

# **FINAL REPORT**

## **NSF WORKSHOP ON COLLABORATION AS BIG DATA ETHICS**

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**September 19-20, 2016**

**Arlington, VA**



Organizers:  
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## 1. Executive Summary

### 1.1 Introduction

The landscape of knowledge production has been transformed by the advent of information technologies that dramatically expand and accelerate our capacity to produce, process, and analyze data about the social and natural world. Today, your child's Barbie doll can tell "Alexa" what he wants for his birthday, feeding what were once private concerns into a river of data that shapes everything from manufacturing and marketing to social research and government policy. Our technological ability to collect and process data outstrips our human capacity to reflect on its production, or to interpret its meanings thoughtfully. Increasingly, scholars and decisionmakers rely on the black box of algorithms and systems developed in distant contexts to tell us what it all means and what we should do about it. The data revolution is transforming the questions we ask and the ways we seek answers, but also the relationships between actors and disciplines taking part in this shifting knowledge production landscape. Technology is again reshaping social relations and social imaginaries, and alongside growing excitement there are growing concerns. As has been true in prior knowledge revolutions, we are called as scientists to address new theoretical questions and ethical challenges that arise in these new modalities of research and analysis.

What do new data analytics, relying on computer programs, algorithms and administrative records once not treated as data for analysis, mean for governance? How can, and why should we, understand the emphasis on computer science and engineering in knowledge production through an ethical lens in governance? To answer these questions, this report draws upon data analytics in use in local and federal governments and health management to argue that for big data to have a positive impact on policy, equality, and governance, we need to question how research questions are developed, how data validity is understood and operationalized, how differential impact on human and nonhuman groups is anticipated and documented, and how findings are translated into action. The report demonstrates that we can "design in" ethics by designing in collaboration; knowledge about subject matter, analytical tools and ethics are distributed across people and fields, and ethical approaches to big data must highlight collaboration across different kinds of expertise. To treat ethical dimensions of policy as something to be designed into an algorithm or model, and not reconsidered as analyses are designed, deployed, and with any luck redesigned, is to invite analyses that replicate histories of promising too much and leading in troubling directions, such as exacerbating existing inequalities or focusing on issues not designated as primary by stakeholders. Cautionary tales about big data have been the subject of critical analyses (boyd & Crawford 2011; Crawford 2016; Eubanks, 2018; Gillespie 2016; Mah 2017). Other projects develop the use of analytics, including visualizations, for purposes of advancing justice, sometimes designed in partnership with interest organizations and other times defined as work that has impact (See e.g. Data for Progress; Data Science for Social Good; Mapping Police Violence); the external concerns and the partnerships rather than something intrinsic to the technology define what the technology means. This body of work reminds us that we "urgent[ly] need to reflect on the epistemological implications" of current formulations of big data (Kitchin 2014).

Ethical frameworks conventionally address action that is individual and intentional, and operate through prescription and rules. In research ethics, this has meant protocols for the

protection of human subjects that rely on notice and consent, and identifiable relations of accountability between subject and researcher. However, in the world where administrative records are repurposed as research data, and a person's moving through space produces a trail of signals captured by the "internet of things," notions of consent and confidentiality have little practical meaning. The unprecedented scale at which data aggregated from disparate sources shapes every aspect of life today generates distributional and symbolic effects well beyond the level of the individual researcher-subject relation. An ethics of big data demands a broader framing, one that recognizes the human nature of data, and addresses the disparities and harms that can arise from big data analytics' surveillance – or erasure – of entire social categories, systems and processes.

The collaboration required to produce, manage, analyze and interpret many of the new forms of data available to researchers further complicates discussion of ethics in this new era (D'Ignazio and Klein, forthcoming). While the computational sciences and engineering hold the spotlight in data analytics, the data fed in to computational algorithms represent the experiences, actions, thoughts and relationships of actors in a wide range of fields. These include the individual whose lives produce the data-worthy phenomenon, the frontline service provider who captures information about those lives in a transaction record, the administrator who codifies that information in the form of data, the engineer who aggregates and connects data according to principles of aggregation, the analyst who applies a different theoretical framework to connect, code, categorize and interpret the data sets, and the decisionmaker who acts in ways that directly or indirectly affect the original and unwitting data producer. The open data movement, which asks scholars and officials to make all the records that go into analysis or decisionmaking available, promises to hold governments (Ruppert 2015) and scholars accountable; the conditions required for making data useful to others often go unanalyzed (Gitelman 2013; Levy and Johns 2016; Sterett 2019)

Each of these interacting players may bring a different understanding and ethical framework regarding the information that is ultimately produced, as well as bear different consequences from its use. Not only may different values define what counts as valid knowledge within their professional disciplines, these professions themselves are marked by hierarchies of race, gender, class, age, and nationality that elevate the questions and concerns of some over those of others in ways that reinforce systems of inequality. And yet, these diverse actors are unevenly thought of or convened as collaborators whose differences can enrich the ultimate analysis. We know from the social sciences that collaboration is inextricable in scientific and lay knowledge production, and that unexamined differences across groups are the source of many failed collaborations. By attending to the social nature of data, and to the underlying and unequal relations shaping its production and use, we can leverage the insights of all involved parties, and prevent considerable harm that can arise from a failed collaboration at the scale which big data can affect.

## **1.2 Workshop Overview**

The NSF Workshop on Collaboration as Big Data Ethics was held on September 19-20, 2016 in Arlington, Virginia. A diverse cohort of computer science, engineering, and social science researchers and practitioners, health management experts, and local and federal government employees were brought together to address large-scale ethical questions raised by

the use of big data and algorithms in research and practice, and their ultimate effect on decisionmakers in creating and implementing policy. A multidisciplinary team of this nature has the potential to foster the ability of data analytics to have the broadest impact by collaboratively imagining the continuously evolving field's biggest ethical challenges in creation and usage of big data. Participants were invited to consider a collective process to doing so, modeling consulting and building community across citizen groups and organizations. Building users and producers into the analytical process makes for more usable knowledge and creates a more ethical process (Neff et al. 2017).

We urge an empirical approach that examines (1) the disproportional, often unintended, effects on social groups due to the creation and use of big data; (2) scientists and engineers' articulated and unarticulated ethics and values and their connection to scientific practice; and (3) the individual and institutional values that drive big data work. Working with stakeholders provides insight into the work practices that will be impacted, the cultural contexts, the meanings that may be provoked by new socio-technical systems, and the key challenges faced by particular communities; failure to take into account cultural contexts, work practices and community priorities can result in adoption failures (Cockburn & Ormrod 1993; Joyce 2006; Joyce 2008; Neven 2010; Oudshoorn 2003), undone science (Hess 2015), surveillance of people who have not meaningfully consented, and the production of less useful knowledge. As large scale funding opportunities for data analytics continue to rise, a theoretically and empirically driven approach to ethics in the field contributes to a more useful approach (boyd & Crawford 2011; Brown and Davidson 2013; McAfee and Brynjolfsson 2012). There is good evidence that diverse teams are more creative in developing ideas, and can develop more useful knowledge (Page 2007; Jehn 2008). Without this diversity, teams can imagine technological fixes to social problems, but such "fixes" may not translate to adoption or usefulness. We can work with government officials, nonprofits, computer scientists, engineers, and social scientists to identify grand challenges and create data sets that speak to these challenges.

