

Making Data Ethics a Leadership Priority

Community Roundtable

**Data
Leadership
Collaborative**

The Tableau logo, which consists of the word "TABLEAU" in a circular arrangement around the word "SPONSORED" in a smaller, circular arrangement.

Table of Contents

Introduction and Panelists pg 3-4

01. Defining Data Ethics pg 5-7

02. Data Ethics and Technology pg 8-9

03. Defining an Ethical Data Use Model in Organizations pg 10-13

04. Who Should Oversee Data Ethics? pg 14-16

05. Data Ethics as a Leadership Priority pg 17-18



Making Data Ethics a Leadership Priority

Organizations from financial services to healthcare and government should be operating in a way that honors principles about the proper and ethical use of data, especially data from customers and the public. This sounds like a straightforward initiative, but most organizations struggle to understand how the internal and external use – or even collection – of data can invite unintended consequences.

In this discussion, five data leaders share their experiences with data ethics and highlight why it will only become more important to their success and the success of their organizations.

Panelists



Bridget Cogley

Chief Visualization Officer and
Co-Founder, Versalytix



Allen Hillery

VP of Community and Impact,
Data Stories
Co-Founder, BeDataLit
Tableau Social Ambassador



Sarah Nell-Rodriguez

Senior Manager, Customer
Success – State & Local
Government, Education,
NGO, Tableau
Co-Founder, BeDataLit



Luke Stanke

SVP Analytics, phData



Krystal Tsosie

Ethics and Policy Director,
Native BioData Consortium
PhD Candidate,
Vanderbilt University
Incoming Faculty,
Arizona State University School
of Life Sciences

01.

Defining Data Ethics

Data Leadership Collaborative (DLC): Ethics is commonly defined as a set of principles that are concerned with what's morally good and bad and morally right and wrong, so how does this idea extend to the way we gather and use data?

Bridget Cogley: I'll jump in because I spend a lot of my time blogging about this question. Data ethics are applied ethics that sit between our personal value sets and laws. It's what we use when we make a decision on someone else's behalf. And very much like doctors, lawyers, and other people, we as data leaders know more about data than others will and so we are making decisions on others' behalf.

It's that informed consent piece and it's also the autonomy. It's making sure that people can truly have informed consent. Do I have informed consent if I don't know what data you're collecting, what you're doing with it, and how long you'll keep it?

Allen Hillery: I'll add to that and say data ethics needs to happen from end to end, from data collection to the actual data presentation. Most organizations have gotten really good at the laws and regulations around importing data and storing it, but there really aren't any formal rules around how we present data or how much of it we use.

Krystal Tsosie: For me, it's about ensuring that the people who generate the data or retain ownership of the data also retain decision-making authority over what happens to their data. That doesn't really happen enough because in ethics, unfortunately, we disentangle the human elements of data. Once it becomes supposedly de-identified, data becomes nonhuman subject data; therefore it could be harmonized and operationalized and considered a nonhuman element, as if it removes the risk related to the data itself.

01. Defining Data Ethics (cont'd)

So data ethics is a huge concern, especially when you think about the commercialization and co-optation of data and the value of data, which is something that nobody wants to talk about. I think that’s also part of the role that I hope ethicists will embrace, to become a little bit more assertive actually in disentangling these questions of commercialization of data.

I like to think about data ethics in terms of data access and data justice and also ensuring that those decisions are not just turned back to the individual, but also back to communities, particularly underrepresented communities, especially if the data’s being represented and there are inferences being made that could harm to communities of color, who historically have been disenfranchised by these types of suppositions and inferences about data.

DLC: Luke, Krystal’s point about ethical data practice extending beyond the organization recalls a recent conversation about the role that data literacy plays in how you think about data ethics and data use.

Luke Stanke: Absolutely. I think Bridget hit it on the head with the definition. Data ethics is not just about the collection, storage, or even the analysis of data. Even the intent of the analysis isn’t enough. There has to be someone who is a true steward of the data and can help represent it appropriately, and that’s a really difficult challenge amongst organizations. A steward is someone who is there to advocate for the proper uses of that information. I know it’s a small change in terminology from “owner”, but it represents the impact that that data is going to make and the responsibility of that individual to protect it.

Sarah Nell-Rodriguez: I think this is already a really interesting discussion based on what Bridget brought up as far as informed consent, and Krystal as she was talking along the lines of the commercial use of data, too. We’re all in the data sphere right now, but this has to become something that we start to talk about in the mainstream as well. Who are the people outside of the data sphere who are impacted by this? A steward is part of managing that, but how are we making sure everyone knows exactly what is going into that collection of data? Are we really educating people on what’s happening in the world of data?

