared to white patients.
- Furthermore, the exclusion and misrepresentation of historically marginalized communities can distort important narratives or create harmful new ones. For example:
  - Nuances within demographic categories, such as sex, sexual orientation, and gender identity (SSOGI), are lost when data are collapsed and grouped together. Currently, there are no agreed upon best practices for measuring SSOGI. Collapsing or neglecting to measure SSOGI factors leads to the systematic dehumanization of SGM.
  - Structural racism in police departments contributes to an abundance of arrest and crime data on Black and Brown people versus white people. In any given criminal justice dataset, representation can have dangerous implications.
  - The utilization of convenient but inaccurate data proxies distort the true drivers of health. (e.g., use of ZIP codes over more nuanced measures of identity and experience.)
- Accurate and equitable solutions require accurate and representative data.

Broad Needs

- There needs to be greater representation of a broad range of identities in data systems. In the context of sexual and gender minorities, transgender people are grossly under-sampled and therefore under-represented in datasets used to make important societal decisions. Additionally, no population health surveys capture intersex people, and asexual or ace people are only captured via community-led survey efforts. (See The Ace Community Survey, below.) There needs to be an active and intentional effort to increase representation of transgender, intersex, and asexual populations in data systems.
- We must draw on the knowledge and expertise of marginalized communities when making decisions about measurement, analysis, and interpretation.
- It is critical that we contribute to the evaluation of data-enabled models that significantly impact people's lives. Specifically, we ought to evaluate and speak out against existing deployed algorithms that are known to negatively impact marginalized people. We must apply an intersectional lens when considering disparate impacts on historically marginalized communities.
- We must amplify organizations working towards positive representation through inclusive surveys, for example:
  - The Ace Community Survey
  - Queer the Census 2020
  - The Black Census Project

Theme IV: Silos are everywhere.

We need people with different levels of expertise in all different areas to critique algorithms and datasets.

-Michelle Birkett

Northwestern University

Silos are everywhere.

- A silo is a system or process that operates in isolation from others. In this context, we refer to those with the power to shape data narratives as operating in silos, whether in isolated workflows or specializations within the same institution, or within institutional silos that are removed from the broader community. The work conducted by data scientists is often shaped by their isolation from those who come from different communities, those who hold different training experiences or expertise, and those who hold a different perspective or priority.
- These silos can enable misunderstanding and create inaccurate solutions which miss the big picture. Furthermore, they allow inaccuracies to go unchecked and allow dominant narratives to persist – like patriarchy, meritocracy and capitalism.
- When seeking to disrupt silos, it's critical to follow the leadership of communities who have been affected by bias in big data.

Broad Needs

- Existing power differentials which have historically isolated data narratives into the hands of a few must be acknowledged and challenged.
- We must create and participate in transdisciplinary spaces which enable communication, understanding, and relationships across scientific and non-scientific stakeholder communities. In particular, these spaces should:
  - Cross sectors and disciplines.
  - Include community-based organizations, nonprofits, activists, and advocates.
  - Be representative of those most impacted by technological outputs.
  - Equally value the time and expertise of non-analytical domain experts and those who bring lived experience to the table. This may be evidenced by ensuring equal pay and acknowledgement for equal work.
  - Foster dialogue for nuanced research questions, and serve as a means to develop further partnerships.
- Data training programs have a disproportionate role to play as they shape the future. In particular, these programs should:
  - Teach about the limitations of data science, not just the potential.
  - Offer models of how to include the perspectives of other disciplines, sectors, and the wider community in order to do better work.
  - Value the expertise of trainees with non-traditional and diverse backgrounds.

Theme V: Priorities shape solutions.

Some of the power in what questions are asked comes from the power of who gets to ask those questions.

- Michelle Birkett

Northwestern University

Priorities shape solutions.

- Differences in the priorities across various sectors likely determine how solutions are constructed, validated, and chosen for implementation. For example:
  - Industry often utilizes data and data systems to maximize profits and efficiency.
  - Academia may prioritize scientific or methodological innovation.
  - Advocacy and non-profit organizations may value transparency, privacy, and/or community accessibility.
- Many decisionmakers, across sectors, are cisgender, white and wealthy. Homogenous consolidation of power often leads to a failure to include the priorities of SGM people and BIPOC. For equitable data practices and priorities to be implemented, it's essential to include the voices of BIPOC and SGM people at the decision-making table.
- Currently there is little incentive for the most powerful sectors to prioritize essential rights and values such as like integrity, justice, equality, and the ethical use of data.