The workshop was guided by the following central questions: how do we ask meaningful research questions? How do we know that we have good ways of analyzing problems? What are the criteria for what counts as good? How is data validity understood and operationalized? What are the ethical implications of asking different kinds of questions? How does the data collected result in new paid and unpaid labor relations? A central premise of the workshop is that asking and addressing problems effectively requires inclusion of various stakeholders in design and use (Ahern et al. 2011; Chismar et al. 2011; Heikkilä & Gerlak 2005; Kristensen et al. 2006; Monahan & Fisher 2011).

The workshop also highlighted two areas where ethics, big data and society intersect. The first centers on inequalities and big data, investigating how decisions at every step of the way (e.g., from the definition of the research question to the collection and use of big data) can unintentionally have differential effects on different social groups or ways of knowing the social world. Without taking into account inequality, we can misunderstand what we find, both in producing data and using it. For example, if a goal is to try to understand people's health but environmental hazards are not in patient records, then we will not be able to analyze the role of environmental vulnerabilities in relation to health. Such environmental vulnerabilities are often distributed by social class, with lower income individuals bearing a disproportionate share. The

kind of data we collect sets the analysis and solutions in motion; if data focus on the individual level then solutions will be at individual level too. In addition, trust in officials is distributed unevenly by socioeconomic status; people may wish to find ways to evade data collection, or not participate where they can, and we will think our aggregate level data capture individuals better than they do (Nelson 1979; Gilliom 2001). Finally, despite the good intentions of computer scientists and software engineers, data can be applied differentially to various sectors of the public, with the poor, women and people of color being differentially targeted by socio-technical interventions and scrutiny (Eubanks 2018).

Examples are multiple, and in sum lead to the conclusion that including communities in design and use and a commitment to epistemic justice is essential to emergent data analytics (Fricker 2009). The following lists just a few examples. Kate Crawford has argued that machines can discriminate as they scan resumes or approves bank loans (Crawford & Hasan 2003). Institutional discrimination does not require intent to discriminate, just differentiation on the basis of characteristics associated with race or gender. Depending on how machines learn to rank different factors, outcomes can disadvantage the already disadvantaged, exacerbating the inequality that is already a policy concern in the United States. Next, machines can perfect law enforcement in a way that blames individuals and excludes other problem definitions. For example, African Americans are more often subject to wage garnishment; African Americans are less wealthy and can call on family or friends for help less readily. Improving wage garnishment for debt collection does not require intent but will contribute to racial inequality. Conversely, technological fixes can imagine citizens who monitor the use of their data in a way that everything we have learned from cognitive science belies. Thinking through what our assumptions are and how we imagine people and institutions is crucial in new analytical models. The goal of this workshop was to bring together those who work on technological fixes with those who analyze the assumptions and implications of big data analyses to collectively define and contribute to the impactful use of big data.

The second takes up the issue of privacy and big data. For big data to both speak to societal grand challenges and be used, the human component of big data must be examined. The black box of users, in other words, must be opened up and understood in its complexity. Doing so, shows that privacy, for example, is not simply a code problem, and code alone will not address it. Data breaches in recent years have demonstrated people's incentives and mistakes to share information without meaningful consent. How are computer scientists taught to protect data? What are the assumptions built into these protections? Will these steps protect individual's information as hoped? How do we make people aware about the data they are contributing to and understand how it may be repurposed? Most obviously, many people would not yet be aware that sensors might map wherever they are in a city or building. They cannot forego living their lives, even if they do become aware, so they cannot opt out of sharing their information. People can forego posting on social media, but people can post for one purpose and find their data used for another. For example, #BlackLivesMatter was under surveillance for threat assessment (Theriault 2015). The city of Chicago has used bar codes on dumpsters to improve the collection of waste disposal fees, which can disproportionately affect poor people (Byrne 2014). Electronic data collection and management have been used to enforce safety rules for truckers (Levy 2015), and to monitor recipients of public assistance (Gilliom 2001). Such use of data can exacerbate mistrust in government, already a substantial problem. Furthermore,

medical research in other fields has raised questions about data ownership and those who generate the data, and how they benefit. Perhaps most notoriously, in 1951 Johns Hopkins Hospital collected cells from Ms. Henrietta Lacks, a poor African American woman who died of cancer, and her cells have remained essential to medical research since. In 2013 NIH revised its protocols for use of cells to include oversight by Ms. Lacks' family (Johns Hopkins University HUB 2013).

A theme of three ethics arose: in method; in outcomes; and collaboration as ethics. Ethics in methods entails developing meaningful research questions aligned with commitments to equity and participation. At the fore of data creation, cleaning, linking, analyzing and the continuing cycle thereof, are ethical human subjects protection and privacy implications taken into account? The implementation of this analytic cycle by policy and decisionmakers risks reinforcing inequalities, the ethics in outcome, if ethics in method are not in place. This should be true prior to data collection to ensure accurate data representation of social groups and processes, and help eliminate unexamined biases in analytic tools. Collaboration as big data ethics makes it all the more likely to eliminate the “don't knows” of who is or is not involved, or should be. What are the academic disciplines, new and old? Are these stakeholders collaborating, and how can they best do so?

## 2. Panel Session Reports

### 2.1 Introduction and Keynote

#### **Introduction: Big Data, Disciplinary Expertise and Building**

Kelly Joyce, Drexel University  
Susan Sterett, Virginia Tech  
Srinivas Aluru, Representative from South Data Hub

- Workshop as a discussion in preparation for NSF solicitation for multi-sector “data spoke” collaborations for its regional big data hubs.<sup>1</sup>
- Growing excitement and investment in these data science hubs, bootcamps, programs and initiatives also raises ethical concerns. Are these truly partnerships, or are fields, organizations and individuals operating from different worlds?
- The framing of ethics as individual, intentional, prescriptive and rules based brings unintended impacts and harms to groups. Need principles to guide new kinds of problems. What is human subjects research if databases can be de-identified (Metcalf and Crawford 2016)?
- Collaborative learning, such as in this workshop, is an exercise in these ethics, to garner inclusion and trust, and consider human costs.

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<sup>1</sup> See [https://www.nsf.gov/funding/pgm\\_summ.jsp?pims\\_id=505264](https://www.nsf.gov/funding/pgm_summ.jsp?pims_id=505264).

- The disciplinary training and orientations of different teams working with big data shapes the values and foci of their research. For example, computer scientists may be more concerned with speed and elegance, rather than data validity. Computer scientists and engineers are not necessarily trained to think about the validity of the human subjects data they utilize. On the other hand, social scientists do predict or expect issues with data and privacy, which represents their disciplinary values – and can't do the coding well.
- Interdisciplinary work is fraught with differences in meanings, values and rewards. It is necessary to think about equity and incentives, especially in this fast moving field.
- Key questions: what makes a good question? Who decides? How are data produced? Who investigates and negotiates data validity and uses? How are individuals and groups protected? How are they made more visible/vulnerable/invisible?