Do they know that anytime you see a cookies consent request pop up on a website, that’s your information being sold and connecting you to who knows how many different places? How do you know if they’re capturing the right information about you and that they’re not going to misuse it?

Bridget Cogley: I want to go back to what Krystal was talking about with the abstraction layer. When I was doing American Sign Language interpreting, I could very directly see the people I harmed. If I made a mistake, I could very clearly track it down to a person, a name. Right now, to quote Ruha Benjamin, “Too often technological ease and speed are inversely related to social progress because only a small sliver of humanity currently shapes the digital worlds the rest of us inhabit.” [“Parable of the Black Designer” foreword, *The Black Experience in Design: Identity, Expression & Reflection*: 2022.] So what I see as harm is not what everyone else sees as harm.



Just like data literacy and a lot of terminology, we all need to agree on what we're talking about when we say it. But with data ethics, being mindful of data from end to end as well as just having a basic level of compassion and just seeing that there are people behind data points is a great start.

– Allen Hillery

VP of Community and Impact, Data Stories | Tableau Social Ambassador | Co-Founder, BeDataLit

02.

Data Ethics and Technology

DLC: Krystal, can you speak to the idea of ethics being somehow outpaced by technology?

Krystal Tsosie: Yes, because I actually find that to be untrue in certain circumstances, particularly in my domain of genomics. If we actually take a look at the history of biology and science, a lot of these ethical questions about whether or not something should be collected have already been posited, in some cases decades ago. It's just a matter of this artificial separation of disciplines that we have carved out, so we don't speak across disciplines.

As an example, scientists are just now starting to bring community-engaged practices into their research, yet community-based historical research is something that started in the seventies. It's not innovative at all. So is ethics actually being outpaced by technology, or is there just a willful lack of acknowledgment that these previous ethical conversations have taken place and that we're not listening to the advocates and the people who are actually trying to position ethics as being necessary in these spaces? In the case of community-based historical research, it becomes purposeful negligence in ignoring these valuable conversations if we just buy into this notion of ethics being outpaced.

02. Data Ethics and Technology (cont'd)

Allen Hillery: Well, I do think that data is outpacing ethics to a degree because of the volume and the access. So even on an everyday level, we are indirectly being opted in to customer loyalty programs without even knowing it sometimes.

Or look at how COVID has been reported. There was a sense that as far as COVID is concerned, everyone should be aware of what's happening. The problem is, it wasn't being reported correctly at first, so there wasn't enough time to stop and think about how that was being presented.

There definitely are a lot of flavors from commercialization to media, so I do agree that we probably are ignoring some levels of morality or law. But at the same time, there's just so much data. So I do think there is some outpacing that's happening.

Bridget Cogley: Looking at practice professions, when we did a lot of this analysis and reporting historically, everything was very disparate. There were a lot of things we couldn't do because the technology was the limiter. After a certain point, that shifted, and the only limiter now is ourselves. It really is us standing up and saying, "Wait a minute, maybe we shouldn't do this."

It's incredibly important that consumers have a healthy amount of skepticism that requires a level of transparency and openness about how industry and corporate leaders actually utilize data.

– Krystal Tsosie

Ethics and Policy Director, Native BioData Consortium

PhD Candidate, Vanderbilt University

Incoming Faculty, Arizona State University School of Life Sciences

03

Defining an Ethical Data Use Model in Organizations

DLC: It would be interesting to hear whether any of you have worked for organizations that defined an ethical viewpoint, then translated it into how they used data. Or do you find that most organizations are backing into a viewpoint - or even indifferent to it?

Allen Hillery: I feel on a high level that some organizations have backed into it. Some organizations definitely want to make sure they're adhering to certain laws that are out there as far as privacy goes. I remember in parts of my career where we had to make sure that even though we were collecting a lot of customer data, we had to anonymize pieces of it, or we weren't collecting it at all. So I think a lot of larger companies have to make sure that they're adhering to all the legalities. That takes precedence.

Luke Stanke: If I were to guess, many companies are backing into some level of corporate responsibility around data, because there's this constant push and pull for an organization to be rewarded through their data at some level of let's call it profitability, and then separately the pull of using that data responsibly.