Broad Needs

- To ensure data and data systems are utilized with integrity and in ways which protect the most vulnerable and marginalized populations, new incentives must be leveraged so that integrity, justice, ethical data use are re-prioritized. Equity should always be a priority.
- Leadership, across sectors, must be diversified so that the priorities and perspectives of SGM and BIPOC people are represented. Anti-racism and anti-[homo/bi/trans]phobic initiatives should be a focus of organizational structures and business plans, especially for powerful data collectors and distributors.
- By educating and organizing broad communities on the fallibility of data and how technology can reproduce or amplify inequities, we can create leverage to demand accountability.
  - For example, Yeshimabeit Milner published an Open Letter to Facebook that resulted in a response from Facebook's public policy team, as well as legislative action in the United States Congress. Now, when elected officials have questions about policies relating to algorithms and data usage, they contact Data for Black Lives first. By publicly demanding algorithmic accountability, Milner ensured that the Black community is represented in legislative activity.

Theme VI: There is a need for ethical standards.

If we look at social systems and power, we can see that big data without ethics can have a fascist effect. Data in the hands of a few is a data oligarchy.

- Lauren Beach
Northwestern University

A need for ethical standards.

- Despite the increasing capture and use of highly personal data, there remains little to no standards for ethical oversight.
- The ethical standards that do exist vary markedly across sectors and contexts. For example:
  - Federally-supported researchers, such as those in academic sectors, must follow strong regulations to protect human subjects and are subject to institutional oversight through Institutional Review Boards. However, most research in the US – such as research conducted by industry – is not federally supported and currently not mandated to comply with the Federal Regulations.
  - Oversight varies substantially by country, with the EU leading the world with individual data and privacy protections through the General Data Protection Regulation (GDPR). In California, the recently passed California Consumer Privacy Act gives consumers knowledge of and access to personal data that companies may collect, as well as the option to restrict sale and collection of personal data.
  - Existing ethical standards are often outdated and not built to regulate the risks inherent in big data. They often prioritize risk related to how data is captured more than how it is used.
  - Further, these standards often treat data as either identified or de-identified, but ignore the new data landscape where single de-identified datasets – harmless by themselves – can be combined in unintended ways, which can violate privacy.

Broad Needs

- Ethics must be a core tenet of all data science training. Just as many professionals who impact human society receive training in ethical conduct, so should computer science and data science students.
- Legislation should be updated and extended to fit existing regulations within a new data landscape and unify oversight across sectors and contexts.
- Ethically tenuous practices are typically justified by arguments about the need for a "greater good." Therefore, researchers and consumers of research must critically interrogate whose greater good is prioritized, who stands to benefit, and who stands to inherit risk and lose their privacy. For example, all examples of harmful data practices listed in the "Data representation can be dangerous" section were pursued for reasons that do not immediately present as unethical, such as increased efficiency or neighborhood safety. But when these "greater good" reasons are pursued without consideration for potential bias, marginalized populations are almost always at risk of harm.
- In addition to the need for ethical standards, there is also a need for open and transparent science which allows researchers to be accountable for their work.

Continuing the Work

The Bias in Big Data workshop is not the first space to consider the harms caused by data science and data collection. The movement against bias in big data is led by BIPOC and SGM individuals, and most significantly by Black women, Black queer women, and intersex and transgender people. For those of us who hold privileged identities, it's time for us to amplify the work of communities most affected by bias in big data, and resist the urge to divert critical attention and resources by painting ourselves as leaders. There is a need for efforts by multiple stakeholders to highlight and amplify this work in a way that centers community voices and the voices of those who are vulnerable and marginalized.

As the movement to dismantle bias in big data grows, it's critical that this work continues to follow the lead of communities affected by these practices, and organizations who support these communities, such as Data for Black Lives. As academics and other industry stakeholders with access to power and resources join the movement, the creation of ethical standards that work to dismantle bias in big data should be aligned with justice-centered recommendations groups led by marginalized communities.

Addressing Gaps

Following the workshop, CONNECT sent out digital and physical surveys asking participants about their experience and any suggestions for improvements.

An attendee spoke to their experience with geographical isolation that can occur in the physical locations where these workshops occur. The Bias in Big Data workshop was held in the Institute for Sexual and Gender Minority Health and Wellbeing at Northwestern University, which is located in downtown Chicago on Michigan Avenue. We realize this location was most convenient for many individuals who already hold power. In the future, we are looking for new physical spaces to continue to hold these important conversations that are more easily accessible to Chicago residents who do not live downtown. Additionally, we will seek to show up where we are invited to community discussions that are already happening across the city.