**Keynote: Electronic Health Records:  
What are the societal impacts of the measure?**

Ana Diez Roux, Dean of Dornsife School of Public Health, Drexel University

- Why is the medical world interested in electronic health records (EHR)? The use of value based payment systems, in which providers are paid based on case characteristics. The Affordable Care Act (ACA) also incentivizes attention to “pop health.”
- Why is the public health world interested in EHR? Research, surveillance and monitoring, and policy evaluation; not just in terms of individual health intervention, but also of any policy that might impact population health.
- In a world of complex inequality, incorporating information from other levels of determinants to health outcomes in EHRs, such as measures of social and behavioral factors, is important.
- Very little is currently linked to patient records, to enable linked analysis, in terms of population health patterns. Inclusion of both individual biological, social and economic factors, as well as factors of differing levels of societal organization, allows for analysis of possible interventions outside of the health care system, such as education and urban planning. Today, population health in the medical world maintains a managerial efficiency perspective.
- Example: the relationship between childhood obesity and community level determinants such as the presence of a soda tax.
- There would be many benefits, in terms of targeting patient and population services, but possible risks, in context of price discrimination and segmentation, or other adverse interventions in a patient’s life. Stigma is likely to have a continuing impact.
- Ongoing efforts to integrate these environmental and behavioral measures, or upstream and downstream determinants of health, in EHRs are discussed. There are methodological and ethical issues to be worked out if the 11 or so measures across 12 domains are used, including possibility of implicit bias and systemic discrimination. Further research is required to track impacts across a variety of affected areas.
- Potential measures: U.S. Census socioeconomic status based measure; access to healthy foods; food insecurity; public transportation; social context (segregation); and risk and response to treatment.
- Implementation issues include: linking data systems and permission to do so; self-reported data; privacy protection; and resource considerations (time, money, etc.).
- Geographic health information systems, database linkage, and automated geocoding raise informatics issues such as reliability and confidentiality.
- It is likely that the benefits outweigh the costs to increasing surveillance and data collection in this way, furthering “precision medicine,” but it is also worthwhile to develop measures to mitigate anticipated adverse consequences.

## 2.2 **Panel 1: Professional Challenges to Collaboration: Asking Good Questions, Developing Useful Answers**

### **Professional Challenges to Collaboration: Asking Good Questions, Developing Useful Answers**

**Chair:** Justin Abold-LaBreche, IRS

Michelle Rogers, Drexel University  
Srinivas Aluru, Representative from South Data Hub  
Eta Davis, Fairfax County Government

**Discussant:** Hugh Gusterson, George Washington University

Justin Abold-LaBreche: Introduction

- Making analytics work by introducing ethics. Taxpayer assistance panels provide the opportunity to understand the consequences of using data at the IRS.

Michelle Rogers: Impact of Health Care Data on Work Practices

- How does clinical health information for health care practitioners impact patient safety?
- Engineering and socio-technical systems perspective of organizations as complex interactions of a composed work system composed of people, tools, technology, tasks and environments.
- Distributed cognitive system works across multiple agents, part of a stream of activity, embedded in larger organization, with phases of ebbs and flows, shaped by tools.
- In patient data this means multiple sources of data with variable meaning and validity, funneling in to a system and processed through technology filters/tools, tying together physical, cognitive and social/behavioral processes and shaping multiple kinds of outcomes: patient, professional and organizational.
- In 2012, there were more than 40,000 health apps. Most not having an enormous impact, but all generating data. What happens to that data?
- In health care informatics, multi-disciplinary teams essential. These teams should be composed of anthropologists, clinicians, computer scientists, human factors and ergonomics, organizational psychologists, information/graphic designers, patients, and others.
- Concerns: how is patient experience being codified, visualized, processed and communicated, interpreted? What is the professional's physical condition and experience, in using the data (i.e., in telemonitoring at electronic/virtual ICUs)?
- Coping responses with potential unintended consequences to overwhelming data bombardment: trade accuracy for speed, reduce performance criteria, deviate from procedures, batch/defer tasks till later, shed tasks, recruit additional resources, and rely on work arounds.

- To ameliorate these risks we can design “solutions” to these problems, such as expanded data views, integrated workspaces, overview displays and graphic visualizations of data relationships.
- Uganda national health system case project provides a good example of information management in a low resource setting. Current practices are supported, creating a bridge between traditional and modern practices by negotiating cultural practices and infrastructure and human resource challenges.

#### Srinivas Aluru: NSF Big Data Regional Innovation Hubs (BDHubs)

- Co-Executive Director of Georgia Tech’s Institute for Data Engineering and Science (IDEaS), which uses computer systems for high-performance computing driven by speed to examine large, complex and global problems. Ethics in genomics, the study of functions of unknown genes, one such issue, critically requires the involvement of public policy and social science expertise at the outset.
- The NSF BDHubs similarly address societal big data challenges, by bringing necessary stakeholders together – research centers, industry, and government - to build shared standards, data infrastructure and resources; to assist in knowledge and technology transfer, education and workforce training, and public education and trust-building. Data is generated in the field, and will not be fully analyzed by academics without industry engagement, public awareness and data sharing. Public trust about data usage and privacy is key.
- There are four BDHubs. The Northeast BDHub is located at Columbia University and is affiliated with 99 institutions and 193 personnel.
- Regional hubs have launched Spoke projects, which are multidisciplinary initiatives based on key themes and funded by NSF. The West hub focus on water and environment; Midwest - digital agriculture; Northeast - cities/regions and finance, energy, education; and South – health, coastal hazards, engineering.
- For example in the South, the hub examines health disparities in genomics and precision medicine to improve health outcomes for minority populations. Similarly, the hub advances computational approaches and analytical models to improve response to environmental disaster hazards.
- How to best use the hubs? Identify big projects underway and engage them in terms of validity and ethics. In the South we are trying to create and host data repositories; transfer capabilities; harness intellectual resources; host meetings and workshops for partner institutions; and connect with regional industry. Grand challenges include efficiently and effectively sharing assets, and automation.

#### Eta Davis: Economic Success Strategic Plan Measures and Indicators

- The Economic Success Strategic Plan for Fairfax County, Virginia was adopted in March 2015, to respond to changing realities of county budget and revenue expectations and future growth fields. How people use space has changed over time: housing vacancy impacts the real estate tax base.
- The plan includes six goals: economic diversification, increasing physical innovation districts, bureaucratic process streamlining, natural and physical infrastructure investment, equality/education for growth, and government agility.

- How do we measure progress or success on these goals? Virginia Tech is helping to define the system, based on stakeholder consultation.
- Characteristics of good measures: stakeholder buy-in, not output/input measures, not just about efficiency, contextually oriented, rely on more than one item, can be measured, are adaptable, don't start out as symbolic, etc. – “not ways we [as bureaucrats] typically think.”
- Where bureaucrats view the world in measures and how those measures influence plans and programs, political actors respond to different incentives and are driven by a need for sound bites to sell a product, consultants sell themselves, and academics will always find more problems and questions to probe.
  - Example: Governor of Kansas pulled measures offline because they did not tell his preferred narrative of tax cuts stimulating the economy. Questions: were the measures valid for the underlying phenomenon? Can a nuanced story about processes of growth be told with metrics?
- We want measures to be a galvanizing force – a key part of the message and built into plans/programs specific for Fairfax County players.
  - Example: Child Opportunity Index taken up by local service organizations.
- “Never underestimate the intoxicating power of good graphics.”
- Call to scholars to help multiple governments that want to accomplish these same things, but don't know how to measure change, and do so in a way that is valid and sellable.

Discussant: Hugh Gusterson

- The conditions under which bodies of knowledge are mobilized and deployed are significant.
- Military and security forces are big users of data to locate and take out “bad people.” There is dysfunction in the data usage through drone warfare, by honing in on cellphone targets rather than specific people. Policymakers in D.C. think war is going better than people on the ground, because of the kind of data they are getting. There are incentives to interpret and view metrics in war positively, such as when junior officers put on their best face regarding the situation in order to get out or promoted. Vietnam data on the ground was inaccurate as seen in Ellsberg's “secrets.” Qualitative ethnographic information can be illuminating.
- Distorted input data issues involving limitations in what can be captured, who is connected and therefore measured, and incentives on sharing. Millennials with cellphones not captured by polls.
- Quirks of measurement involving accurate but wrong numbers – i.e., what does it mean if traffic goes down? Good, or bad?
- Big data does not illuminate what people are doing. It is a culturally illiterate product with no inherent meaning in the data. Statistical probabilities on aggregates don't tell you how individual experiences will play out.
- Recursivity – decisions made on the basis of big data have real-world effects, and change the ways we view and understand the phenomena being examined. As people work through the data, it changes what's being measured (i.e., mapping software that identifies a quicker path, which quickly becomes a slower path).