I think part of the challenge there, frankly, is that when we think about how some of these data points come to be, it may be an individual or a small team coming up with some data collection methodology where data is collected in isolation, but it is then stored centrally. And guess what? Another team does the same thing, and then there's a broader enterprise corporate part of the company that's saying we have data point A and data points C through F, and over here we've got X, Y, Z, so guess what? We have the magic combination - L, M, N, O, P - that brings it all together, and now we can tell this full story about one of our customers because they want this better story.

03. Defining an Ethical Data Use Model in Organizations (cont'd)

So the intent, I think, is often positive. However, we don't realize the broader impact, and this comes back to my earlier point about the need for those individual data points having a steward and having an organization that understands not just the steward but also the actual users of that information and how that use can impact the organization - or everyone, frankly.

Allen Hillery: That's a good point, because sometimes once you've stitched the whole story together, that's when it becomes a privacy issue because now you have the whole story about customers.

Another point Luke made is that someone could be stewarding one piece of data, and another person is stewarding another piece of it, and they're not operating at the same procedure level. So yes, sometimes these things are happening with good intent, but they just indirectly end up becoming a privacy issue.

Sarah Nell-Rodriquez: One of the things I take from this is that positive intent isn't always positive execution. Given how data works within an organization, there are going to be a lot of similarities in how companies collect data and use it. Add GDPR to those privacy policies for some companies and it's rarely the same from one to another.

Everyone has silos. There are things happening in vacuums that you don't know about. And if you don't know about or have visibility into your data, you don't know if ethics are being adhered to. If there's not regulation in that system, how can you make sure that the data is regulated?

Krystal Tsosie: I see a lot of interest in Indigenous data, especially for commercialization, co-optation, and exploitation. We are very wary of these for-you arguments where an entity states, "Oh, we can do this for you as a benefit," because chances are those benefits rarely happen.

Part of this is actually building in transparency. I actually think that it's incredibly important that consumers have a healthy amount of skepticism that requires a level of transparency and openness about how industry and corporate leaders actually utilize data. Because without that, there's nothing for consumers to actually respond to to call for these types of changes in data access. I really am interested in companies that are starting to shift their narrative in terms of limiting data access. But that's only happening because of data literacy, and that data literacy can only happen if there's transparency and knowledge about these inner industry practices.

The people that are least likely to be transparent about the practices are the industry people themselves. So it really requires having other entities, people to just illuminate those practices and serve as that communicative go-between. But that's a dangerous position for people to be in, especially if you're talking about putting somebody who is a member of a disenfranchised group who is disempowered already to be in those roles. That's not something, as a young scholar, that I particularly want to be positioned as because there's just a lot of risks involved for my own personal life and professional career.

DLC: Bridget, given all of what's been said in the last couple of minutes, especially about unknown or siloed use of data in organizations, what for you are some of the essential elements of having a codified approach to data ethics in an organization?

Bridget Cogley: When we look at codifying ethics, I am very leery when the company is like, "Yeah, we do this." I know when I do a lot of consulting, I do a lot of asking: "What are you doing, to what extent, and why?" And then really trying to push to make sure that we're getting diverse voices. I think we like to draw this really hard binary of, oh, there might be harm. It's like, no, there is harm. It's the question of who. That's what we have to pick apart: What are you doing to what extent?

The Deaf community has the saying "of, by, and for," and your words, Krystal, really brought that to mind. It's not, "Oh, hey, let me do this for you." It's from us, by us, for us.

I'm also leery when people are like, "Yeah, we've got this whole ethical practice and we've got an expert." Well, does this expert get to say no? They may be thinking, "No," then they get shoved into the room and can't truly say no.

03. Defining an Ethical Data Use Model in Organizations (cont'd)

Luke Stanke: I just wanted to add to that. I feel what Bridget brings up is actually a huge issue because people tend to elevate specific brands for their perceived efforts around ethics and data. I equate this to the way greenwashing happened in the early 2010s around sustainability. A lot of what I hear today sounds like “ethics washing”. Because ultimately, when we think about an organization, part of this is about reducing risk. Having to roll back some of your data use or at least figure out how to fix it. It’s easy to say, “Hey, check out our organization, we’re doing these great things,” when a lot more has been happening behind the scenes.

We need to treat every organization and every problem on a continuum. It isn’t a yes or no from anyone.

Sarah Nell-Rodriguez: One thing I want to draw attention to as well, and Krystal called it out specifically, is that some of these areas are improving because of data literacy. I also want to say that there’s a different point of view there too, that some of these things that are not positive that are happening - because Bridget said bad things are still happening - is also because of data literacy.