Two participants also expressed that intersectionality could have been more present in our conversation. We agree. There is a historical tendency for SGM work to focus on the experiences of sexual and gender minorities who are white, male, and middle class, and conversations at our event often discussed big data's effects on SGM populations and big data's effects on BIPOC as separate experiences. We missed an opportunity to have an intentional conversation about how big data affects people who identify as SGM and BIPOC. In the future, we plan to make similar events more inclusive by better centering those from a wider variety of identities, in particular Black and Brown trans women from a variety of class backgrounds. We are thankful for these participants sharing their experience and giving us the opportunity to learn and improve our facilitation going forward.

Recommendations

None of this is new - but in data science and big data, biases can be amplified at scale and more easily hidden.

- Michelle Birkett

Northwestern University

Data Scientists

Examine how your technical training has not included interdisciplinary considerations that would reveal the social implications of your work (sociology, critical race theory, etc.) and address these shortcomings. Challenge the assumed objectivity of your work and your technical training by considering the perspectives of historically marginalized communities along the axes of race, class, sex and gender. Be intentional about ensuring that those affected by your work, especially BIPOC and SGM individuals are consulted, and paid for their labor. Work to seek out those perspectives and continue to do so with each new project. Before beginning new projects, engagement with key stakeholders including users, audience members, and/or community members is essential to ensuring equity and user/audience/community needs are prioritized throughout your project.

Open your research process by decentralizing it. Practice open science. Don't allow your research to sit behind paywalls of for-profit research publishers, and take time to translate your work to those outside of academia. Share your data and analyses in a format that is easy for others to audit. But also, do not just wait for others to approach you. Instead, actively work to build partnerships with community organizations led by community members from the marginalized backgrounds that the work most impacts, before your project begins. Even if you yourself are a member of those 'same' marginalized communities, the community voice/community role remains important to be centered in the work. An excellent example of this is the Detroit Digital Justice Coalition, which has been working to build community access to technology for over ten years and has established a set of digital justice principles: access, participation, common ownership and healthy communities. [6]

Many leading data scientists working on addressing bias in big data are Black, Indigenous, and people of color, and/or identify as LGBTQ. However, the data science sector at large is overwhelmingly white, male, straight, and cisgender. Every data science organization, or team, can and should devote resources and effort to promote greater diversity. For suggestions for action here, we pull from the #MoreThanCode report, which recommends several action steps for improving diversity and inclusion: gathering and sharing demographic data, creating and publicly disclosing time-bound diversity targets, adopting research-based best practices for inclusive workplaces and hiring, mentorship, and advancement practices, diversifying leadership, and transforming conferences and convenings to be far more diverse, inclusive, accessible, and affordable.[7]Although these steps are recommended in the context of non-profit organizations, we believe they are applicable across sectors.

Regardless of the presence of state or federal laws requiring ethical guidelines, the ethical impacts of data science projects should be considered before data collection and planned analysis. The Center for the Study of Ethics in the Professions has assembled the Ethics Code Collection, the largest repository of ethics codes and guidelines in the world. Search to see if your organization is represented and evaluate the effectiveness of its ethics code. Encourage your coworkers to do the same. If no ethics code is represented, or the ethics code is not followed out in practice, identify stakeholders in your organization willing to implement stronger ethics guidelines. Following the European Commission's Ethics and Data Protection guidelines are recommended.

Policymakers

Policymakers can model transparent ethical data practices by enacting open data practices within governments, which ensure that data is legally open (placed in the public domain or published with minimal restrictions) and technically open (published in electronic formats that are machine readable and non-proprietary.) However, there are still important implications to enacting open data practices. When the City of Detroit launched the Open Data Portal and GO DATA policy initiative in 2015, the Detroit Digital Justice Coalition and Detroit Community Technology Project researched the benefits and harms of various open data sets. They published a report including the following recommendations: Protect the people represented by the numbers; don't retain personal information tied to accessing government services; publish data about all government services, even for privatized "public" services; prioritize the release of new datasets based on community interest; increase transparency around how data sets are defined and processed; engage residents offline about open data, and share what's coming next. We also encourage policymakers to critically evaluate the use of algorithms in their programs, such as in predictive policing. As discussed at length in this white paper, algorithms used in the name of increasing efficiency of social services or public safety often replicate and increase existing inequalities.