## 2.3 Panel 2: Data Veracity and Model Validity as Ethical Challenges

### Data Veracity and Model Validity as Ethical Challenges

**Chair:** Kaye Husbands-Fealing, Georgia Tech

Naren Ramakrishnan, Virginia Tech

Edgar Chou, Drexel University

Killian Vieth, Research Associate at the Center for Internet and Human Rights, Sciences Po Paris and Freie Universität Berlin

**Discussant:** Kevin Finneran, National Academy of Sciences (NAS)

Kaye Husbands Fealing: Introduction

- What does it mean, how do we assess it and how does it make us smarter?

Naren Ramakrishnan: Veracity, Validity and Ethical Challenges

- Surveillance, forecasting, ethics.
- IARPA Open Source Indicators project (EMBERS) – methods for automated analysis of publicly available data and use it to forecast significant population-level events.
  - Forecasting tournament hosted among three teams. The team from Virginia Tech, which included social scientists, IT, epidemiologists, regional/language specialists, won.
  - Ethical issues – surveillance; violations of “collective privacy;” recursiveness into the system (whether forecast was good or not); and misused resources. There are “nefarious” purposes for forecasting protests, but “practical” ones as well.
- UrbComp National Science Foundation Research Trainee Program (NRT) aims to train graduate students in interdisciplinary urban data science.
  - Every department, and a cohort of students, was brought together to create the Urban Computing program.
  - Ethical issues – profiling places (predictive policies); every time you click yes on an app, you’ve given your full information away; discriminatory pricing; movement modeling based on movement of your phone sim card; modeling of specific subpopulations (e.g. people on probation, children); discriminatory housing practices.
  - Creating a course on ethics and professionalism in data science. Every question has ethics component. Alert students to potential risks of using the algorithms. What safeguards can you put in place?

Edgar Chou: Impact of EHR Design and Operational Procedures on Health Care Data for Research

- What are the drivers for EHR design? What factors impact data integrity in the EHR? What are the limitations of data sets?
- It is possible to deliver better health care and “cross the quality chasm” by rallying health care organizations and users to coordinate and use info. If the patient is considered the

source of control in which there is shared knowledge and cooperation amongst clinicians, evidence based decision making is in place, safety, transparency anticipation of needs and decrease in are system priorities.

- The status quo of the healthcare system involves higher spending and lower quality of care.
- Meaningful Use is the government's effort to incentivize doctors to use EHRs.
- ACA's "triple" aim (quadruple): deliver care, cost effectively, while increasing patient satisfaction, and maintaining the health of the provider.
- Quality payment program: Merit Incentive Payment System: For every 1 hour of clinical care, 2 additional hours of clerical work in office and 2 more hours of work at home are required, meaning an increased risk for physician burnout and for lower quality care (and documentation). How did EHR get to be this way? It follows the algorithm of how doctors are trained to diagnose.
- Data integrity refers to data completeness; consistency and accuracy of data an issue when so many questions and sources of data.
- EHR contains much more information, if diagnosis is complete, than what gets submitted for claims (Medicare limits to 10 submissions). Adverse consequences: health outcomes and reimbursements.
- Improvements to make: understand data entry to understand limits of the data itself, and focus less on programs that don't necessarily improve quality.

#### Kilian Vieth: Human Rights and Performing Security Through Big Data

- Center for Internet and Human Rights Programs: technology in international relations, norms embedded in technology (how norms define our tech, but also how tech defines our norms), and digital trade and development.
- Dutch government program "Ethics of Algorithms" – view big data issue as ethics of algorithm issue.
  - What algorithms are of public concern? Why do they raise ethical concerns? Gatekeepers keep information away from us, make increasingly subjective decisions (not yes/no, but discretionary judgment and choice rankings), and are opaque (we, don't know how they work, even owners especially regarding machine learning algorithms).
- Algorithm is a condensed information system. A recipe – set of instructions followed one by one, at the heart of software that animates our IT environment.
- Big Data as a question of ethics of algorithm (boyd & Crawford 2012):
  - Technology – maximizing computational power and algorithmic accuracy to gather, link and compare large data sets;
  - Analysis – drawing on large data sets to identify patterns and make claims;
  - Mythology – the belief that large data sets offer a higher form of knowledge that can generate insights that were previously impossible. Cultural. Discourse. Aura of objectivity.
- This perspective takes for granted the notion of large data sets as digitization continues to grow. Data is unstoppable, and we need to address the issues in how we make sense of it.
- Example: risk-based logic of (national) security is anticipatory.
  - Used to couch policy in terms of threats, now the focus is on risks we calculate, based on anticipation of likely threats.

- Risk = potential damage x probability. It's a question of perspective.
- (In)securitization (Collective 2006) – this moves from prevention to preemption. Permanent monitoring for “social sorting” (Lyon 2003). Logic of “collect it all.” Shift from individuals to “types of people” – a form of security that classifies groups of “the risky” to “at risk.” Examples include predictive policing, no-fly lists, border checks, and intel-based airstrikes (profiling).
- The risk of “Minority Report” – if system acts towards you in anticipation of your future behavior the rule of law and due process are suspended, individual privacy is invaded and other constitutional concerns are raised.
- Summary: Mythology of Big Data
  - Big data does not speak for itself. No such thing as raw data (Gitelman 2013). Theories and models are still needed.
  - Methods and assumptions have to be made explicitly in dealing with big data.
  - Practice and discourse-based approaches may help to disrupt the mythology.
- Summary: (Insecurity) and Big data
  - Risk-based security abandons causality.
  - Shouldn't depoliticize data in performing security. Algorithm has to be transparent.
  - Government regulates through algorithms, so algorithms have to be regulated.

Discussant: Kevin Finneran

- Jorge Louis Borges' “On Exactitude in Science” (1946) map story involves an empire in which cartography became so exact, only a map on the same scale as the territory itself would do. To make it accurate it has to be as rich as what it models.
- Question: we worry about the uses of big data – but is it really worse than what we already do, by more sloppy means? What is new here? Are algorithms our “driverless cars” that are safer or less safe than the methods we currently use? Do they reflect better methods than those currently used: faster, less expensive? Does technology have an embedded ideology, or does it actually change what is happening?

## 2.4 Panel 3: Conceptualizing Privacy: Producers, Users, and Institutions

### Conceptualizing Privacy: Producers, Users, and Institutions

**Chair:** Adam Eckerd, Virginia Tech

Meg Leta Jones, Georgetown University  
Michael Planty, Bureau of Justice Statistics, U.S.  
Department of Justice  
Sallie Keller, Virginia Tech

**Discussant:** Kelly Moore, Loyola University, Chicago

Adam Eckerd: Introduction

- What does informed consent mean when no one reads it? How is individual level data controlled?