It’s the issue of putting these skills into the hands of people who do not necessarily adhere to these ethics principles. We need everyone to have access to these skills so they can also hold other people responsible when it comes to not adhering to ethics.

What I’m saying is, we cannot allow some people to have ethics that they can just blatantly disregard if we don’t provide those skills to everyone. If you only put those skills into a subset of the population and remove it from a subset of the other, that’s when trouble starts rising. We don’t have the checks and balances that we need that we’ve been talking about.

Krystal Tsosie: I think Sarah has a great point about data literacy being a double-edged sword because it gives people the language to be able to do the ethical washing that Luke mentioned. Every organization wants to create a set of ethical best practices. But I hate that term because what it ends up becoming is a checklist of bare minimum behavior and practices. So that becomes the ethical floor for how an organization should engage. But it sounds happy, and inevitably the people that are making these ethical best practices are not trained in ethics themselves and they’re not asking critical questions about who should be making the rules and whom the rules are ultimately benefiting.

I just really wish that people would more critically think about these types of questions rather than just going for the happy PR veneer of it all. We don’t get enough agents that are willing or even able to see these types of attempts to pull the wool over our eyes.

Bridget Cogley: Or we see that they raise alerts and then are ultimately chased out of the organization. I see that a lot.

There are things happening in vacuums that you don't know about. And if you don't know about or have visibility into your data, you don't know if ethics are being adhered to.

– Sarah Nell-Rodriguez

Senior Manager, Customer Success - State & Local Government, Education, NGO, Tableau | Co-Founder, BeDataLit

04.

Who Should Oversee Data Ethics?

DLC: Is there a need for some sort of governmental oversight of data ethics, and if so, what would that look like? Is there any way to start to give some teeth to some of these ideas that if you do intentionally cross a line with bad intent that there are serious consequences?

Luke Stanke: Before anyone answers that, I just want to make the point again that it's not individuals with bad intentions. It's the unintended consequences of these decisions that are often the problem.

Krystal Tsosie: I think in the ideal world we would love to have some sort of oversight and that be at the government level, but I'm too cynical and I've been alive too much in the current political world to know that's just not feasible. When you consider how much corporate lobbying occurs for all the different government agencies, that's not adequate. There are just so many loopholes.

I would love there to be a mechanism that provides oversight; I just don't know what that is. I am, as an Indigenous person specifically, way too cynical to allow the U.S. government to be that entity - or even the NIH.

Bridget Cogley: When I look at interpreters for the Deaf, there used to be two different entities: the National Association of the Deaf, which represented the Deaf perspective, and the Registry of Interpreters for the Deaf. At a certain point they kind of merged, creating a combined cast so that it could be run by and represent the needs of all the stakeholders. That's not government. That is an independent entity.

04. Who Should Oversee Data Ethics? (cont'd)

I keep going back to independent entity “of, by, and for” the stakeholders. It absolutely has to be interdisciplinary because, as Krystal has mentioned, a lot of these problems have already been solved. We are not creating something massively novel.

Sarah Nell-Rodriguez: I work with the state and local levels, but there’s a counterpart that works with the federal side. The worry I have if we end up going to government regulation for something like that is there are two things that really are distinct about working for the government. One, change happens at the pace of a snail. Then once change does happen, it can change again because you have all these different governors and state and local officials who go in and out as well. So you don’t know what the staying power of that is either.

Bridget Cogley: You always have that neutral entity pushing further and further, and yes, it will feed into regulation. Historically we didn’t have to have certified interpreters for anything, and it’s like, okay, if we’re doing a court hearing, maybe we should have a certified interpreter. If we’re doing medical, hey, maybe we should have a certified interpreter. We’ve had to fight for that legislation, but as Krystal mentioned, legislation alone isn’t enough. People will still find loopholes.

DLC: So Bridget, do you see those “of, by, and for” bodies existing by industry - like a financial services one, a healthcare one - or do they have to be even more discrete than that?

Bridget Cogley: The beauty, I think, is that there will be multiple ones. Like with the National Association of the Deaf, they oversaw interpreters for a bit, and then you also had the Registry of Interpreters for the Deaf, and so you had kind of two different entities overseeing interpreters, but then we had breakouts. So when you go to Registry of Interpreters for the Deaf, there is an actual “Here’s school interpreting; here’s medical interpreting,” and there are standard practice papers.

I see that forthcoming. You’ve got Data Visualization Society; you’ve got Data & Society. You’ve got a lot of these entities forming, and I’m really, really interested to see where they go, because that’s where the power is going to concentrate. That’s where you can get people at a critical mass to make that change.