The United States is notorious for its patchwork approach to data protection legislation, including a collection of sector-specific laws that are usually implemented in reaction to a problem, such as a data breach. We encourage federal policymakers to prioritize the creation of federal data privacy legislation that will apply to all private and public sectors. The Center for Democracy and Technology has begun this work with a Federal Baseline Privacy Discussion Draft. We encourage federal lawmakers to model efforts on the European Union's General Data Protection Regulation Act and Ethics and Data Collection Report. State lawmakers can also take action on this issue, as California did with the California Consumer Privacy Act, which empowers consumers with the right to know how their data is being used, stored, and shared. As these efforts expand and continue, it is crucial that policymakers take steps to gather feedback and input from their constituents, including extra effort to reach those who do not have easy access to government communication channels, to ensure that the data protection and privacy needs of the most marginalized are being addressed through any new policy.

We encourage lawmakers to reexamine outdated regulations for products and services that are developing new AI and machine learning capabilities. For example, the FDA is currently reexamining its process for premarket approval for medical devices. The new process includes a commitment to transparency and real- world performance monitoring and updates. More recently, the White House's Office of Science and Technology has released 10 principles that government agencies must adhere to when developing AI regulations for the private sector. Notably, principles of "Public Participation" and "Fairness and Non-Discrimination" are included. It remains to be seen whether these principles will encourage agencies to create thoughtful regulations, or whether agencies will find ways to skirt around them. Nevertheless, we recommend investing in a mandatory regulatory framework and approval procedure to ensure responsible and ethical use of AI.

Advances in data science and technology can move at a breakneck pace. Policymakers at all levels should seek to develop regular training and information sessions for legislative bodies about the basics of ethical data practices, as well as advances in technology like AI and machine learning. We also encourage policymakers to share resources with their peers, and to seek out expertise and build relationships at local higher education institutes and data justice organizations for assistance with training and learning programs for lawmakers.

Community Members

The perspective and expertise of people outside of the data science community is essential to incorporating ethical and accurate data standards into individual projects, organizations, and legislation. We encourage all community members who are interested in the movement for equitable data, regardless of their data science expertise, to connect with like-minded individuals and organizations who are advocating for ethical data practices. Each person is an expert in their own real-life experiences which are crucial – and often missing – considerations in any work that involves big data. Please refer to the appendix of this report, where we have compiled an extensive, but not exhaustive, list of organizations who are doing this work, including bringing community members together to use technology and data for good.

Funders

Every institution or organization that receives support from the United States federal government is required to utilize an Institutional Review Board (IRB). The IRBs vary from one institute or organization to another, and there is currently no standardization for ethical requirements across the United States. This variance does not ensure that all research is being conducted following the highest code of ethics. We recommend that funding institutions adapt a standardized code that follows the lead of the European parliament's Ethics and Data Collection.

Beyond ethical considerations, funders also wield the power of determining what projects receive support. During the Bias in Big Data 2019 Workshop, an audience member discussed how bias can infiltrate into the funding process. They said, "Usually, the voice that gets funded is not the voice that is impacted." This truth comes from the intense scaffolding and elitism that is embedded within academia. Dismantling this from the funding perspective means separating name recognition from quality, importance, or qualification. We encourage funders to follow the recommendations listed for funders in the #MoreThanCode report, especially, "Respect community articulations of their own needs," "Fund increased tech capacity in already existing POC-led organizations," and "Stop supporting projects that are not emerging from real needs of community organizations, although they sound like a cool idea." We also support #MoreThanCode's recommendation to fund investments in tech infrastructure and maintenance, not just pilots of new projects.

Academics

Academics play an outsized role in shaping data analyses, processes, and policies across sectors. Tools created in academic labs are often implemented widely and run the risk of reinforcing biases and harming Black people, queer people, and other marginalized groups unless those risks are intentionally addressed. When beginning a new project, academics must consider the implications and harms for marginalized communities. Seek opportunities to bring leaders from community-led organizations into your team as paid consultants, and center the calls to action from data justice organizations led by marginalized communities.

Ground all data science training in ethics, including examples and methods for safe data practice and bias consciousness. Consider ethics training courses as prerequisites for entry to higher-level data science classes, and look for ways to collaborate with other instructors who specialize in studying race, ethnicity, and historical patterns of marginalization in society. We encourage all instructors to make use of the resources, particularly those relating to STEM fields, in the Ethics Education Library by the Center for the Study of Ethics in the Professions. Additionally, actively consider the contributions of and connect with community experts and community-led organizations in your research domain.