Meg Leta Jones: Privacy Without Screens

- Privacy as consent and control, in online privacy policy generator for businesses.
- Privacy as fairness, involving transparency as to data collection and choice in how their data will be used. Information review and correction, information protection, and organizational accountability are all components.
- Privacy policies since 1970s: notice and consent, now based on reading a bunch of stuff on screens. Data subjects are able to participate, with more rights in Europe such as the right to be forgotten.
- In the near future, the smart world in the Internet of Things, there are no screens, but wearable technology. Often in these smart environments, we do not own the technology gathering data (“the internet of other people’s things” - i.e., drones, satellites). We can’t choose to participate in the data they’re collecting on us, which raises questions as to the premise that notice and consent is adequate to govern data use.
- Hello Barbie. The perfect toy to raise the dangers of this new terrain; it provides no information to user about privacy/information practices of this toy that claims to be your best friend.
- Collaborative ethics: smart privacy requires collaboration across multiple sectors of the economy, so as to develop meaningful law and policy, produce privacy-supporting technical design, and respond to the requirements of situated interaction.

Michael Planty: The Role of Privacy in the Design and Dissemination of National Statistics

- Overview of governing policies of federal data security: privacy from a design approach.
- Principles and practices for a federal statistics agency (National Academy of Sciences, Engineering, and Medicine 2017): Development and capturing information by design; collection of information for statistical purposes; privacy and confidentiality; follow Paperwork Reduction Act (PRA) 1980/1995 and OMB Circular A-130 (dealing with physical security issues).



- Total Survey Error Framework: a way of allocating resources to minimize error for estimates. Trade off between costs (money, burden) and data quality (reliability and validity), completeness, credibility, timeliness and relevance. Fitness for use, the extent to which data/information serves the purposes of the user, which is a subjective criteria, subject to the values that determine “fitness.”
- Statutory requirements. Privacy protections reside in OMB authorization. Bureau of Justice Statistics (BJS) must maintain the confidentiality of all data collected, protect against improper or illegal use or disclosure, reveal information including data identifiable to any specific private person for any purpose other than which it was obtained, which can only be for statistical or research purposes (with focused and targeted questions). Private information once captured is kept confidential, and used only to prepare statistical summaries.
- Data collection lifecycle: capturing and protecting private information.

Sallie Keller: Does Big Data Change the Privacy Landscape?

- Biocomplexity Institute of Virginia Tech – study of life and environment as a complex system. Not genome, but understanding biology in the context of ecosystems and the human-created world. “From molecules to policy.”
- Social and Decision Analytics Lab – statisticians and social scientists collaborate to model social condition, quantitatively, at scale.
- The “all data revolution” changes the focus of the privacy discussion from masking and suppression of data to trust, governance, and regulation.
- Privacy – the amount of information individuals allow others to access about themselves.
- Confidentiality – what data producers and researchers do to protect individuals’ data.
- Security applies to data storage and transport.
- Data – the relationships between measurements.
- Kinds of data: designed data, administrative data, opportunity data, and procedural data (rules, regulations and algorithms).
- Linked data today: IRS statistical data and Census data (Art. 26).
- World Economic Forum: Data as a new asset class, which should be protected that way.
- Craig Mundie (2014) – shifting focus from limiting data collection and retention to controlling the data at the most important point – when it is used (and the uses for which it is requested).
- Issue of data quality when data is repurposed. Traditional protections of clear and controlled ownership, such as control over measurement and collection processes, are not available to the analyst.
- Appeal: move toward a more trust-centered approach. What should government be responsible for? How should non-governmental data influence governmental data development and reporting? What alliances need to be built? Transparency and information sharing will be critical, and the algorithms governing a study have to be part of the transparency in order to ensure re-use and reproducibility.

Discussant: Kelly Moore: Privacy? And Institutional Contexts?

- The idea of “all data” suggests that all data is quantitative. Is qualitative data (essential to understanding what data mean) compatible with de-identified big quantitative data?

- Do you have the right to “data die”? Your data outlives you.
- Is there reciprocity in the consequences of these relations (consumers/users and markets)?
- Is there a way to build an ethical/normative community around data – not only through data rules and algorithms, but by having the actual people together making sense of it.
- We can no longer think about privacy the way we used to because of the blending of private, public, market spheres. Harms and benefits might be a more useful idea.
- Why are we “selling” big data as a social good, when we know these ethical problems? Why are we not focusing on these problems, including “meta-privacy”?
  - Meg Leta Jones: If private/public isn’t useful, and benefits/harms doesn’t feel like you can use it (i.e., the consumer has no real ability to act when your data is misused) – then how should we think about it? Researchers think about subjects retaining agency, which is protected through obtaining meaningful consent (in most cases). We do need to think about it.
  - Sallie Keller: Build data infrastructures that allow people to safely and effectively share data – with policies, resources, protections, etc. NORC is one example, where you can share and cooperate.
  - Sallie Keller: Building ethical communities: researchers getting involved in big data research is a way of leveling the playing field, which commerce has monopolized in the service of private good.
  - Michael Planty: BJS (which invests in careful surveying to collect accurate, private information about people’s experiences of crime) is under pressure from other “providers” who scrape public data that is known to be filtered or distorted (i.e., 50% of crimes not reported).
- How do we move on from the classical human subjects protection of “consent”? Is there something else? What if the subject sets the terms for what data I (the subject) allow be collected about me across environments?

## 2.5 Panel 4: Inequalities, Surveillance and Data Analytics

### Inequalities, Surveillance and Data Analytics

**Chair:** Sara Jordan, Virginia Tech

Solon Barocas, Microsoft  
Torin Monahan, University of North Carolina, Chapel Hill  
Andrew D'huyvetter, County of Arlington

**Discussant:** Barbara Allen, Virginia Tech

#### Solon Barocas: How Machines Learn to Discriminate

- The introduction of bias into machine learning begins with taking large data sets and making them actionable. Law and public policy experts, such as Oscar Gandy, have helped locate the source of bias generate disparate treatment and impact.
- It is possible that data-driven decisions still suffer discriminatory effect. Working to clarify how that happens, the data world only knows what it is fed. It is difficult to work with counterfactuals and correct for past injustices in this data-driven world.
- Under the law, there are two forms of discrimination:
  - Disparate treatment (formal and intentional) and
  - Disparate impact (unjustified and avoidable). Even if decisions are facially neutral, if effects have manifest disparate impact along a class line (4/5ths rule – 20% difference), this constitutes a disparate impact, and is grounds for a case. It is unclear whether this distinction meant to catch current disparate impact or rectify historical disparate impact.
- Scenario: employer wants to use machine learning to improve or automate hiring decisions. If the employer follows the logic of correlating new hire decisions to characteristics of successful past hires, any bias present in the prior decisions will be learned and replicated by the machine algorithm. It is difficult to clean up past decisions and remove the data bias.
  - Past performance may be a function of bias in the workplace, or other structural inequalities. This is an example of omitted variable bias, not a large concern within computer science.
- Set of features on which we know data does not do a good job of characterizing the population – redlining used zip code as a known proxy for race. What if the data we have produces unintentional redlining, by virtue of a coarse variable proxy? Discrimination here is an artifact of insufficiently precise data, or the average case versus specific. We need to know how the error term varies across the population, and whether that variance is racially marked.
  - Absence of credit information makes (patterned) groups “credit invisible” – no data on which to justify a decision to grant credit - so (patterned groups of) people get dismissed out of hand.
- 2x2 analysis: the granularity of data (either high or low) and the impacts on disadvantaged communities (benefit or harm). Various levels of granularity serve policy goals differently.

- Sometimes, you do not want accuracy – coarse data can have a redistributive effect, as all are priced at the average rate (i.e., insurance), while precise data would allow perfect price discrimination.
- How you define the target variable (i.e., attrition rate, versus performance rating) shapes the biases produced. Using distance from work as predictor for attrition will likely introduce bias because it is correlated with race and ethnicity.
- Redundant encodings – protected attributes might be “encoded” in a number of variables, so even if you don’t collect (race) data, the machine can “learn” to discriminate by race if it’s correlated with a number of the observed variables.
- Rather than reject machine learning, collaborations are recommended to explore and address issues that are currently “black boxed.”