Now, those entities still have to do work; they still have to make sure that they’re representative of the population - and right now they’re not. Because again, you look at the power dynamics and who gets elevated versus who has to fight for any level of elevation.

Luke Stanke: I really do like the idea of having industry-specific consortiums that are focused on data ethics. Because ultimately you want to bring together leaders within the industry who have agency within their organizations to at least create leverage on the topic, and the combined voices will provide a lot more power than individuals can.





There has to be someone who is a true steward of the data and can help represent it appropriately, and that's a really difficult challenge amongst organizations.

– Luke Stanke
SVP Analytics, phData

05.

Data Ethics as a Leadership Priority

DLC: Coming full circle on the topic of the discussion, do any of you feel that data ethics is at any level a leadership priority? And if not, how do we start to make it one?

Allen Hillery: I feel it's definitely a priority, having data ethics. But just like data literacy and a lot of terminology, we all need to agree on what we're talking about when we say it. But with data ethics, being mindful of data from end to end as well as just having a basic level of compassion and just seeing that there are people behind data points is a great start. It needs to start throughout the organization and not just sit at the top.

Bridget Cogley: I'll say I started a lot of these conversations in 2015. I had a session and I think maybe 30 people showed up to it - and it was a lot of me screaming that we need to have these conversations. I feel like we've finally gone from "We need to have these conversations" to actually having some of them. So to me, that's the progress. Now it's going to continue to be messy - it always is - and as we progress we're going to have different conversations. So they're never going to stop.

Luke Stanke: Are leaders having these conversations? Yes, they definitely are. To what degree? I think ultimately it depends on how frankly they can quantify the value that it provides the organization. We have to look and sound very economic. We have to think about what is incentivizing leaders at any level to prioritize.

05. Data Ethics as a Leadership Priority (cont'd)

A lot of that has to do with quantifying the value that will come for an organization, whether it's increasing potential sources of income from making these decisions or reducing risk as another option. There are plenty of buckets, but those are the two where the conversation can be had.

But simultaneous to that is a lot of what Sarah has been saying: these organizations need training, and it's not just data literacy. It's specific content woven in at every level that addresses the fact that in a silo, things feel right. But you have to understand the process and weave together the ideas and foundations of corporate responsibility that each individual has, so they can use data in an appropriate manner.

I also want to lean into the values of an individual or a company. Of course, there are going to be outliers to that, but I think a lot can be said about any single individual in terms of the values that they personally believe in and having that tied to all of our personal values systems. Because at the core of it, I believe, almost everyone truly does believe that they're doing things the right way.

Bridget Cogley: I'll always push against that because what may be good for you may not be good for me. I could definitely go into a room with great intent for somebody, but if their value set and my value set aren't in alignment, even with good intent, harm is often done. So I will always, always, always caution against good intent, because good intent can be a silencer.

The other thing I'll also say that gives me optimism is I'm seeing real-world consequences for when people aren't covering their bases, if you will. So I actually saw in the news yesterday about algorithmic destruction. So if you collect data, you make an algorithm on it and you didn't get the appropriate consent, guess what? You get to destroy that algorithm. That's the first time I saw that, and I won't lie, I was kind of excited.


Sarah Nell-Rodriguez: I think right now if we decided to go out into the streets of our collective neighborhoods across the U.S. and polled people walking on the street, our neighbors, different

businesses, and said, "Tell me about data ethics," most people wouldn't know what to say and they wouldn't know how to respond. Until they do, I think we're going to continue to have this conversation.

I'm grateful for the people on this call who are bringing such different opinions and such different perspectives. I love that Bridget has been such a strong voice in this space for a number of years. I know what it's like to talk about something for many years and never be heard. Data literacy: we need so many people to be talking about this. But we have to invest in the people who don't talk about it, the people who aren't even aware of it. Until we do that, I don't think we're ever going to see that fulcrum change.

Luke Stanke: That's where I'm saying we need to be speaking to the values of those individuals in terms of their beliefs of how data ethics can be woven into their systems.

DLC: I think these are great points to end on. Thank you all so much for a great conversation.



Data ethics are applied ethics that sit between our personal value sets and laws. It's what we use when we make a decision on someone else's behalf.

– Bridget Cogley

Chief Visualization Officer and Co-Founder, Versalytix

Want to be part of the conversation
about data ethics and other
topics essential to building a
data-driven organization?

Follow the DLC  

Data Leadership Collaborative 

**Data
Leadership
Collaborative**