An understanding of the context in which data science is being utilized in can be immensely helpful in identifying and articulating the effects of bias. In training, it is common to make known the utilities of data science and big datasets, but it is important to also address the limitations of particular methods for students. Strive to use datasets that reflect a diversity of identities and experiences in didactic exercises. For example, strive to model best practices for students and trainees by making an effort to use inclusive datasets, rather than "settling" for a dataset that includes known limitations. We recognize that even the most bias-conscious researcher has been forced to settle for big datasets which are missing key elements, such as accurate sexual and gender identity data. While using these, carefully evaluate if your work will be damaging due to an absence in data analysis. If there are clear limitations in your analysis, then be transparent and report this in the dissemination of your findings.

Create and participate in transdisciplinary spaces during your research and classroom process that enable communication, understanding, and relationships with those across broad scientific and non-scientific stakeholder communities. We encourage academics to recognize and step into their power to make a difference, and to take the responsibility to push data science towards a more ethical and community-centered future.

As mentioned in our recommendations for funders, it's important for academics to respect communities' sovereignty in stating their needs and governing the storage, collection, and analysis of community data. When designing research projects, strive to include the voices of community members who are affected by your research, especially BIPOC, and SGM individuals. It is critical for researchers to actively engage with stakeholder communities before a project begins. The Center for Community Health at Northwestern University has assembled a helpful FAQ page for researchers seeking to incorporate community engagement into their research projects.

One example of leadership surrounding AI bias checks is the University of Chicago's Artificial Interventions Unit, developed in 2019. AI models that are developed at UChicago Medicine should now pass through the Artificial Interventions Unit for a discussion on potential biases, and to identify opportunities to advance clinical delivery. With input from the University of Chicago Biological Science Diversity and Inclusion Steering Committee, UChicago's AI Model Intake Form now requires data scientists to consider equity and bias implications for internal and external AI models going into production.

Students

We encourage all students to hold instructors accountable for incorporating ethical discussions and histories of oppression in their coursework, particularly in technological coursework. While this can be laborious (and sometimes dangerous) as an individual effort, coalitions and communities of students are often extremely successful in spurring change. If you notice a gap in your ethics instructions, we encourage discussing ideas, options, and desired outcomes with classmates and other academic colleagues. Together, students can petition instructors, administrators, and faculty members to include ethics and bias education in their curriculums. One source of curriculum inspiration is the Intro to Data Ethics Certificate course at the University of San Francisco, newly offered in 2020.

Many organizations are working to protest the use of potentially dangerous and harmful technology. Recently, Fight for the Future and Students for Sensible Drug Policy organized a National Day of Action to protest the use of Facial Recognition on Campus. Learn more about opportunities to get involved here. Prioritize interdisciplinary training efforts and seek out coursework and opportunities that expand the understanding of the implications of data science. We encourage students who are majoring in STEM to take classes in the social sciences and humanities, and vice versa. We also encourage students to get in touch with organizations listed in the appendix.

Who else is doing this work?
Resources to get involved with data justice

In addition to resources shared in the reference list and linked throughout the document, we wanted to compile an extensive, but not exhaustive, list of organizations that are leading the data science for justice movement. The following organizations are listed in alphabetical order.

ACM Conference on Fairness, Accountability, and Transparency (ACM FAccT)
ACM FAccT is an interdisciplinary conference dedicated to bringing together a diverse community of scholars from computer science, law, social sciences, and humanities to investigate and tackle issues in this emerging area. The conference attracts hundreds of data scientists each year, and content from all conferences, including papers and videos, is posted online.

AI Now Institute
The AI Now Institute, housed within New York University, is an interdisciplinary research center analyzing the social implications of artificial intelligence. They focus on four core domains: rights and liberties, labor and automation, bias and inclusion, and safety and critical infrastructure. They currently host workshops and their website includes their various publications.

Algorithmic Justice League
The Algorithmic Justice League is a collective that aims to: highlight algorithmic bias, provide space for people to voice concerns and experiences with coded bias, and develop practices for accountability during the design, development, and deployment of coded systems.

Allied Media Projects
Allied Media Projects (AMP) cultivates media for liberation. AMP defines media to include all the ways we communicate with the world. AMP defines liberation as an ongoing process of personal, collective, and systemic transformation. AMP is a network of people and projects, rooted in Detroit and connected to hundreds of other places across the globe. Together, AMP grows and exchanges ways of using media to create the world we need.