#### Torin Monahan: Confronting Privilege in Resistance: Masked Inequality in Artistic Responses to Ubiquitous Surveillance

- Interplay of surveillance and resistance, and the inequality in responses to ubiquitous surveillance. There is a tendency to individualize surveillance encounters, in neglect of more structural uses of surveillance.
- Aesthetics of data – how we visualize surveillance and resistance. Look at artistic projects to conceal oneself from surveillance. Asymmetrical face paint and hairstyles, and hoodies and scarves fabricated with properties to block heat/visual tracking all undermine technological efforts to “fix” a person as a unique entity within a crowd. In the attempt to confuse automated tracking, hiding becomes a form of expression; uniqueness is established by obscuring identity.
- Visuality and marginalizing surveillance: normalization of state control through techniques of classification; denies the right to look back (Mirzeoff 2011); has racist/neocolonial aims – drone strikes, borders, etc. Instead of thinking about exposure to surveillance in universal terms, focus on “marginalizing surveillance” which produces conditions and identities of marginality through its very application (Monahan 2010).
- Does anti-surveillance camouflage achieve countervisuality? Does it denaturalize the discriminatory orders of state and corporate apparatuses? Does it force recognition of people as possessing autonomy and agency? Can it transform the structure?
  - CV Dazzle – Adam Harvey – legible/visible but not traceable. Asymmetrical face paint and hairstyles to confound recognition software. This naturalizes the surveilling gaze and personalizes the responsibility of resistance. If you’re not capable of figuring out resistance, you deserve to be tracked.
  - URME – Leo Selvaggio – 3d resin masks replicating his face, distributed. Masking and weaponizing faces. Incorrect legibility. Notion that when you are surveilled you no longer are, you perform. Idea of a “pure” self to be protected. Normalizes surveillance by accepting it and offering up a different “being” to protect the authentic self. The individualizing effect here will not tell us about unequal impacts.
  - Zach Blas – “facial weaponization suite” – “fag facemask” – grotesque plastic amalgamation of the many faces of self-identified gay men. Erase identity markers “scientifically” correlated with gay men’s faces. “Turn your face into a fog, and fog makes revolt possible.” Erases identity in the service of autonomy.

- Anti-surveillance fashion show – Noisebridge at Maker Faire in San Mateo. A highly visible event, displaying invisibilizing devices. Delegated forms of patriarchal protection – make women resist without challenging the underlying cultural assumptions. Individual avoidance rather than contesting systems of control.
- What does anti-surveillance camouflage perform in claiming an individual right to hide instead of a right to fight back or a collective dismantling of surveillance/domination?
  - Challenges symbolic violence of identification and tracking
  - Play of individual avoidance through adaptation
  - Discourses of universalism and privacy
  - Normalizes structural conditions of inequality and danger

Andrew D’huyvetter: Bridging Data Silos in Local Government: Examples from Arlington County, Virginia

- Local government is a complex and data rich environment with high expectations for service, growing demands that outstrip capacity. County governments have to be able to respond with limited resources. American Community Survey data is unreliable and difficult to understand at small geographic scales, as confidence intervals do not work.
- Local government data is often generated by financial transactions (permits, taxes, billing, grant requirements), and have generally solved the more easy problems faced. Now to tackle the hard problems, we need new research approaches.
- Case 1: Counting housing units (really about school overcrowding), as demographic shifts move faster than projection techniques. We had to build a count system, in order to get an accurate count using multiple databases, linked through GIS.
  - Real estate assessments; rental apartment survey; permitting systems all had big discrepancies in databases that were never intended to interact, but we cobbled together over a year with the help of the mapping center, IT staff, and the Community Planning, Housing and Development division through GIS.
  - Housing unit dataset provided to school system (with privacy restrictions), which maps students, examining housing supply and student growth over time, combined with vehicle registrations.
- Case 2: How many jobs are in Arlington? The number of local jobs impacts the amount of transportation funding received from the federal government. Existing employment datasets do not count everyone, or the same way (address variability), and in top-secret buildings; there is no way to know how many people are legitimately present. A new dataset was built using proxy measures for employment data generated from actual water usage (flushing toilets), cellphones, and Quarterly Census of Employment Wages data.
- Challenges: data silos; financial data not set up for this purpose, requires human and political capital; finding the cross-connection across data sets; inconsistent address formatting (GIS key linking system); lots of data cleaning, little staff; building relationships and trust; data systems are fragmented and need inventorying/updating/integrating; determining who is in charge (of the data, of the processing).

Discussant: Barbara Allen

- We need to harness data not just to do no harm, or to be neutral, but to address the “hermeneutic violence” of communities that have a lived experience of the causes of their marginalization, but no “language” (i.e., sexual harassment, domestic violence).
- As a feminist standpoint epistemologist – how can taking the standpoint of the marginalized change the potential of big data scholarship? Can data justice offer a frame for producing a discourse and scientific “facts” that trigger policy change, by changing what is knowable and known? To do so, “we” (who is we – is it experts, who represent power, or is it a broader “we” in coalition with social actors seeking change) need to collaborate with affected communities to define the questions, the data needs, and the analysis that produces data-driven knowledge.
- For Solon Barocas: Is the issue in data-driven decisionmaking (in that it is not objective) one that makes clear that we need “small data” (qualitative/ethnographic/dialogic) to identify those disparities?
  - The issue in machine-big data is that: we often hear the defense of biased outcomes that “this is just reflecting the data,” but we know that the data and the data processing cannot escape bias. It is a spurious (and powerful because of its normalizing power) defense.
- For Torin Monahan: The right to hide is an expression of white privilege (could Black or Arab men use the mask?). What kinds of action would promote the right to look, the right to challenge surveillance logics? Also critique the notion of community participation – what does community involvement in processes of mapping communities for surveillance look like?
  - The best anti-surveillance works are those that provoke self-awareness, shift the frame of surveillance normalization, so that people can see themselves as agents, being surveilled, and with the capacity to resist.
- For Andrew D’huyvetter: Are there different data available in jurisdictions that vary by class or socioeconomics?
  - In rural Virginia, you may have no digital data, one planner, and a totally different data analytic landscape. Need to adopt, at a governmental level, some means of standardizing across disparities. Regarding vulnerable populations – how do you define that, and then how do you map that to data?

## 2.6 Panel 5: Using Big Data: Reworking Professional Practices and Relationships

### Using Big Data: Reworking Professional Practices and Relationships

**Chair:** Michelle Cullen, IBM

Karen Levy, NYU/Cornell  
Katie Shilton, University of Maryland  
Suzanne Thomas, Intel: The Politics of Expertise

**Discussant:** Andrea Morris, City of Arlington

Karen Levy: Professional Relationships, Data and Expertise

- How data processes alter organizational relations and processes, and how data collection affects marginalized groups. Accountability, legibility and transparency in data systems are key.
- There are behavioral effects of deploying a data collection system into the world. The act of collecting data alters how people interact. The “black boxes” are doing work in the world, by virtue of their presence.
  - Example: people negotiating space based on objects and systems in their environments, such as decoy surveillance cameras.
- U.S. long haul trucking industry is an oddly invisible profession despite its fundamental nature to the economy. Only when something goes wrong do people notice the industry’s significance. The political economy and culture of trucking suggest a tough, sweaty, morbid, masculine and lonely existence. Truckers say they do what they do because they cannot stand to be surveilled.
  - Paper logbooks to track hours require that a driver shows they drove less than Department of Transportation regulated hours, but are often falsified. Electronic logging devices were developed to cut down on cheating, and are used about half of the time.
  - Both systems are often used in tandem. Shift from analog to digital tracking altered relationship between truckers and law enforcement, who do not like the electronic system. By placing an EDC sticker on their truck, decoy compliance may be in effect, in that the awkwardness of the EDC inspection reverses the power dynamic established by police when using the paper log system.
- Data collection and power: illegibility of the system to the administrator or researcher can shorten the interaction and even change the data being collected (through errors, fatigue, etc.) This has large-scale implications for big data accountability. Researchers must look beyond what goes in the data black box, and look at the effects the box has in the wider social system.

## Katie Shilton: Changing Practices in Big Data Research Ethics

- Research involves the cultures that grow up around data. Social sciences, medicine, data sciences – each have their own cultures around the use and management of data. Interested in exploring how norms around data emerge, change, and how decisions get made and standardized.
- Today: emerging data cultures where availability of data about people is newer, such as social computing – scholars who use big data to understand people.
- There has been some controversy, like the Facebook contagion study. When data is considered public, it is often not subject to IRB requirements regulated by the Belmont Report and Common Rule, the responses in the late 70s to controversies in psychology and medicine.
- Three major principles apply: respect for persons (notice and consent); beneficence (do no harm, risk-benefit balance); and justice (fair distribution of costs and benefits to all potential participants). IRB implementation of these principles is not always a good fit for social science. Social computing makes it even more difficult.
- Research questions: what ethical challenges are social computing researchers facing? What are the research ethics practices utilized for online datasets, and what do they think it means?
- Challenges include feasibility in obtaining consent, justice and fairness about who is in/out of the sample, and unknown risks to participants, if they happen to be de-identified.
- Emerging norms: public data, do no harm, informed consent, greater good, established guidelines, risks/benefit tradeoff, protect participants, data judgments, and transparency.
- Areas of low agreement and high variance: Ignore terms of service? Deception? Share raw data? Obtain informed consent?
- Researchers across computer sciences, information systems, and social science researchers are going beyond Belmont re:
  - transparency with participants, community leaders, researchers;
  - data minimization (collecting only what you need, letting people opt out, sharing aggregates only);
  - ethical deliberation with colleagues;
  - caution in sharing results; and
  - respecting norms of the contexts in which online data was generated.
- Is the research a significant departure from its original use? Try not to scrape or crawl public sources.
- Now exploring these questions in Citizen Science (culture of sharing/contribution) and cybersecurity research.

## Suzanne Thomas: Politics of Expertise: Who Does What Work of Computer Vision

- Data is not a thing in itself, but a medium for our practices
- Computer Vision – data generated from light (images/video). What do they look at? What are they trained to see? What do they share with others?
- The people who work with this kind of data ask themselves “do I have the legitimacy to do this work? Am I expert?” Detracts them from questions of ethics in handling images/video.



- Example: two experts in a self-driving car manufacturing system:
  - One, a computer vision research scientist (CVRS), looking at features within images, identifying landmarks/maps, and handing off an algorithm (linear series of mathematical steps, built out of algorithms someone else built) to a visual systems engineer;
  - Another, a vision system engineer (VSE), who then develops that code into optimizing system hardware and software to drive the car.
  - Others, less valued, in the system: a data janitor/wrangler who collect and label images for the CVRS. A person developing code to translate between CVRS and VSE.
  - Each subsystem of the system is using and generating different data sets, with different norms/practices.
- Teams are now diversifying across composition/status, qualifications/pedigree and different product categories. Yet another model is integrated where everyone is drawing on “agile computer software development” and wrangling with data.
- There are tensions between those working in different models, with each defining the other as less “expert.” The team model is ascendant – and those in the initial system are at risk of losing work or status.
- Opportunity: the definition of legitimate work is under some duress. If we listen to those doing the work every day, they will tell us that “the perfect ground truth data set is not possible” even if they want it. We can engage with them, and influence. Product development teams are conscious that they don’t have the time/energy to go test the robot in every environment, so they “have to use common sense” – so ask them, what constitutes common sense? Shape their normalized views, by redefining the nature of their expertise in ways that help them.

Discussant: Andrea Morris

- Relationships are crucial to data, processes creating data, users, and analysis processes. We need to understand these relationships as scholars: in the data, and among the processes built to develop the data; among those who use the data; and between the data and the subject.
- As scholars, the data represents, loosely or not, the subject producing it – have we examined in that way?
- And what are the norms governing these relations, in a given context or cultural landscape? How does exploring those norms shape our interpretation and exploration of the data?
- Role of IRBs as consultants or gatekeepers, with little technical expertise, in the search to balance transparency and privacy. Collective, interdisciplinary, and multi-disciplinary spaces where these issues can be discussed are integral to maintain ethics of big data usage.

### 3. Recommendations and Conclusion

#### Points of Practice

1. Engage in “slow data analytics.”
2. Keep equity (across groups and jurisdictions) in mind.
3. Balance transparency and privacy.
4. Ensure accurate data collection and fitness for use.
5. Use caution when linking datasets.
4. Examine data outcomes and impacts, and the role of the black box itself.
5. Collaborative interdisciplinary big data analysis will help ensure ethical and accurate societal reflection and impact.

- Slow Data Analytics: big data as quick fix will not work, as it takes too much attention and care for it to be handled effectively and successfully. Good data needs labor, time, and money – none of which are sexy requests in lure of big, fast data.
- Equity across jurisdictions: some places can ensure careful data quality and management work, while others do not have the access or ability to do so. What roles exist for NSF BDHubs and spokes, professional organizations, etc.?
- Privacy: we have yet to really figure it out as scholars. What is our obligation to tell people how their data will be used? Old-school spatial notion of privacy no longer applies when “the home” is now just a node from which users connect to servers outside. Context and information norms are key, but do not deal specifically with anonymity.
- Our ability to collect and process data far outstrips our ability to understand what that data means. What gets measured gets done. We are trying to understand what the data means, but the policy world is attracted to the solutions – and lots of people out there will cut short the questioning, and offer seductive answers (no need for democracy, the data will provide the answer). “Smart cities,” “smart cars,” and “smart devices” make us believe the data generated is also smart.
- Facilitate linkages between people with questions, people with data, and people with skills. But computer science community can be very closed to input from social scientists. NSF support for social science is key to their credibility with natural and computer scientists.