Build Tech We Trust
Build Tech We Trust is a collective of tech CEOs, activists, change-makers, and workers who believe the time to act to counter the hate and terrorism exacerbated by tech platforms is now. The collective believes technology should improve the human experience and quality of life for everyone, and that tech companies and leaders should take responsibility for the harm caused by their platforms and tools.

Code for America Brigade Network
The Code for America Brigade is a national alliance of community organizers, developers, and designers that are putting technology to work in service of our local communities. They believe that government can work, for the people, by the people, in the digital age, if we all help.

Data & Society

Data & Society is an independent nonprofit research organization that studies the social implications of data and automation, producing original research to ground informed, evidence-based public debate about emerging technology. Their Health and Data research track may be of particular interest to readers of this paper.

Data for Black Lives

Data for Black Lives is a movement of activists, organizers, and mathematicians committed to the mission of using data science to create concrete and measurable change in the lives of Black people. Programs include leading a movement to Abolish Big Data, forming Data for Black Lives chapters in cities throughout the US, organizing an annual conference, and administering a policy working group.

The Fenway Institute – LGBT Population Health Program

The Fenway Institute of Fenway Health in Boston houses the LGBT Population Health Program. The Program works to develop and support collaborative research and education programs to understand and improve the health of sexual and gender minorities. The Program includes findings and more details on the work they have been doing on their website.

Measure

Based in Austin, Texas, Measure is a data-driven and community-led organization that works to empower people impacted by data disparities and the accompanying narratives. They focus on three goals: addressing systemic injustice using data, connecting people to institutions that serve them for collaborative solutions, and providing disruptive, informative and innovative training.

Media Justice

Media Justice (formerly Center for Media Justice) is building a powerful grassroots movement for a more just and participatory media —fighting for racial, economic, and gender justice in a digital age. Launched in 2009 by Malkia Devich Cyril, Amy Sonnie, and Jen Soriano — Media Justice boldly advances communication rights, access, and power for communities harmed by persistent dehumanization, discrimination and disadvantage.

Research Action Design

Research Action Design (RAD) is a worker-owned collective that uses uses community-led research, collaborative design of technology and media, and secure digital strategies to build the power of grassroots social movements. They are contributors to the #MoreThanCode report.

The Williams Institute – Census and LGBT Demographic Studies

The Williams Institute of the UCLA School of Law houses a plethora of studies on their website pertaining to a variety of topics within the LGBT community. Their research discusses LGBT health, data collection, legislation impacts, incarceration rates, hunger, and socioeconomic wellbeing among the LGBT community.

References

1. Angwin J, Larson J, Mattu S, Kirchner, L. Machine Bias. ProPublica. https://www.propublica.org/article/machine-bias-risk-assessments-in-criminal-sentencing. Published May 23, 2016. Accessed February 20, 2019.

2. Green B, Chen Y. Disparate Interactions: An Algorithm-in-the-Loop Analysis of Fairness in Risk Assessments. FAT* '19: Proceedings of the Conference on Fairness, Accountability, and Transparency. 2019: 90-99. doi:10.1145/3287560.3287563.

3. Chen, A. Why the Future of Life Insurance May Depend on Your Online Presence. The Verge. https://www.theverge.com/2019/2/7/18211890/social-media-life-insurance-new-york-algorithms-big-data-discrimination-online-records. Published February 7, 2019. Accessed February 28, 2020.

4. Plummer, L. This is How Netflix's Top-Secret Recommendation System Works. Wired. https://www.wired.co.uk/article/how-do-netflixs-algorithms-work-machine-learning-helps-to-predict-what-viewers-will-like. Published August 22, 2017. Accessed February 28, 2020.

5. Eubanks, V. Automating Inequality. New York, NY: St. Martin's Press; 2018.

6. Detroit Digital Justice Coalition. Allied Media Projects. https://www.alliedmedia.org/ddjc/principles. Accessed March 3, 2020.

7. Costanza-Chock S, Wagoner M, Taye B, Rivas C, Schweidler C, Bullen G, the T4SJ Project. #MoreThanCode: Practioners reimagine the landscape of technology for justice and equity. Research Action Design & Open Technology Institute. 2018: p108-111. https://morethancode.cc.

8. Detroit Digital Justice Coalition. Recommendations for Equitable Open Data. 2017: https://github.com/datajustice/report/blob/gh-pages/downloads/DataJusticeReport.pdf. Accessed April 1, 2020.