#### Major Themes

- History: rise of big data and the data science industry
- Ethical issues in big data analytics
  - How research questions are developed
  - Locating standpoint of data
  - Labor of data making
  - Troubling validity claims
  - From analysis to action: the translation of findings
- A landscape of risk and opportunity
  - Harms: potential; real; mitigation; bias
  - Opportunities: interdisciplinary and multi-disciplinary collaboration; equity and inclusion
- Collaboration as an approach to big data ethics
  - Discipline and subject knowledge
  - Methods knowledge
  - Ethics knowledge

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## 4. Appendix

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## 4.2 Workshop Agenda

### Collaboration as Big Data Ethics

Arlington, VA  
Thursday, September 29, 2016

- 8:00 AM – 8:50 AM **Registration and Continental Breakfast**
- 9:00 AM – 9:30 AM **Introduction: Big Data, Disciplinary Expertise and Building Community for Empirical Ethics**  
Kelly Joyce, Drexel University  
Susan Sterett, Virginia Tech  
Srinivas Aluru, Representative from South Data Hub
- 9:30 AM – 11:00 AM **Professional Challenges to Collaboration: Asking Good Questions, Developing Useful Answers**  
**Chair:** Justin Abold-LaBreche, IRS  
  
Michelle Rogers, Drexel University: Health Care Data and Clinical Work  
Srinivas Aluru, Representative from South Data Hub  
Eta Davis, Fairfax County Government: Developing Broad, Inclusive, and Meaningful Performance Measures of Economic Success in Fairfax County  
  
**Discussant:** Hugh Gusterson, George Washington University
- 11:15 AM – 12:15 PM **Keynote:** Ana Diez Roux, Dean of Dornsife School of Public Health, Drexel University
- 12:15 PM – 1:15 PM **Lunch – All Attendees Welcome**
- 1:30 PM – 3:00 PM **Data Veracity and Model Validity as Ethical Challenges**  
**Chair:** Kaye Husbands-Fealing, Georgia Tech  
  
Naren Ramakrishnan, Virginia Tech: Modeling Population-level Activity Using Open Source Data  
Edgar Chou, Drexel University: Impact of EHR Design and Operational Procedures on Health Care Data for Research  
Killian Vieth, Research Associate at the Center for Internet and Human Rights, Sciences Po Paris and Freie Universität Berlin  
  
**Discussant:** Kevin Finneran, National Academy of Sciences (NAS)
- 3:15 PM – 4:45 PM **Conceptualizing Privacy: Producers, Users, and Institutions**  
**Chair:** Adam Eckerd, Virginia Tech  
  
Meg Leta Jones, Georgetown University: Privacy After Screens

Michael Planty, Bureau of Justice Statistics, U.S. Department of Justice: The Role of Privacy in the Design and Dissemination of National Statistical Data Collections

Sallie Keller, Virginia Tech: Does Big Data Change the Privacy Landscape

**Discussant:** Kelly Moore, Loyola University, Chicago

5:00 PM – 6:30 PM    **Workshop Reception – All Attendees Welcome**



**Collaboration as Big Data Ethics**  
**Friday, September 30, 2016**

8:00 AM – 8:50 AM **Registration and Continental Breakfast**

9:00 AM – 10:30 AM **Inequalities, Surveillance and Data Analytics**

**Chair:** Sara Jordan, Virginia Tech

Solon Barocas, Microsoft: How Machines Learn How to Discriminate

Torin Monahan, University of North Carolina, Chapel Hill: Confronting Privilege in Resistance: Masked Inequality in Artistic Responses to Ubiquitous Surveillance

Andrew D'huyvetter, County of Arlington

**Discussant:** Barbara Allen, Virginia Tech

10:45 AM – 12:15 AM **Using Big Data: Reworking Professional Practices and Relationships**

**Chair:** Michelle Cullen, IBM

Karen Levy, NYU/Cornell: Data as Common Enemy: What Happens When Data Destabilizes Expertise

Katie Shilton, University of Maryland: Changing Practices in Big Data Research Ethics

Suzanne Thomas, Intel: The Politics of Expertise: Who Does What Work of Visual+ Analytics

**Discussant:** Andrea Morris, City of Arlington

12:30 PM – 1:30 PM **Lunch - All Attendees Welcome**

1:45 PM – 2:30 PM **Closing Remarks**

Kelly Joyce, Drexel University

Susan Sterett, Virginia Tech

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*Drexel University*

*Virginia Tech*

*Virginia Tech Research Center*

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### 4.3 Participants

<b>Name</b>	<b>Institution</b>	<b>Affiliation</b>
Justin Abold-LaBreche	Internal Revenue Service	Acting Director, Office of Compliance Analytics
Barbara Allen	Virginia Tech	Department of Science, Technology, and Society
Srinivas Aluru	South Data Hub	Representative
Solon Barocas	Cornell University / Microsoft Research	Department of Information Science / Postdoctoral Researcher
Edgar Chou	Drexel University College of Medicine	Chief Value Officer / Chief Medical Informatics Officer
Michelle Cullen	IBM	Global Client Advocacy Manager & Senior Writer, Corporate Marketing
Eta Davis	County of Fairfax, VA	Economic Initiatives Coordinator
Andrew D’huyvetter	County of Arlington, VA	Associate Urban and Research Planner
Adam Eckert	Virginia Tech	
Kevin Finneran	National Academy of Sciences	Editor-in-chief of Issues in Science and Technology
Hugh Gusterson	George Washington University	Professor of International Affairs and Anthropology
Meg Leta Jones	Georgetown University	Communication, Culture & Technology
Sara Jordan	Virginia Tech	Center for Public Administration and Policy
Kelly Joyce	Drexel University	Center for Science, Technology, and Society
Sallie Keller	Virginia Tech, Social and Decision Analytics Laboratory	Director and Professor of Statistics
Karen Levy	New York University / Cornell	Postdoctoral Fellow / Department of Information Science
CT Lu	Virginia Tech	Liaison to South Data Hub
Torin Monahan	University of North Carolina, Chapel Hill	Department of Communication, Media and Technology Studies
Kelly Moore	Loyola University, Chicago	Department of Sociology
Andrea Morris	City of Arlington, VA	Arlington BRAC Coordinator
Michael Planty	U.S. Bureau of Justice Statistics	Chief of the Victimization Statistics Unit
Naren Ramakrishnan	Virginia Tech	Engineering / Director of Discovery Analytics Center
Michelle Rogers	Drexel University	College of Computing and Informatics
Ana Diez Roux	Drexel University	Dean, Dornsife School of

		Public Health
Katie Shilton	University of Maryland	College of Information Studies
Susan Sterett	Virginia Tech	Center for Public Administration and Policy
Suzanne Thomas	Intel Labs	User and Ecosystem Research Scientist
Killian Vieth	Sciences Po Paris and Freie Universität Berlin	Research Associate at the Center for Internet and Human Rights
Heng Xu	National Science Foundation / Pennsylvania State University	Information Sciences and Technology

## 4.4 Presentations

<b>Introduction</b>	
Kelly Joyce and Susan Sterett	Whose Analysis, Whose Expertise: Partnering for Data Analytics for Small Cities
<b>Keynote</b>	
Ana Diez Roux	Electronic Health Records: What are the societal impacts of the measure?
<b>Panel 1</b>	
Michelle Rogers	Impact of Health Care Data on Work Practices
Eta Davis	Economic Success Strategic Plan: Measures and Indicators
<b>Panel 2</b>	
Naren Ramakrishnan	Veracity, Validity and Ethical Challenges
Edgar Chou	Impact of EHR Design and Operational Procedures on Health Care Data for Research
Killian Vieth	Human Rights and Performing Security Through Big Data
<b>Panel 3</b>	
Meg Leta Jones	Privacy Without Screens
Michael Planty	The Role of Privacy in the Design and Dissemination of National Statistics
Sallie Keller	Does Big Data Change the Privacy Landscape?
Kelly Moore	Privacy? And Institutional Contexts?
<b>Panel 4</b>	
Solon Barocas	How Machines Learn to Discriminate
Torin Monahan	Confronting Privilege in Resistance: Masked Inequality in Artistic Responses to Ubiquitous Surveillance
Andrew D’huyvetter	Bridging Data Silos in Local Government: Examples from Arlington County, Virginia
<b>Panel 5</b>	
Karen Levy	Professional Relationships, Data and Expertise
Katie Shilton	Changing Practices in Big Data Research Ethics
Suzanne Thomas	Politics of Expertise: Who Does What Work of Computer Vision