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# FROM PARANOIA TO POWER

**Our Data Bodies Project 2016 Report**

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## About the Authors

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Cover photo: NYC Subway Mosaic EYE by Scallop Holden, CC BY-NC-SA-2.0

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# ABOUT THE PROJECT

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The Our Data Bodies (O.D.B.) Project is a collaborative, participatory research and organizing effort working in three cities: Charlotte, North Carolina; Detroit, Michigan; and Los Angeles California. The O.D.B. Project asks three main questions:

- How do marginalized adults experience and make sense of the collection, storage, sharing and analysis of their personal information in housing, criminal justice, employment, and municipal open data systems?
- How, if at all, do marginalized adults connect their ability to meet their basic material and social needs—food, shelter, safety, employment, health, social services, belonging, family integrity, cultural expression—to their inclusion in (or exclusion from) data-based systems?
- What strategies do marginalized adults deploy, if any, to protect their digital privacy, self-determination, and data rights?

To answer these questions, we have embarked on new ground, developing a way of research

that includes and centers the stories of the most marginalized. Our project attempts to combine community-based organizing, capacity-building, and rigorous academic research. We bring this unique lens on how you involve the community, develop research design, and build so that team members will continue to have a research-oriented perspective in the work they do on the ground. We think this approach produces richly textured interviews that grow from mutual accountability. The process is slow, but our ability to engage and elicit rich stories from people seems very strong. It's more than just a research project. The O.D.B. Project is a healing process that allows people to tell their stories, encourages them to move from paranoia to power, and provides better understandings of how they experience data collection in their communities.

We began interviews in Charlotte, Detroit and Los Angeles in September 2016. To date, we've completed 61 interviews of our planned 150. We still have a long way to go, but we are beginning to uncover some fascinating patterns.

# INSIGHTS AND PATTERNS

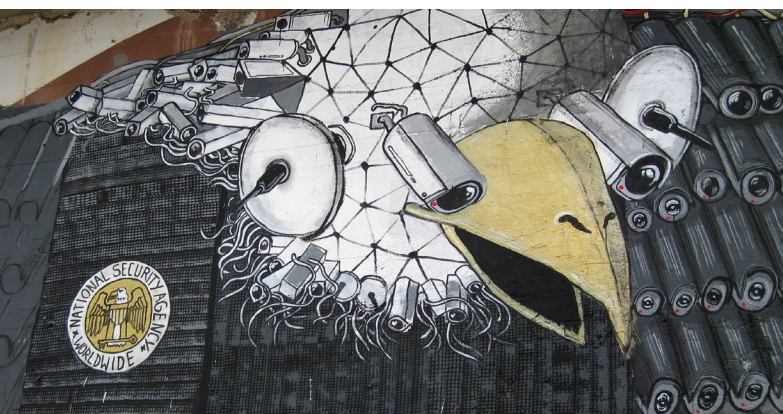
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The O.D.B. Project views data collection and sharing as a lens on our current reality and the way people are accessing their basic material and social needs. People's stories have helped us develop a greater understanding about how systems are set up, how they are interconnected, how they are communicating, how are they impacting human rights and human needs, and how people are understanding the role of data in their lives. Across the three cities, there are many similarities in how people are experiencing data systems. There are patterns like unsafety and safety, resignation and resistance, the separation of family—whether it's incarceration, detention, deportation, or foster care systems—and the continuous trading of our data for our human needs. People feel that they are being

forced to engage with different data-driven systems and their life stories and data reputations precede them into their relationships with other institutions.

Our research is beginning to suggest that our research participants are not afforded as many opportunities to rebound from the negative impacts of data collection compared with other people. The consequences of their data staying with them, whether it's an error or something they've overcome, are profound. Surveillance and data collection are deeply connected to diversion from public benefits, insecure housing, loss of job opportunities, and the policing and criminalization of our communities.

We are uncovering some very troubling impacts of data collection and sharing in our communities. We find, for example, that our data bodies sometimes show up to a place before our physical bodies, like when we give a social security number on an application for public assistance or public housing and it unlocks a whole world of information about us, our families, and our communities. Our data body can also follow behind us like a digital shadow, impacting the choices and opportunities we face in the future. Though our data bodies are mostly digital, the collection, analysis and sharing of data have a profound impact on our ability to meet our basic material needs: food, shelter, medical care, safety, and employment.



Unfinished mural. Photo: [www.upertal.com](http://www.upertal.com), CC BY-NC-SA-2.0

# VOICES OF OUR COMMUNITY

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Our interviewees show us that they know firsthand what is going on. They are living in and embodying the traumas of data collection that feels forced and unsafe. They feel and understand its consequences and impacts. People know that data sharing, system integration, predictive algorithms, data brokers, and other high-tech practices exist. They might not have precise vocabulary to describe the processes they're encountering, but they have very good analyses of their own experiences. They know there are a lot of gaps in how information is shared with them and that secrecy is built into the data-based systems they most commonly encounter, and have developed a level of mistrust in commercial systems, government services, and political systems because of it.

Here are some of their insights:

**Security & Surveillance.** A feeling of being surveilled and insecure is a very real issue for some interviewees.

"No, I'm not feeling all that secure. Some of the way I'm feeling is because I don't fully understand the technology." - Sam (Detroit)

"... When I slept on the curb I was confronted. They took pictures of me, but I didn't know they was taking pictures. I was covered up with a sitting blanket and the girl said 'They took your

picture,' so he took the blanket off my head and said 'We're going to have to talk to you about [this] homeless, sleeping on the bus thing.'" - DO (Charlotte)

**Predatory Data Collection.** Interviewees express feelings of vulnerability in being exposed to systems they experience as predatory.

"Nowadays, there are all these services where you can pay. Anybody can just pay a fee and get access to all kinds of information. It could be somebody who's stalking me. It could be somebody who—it could be a potential employer. I don't know even if it's legal, but who's going to stop them? They never have to tell me that they did it." - Justice Black (Detroit)



Waiting for Services at Crisis Assistance Ministries in Charlotte, NC. Photo: Crisis Assistance Ministries

"I had no option but to give it to them; I need to work, I need a cell phone to work, I need communication, I need a cell phone, so I had no alternative but to give out my information."  
- Una Guerrera (Los Angeles)

"I would love to un-Google my life!" - DETo3 (Detroit)

**Self-Determination, Profit, and Benefits.** Many interviewees expressed feeling a lack of agency when interacting with data-collecting agencies, employers, and companies.

"That's why a lot of companies, they'll mess with you but they don't want you to do nothing but pack and lift boxes, stuff like that. They want your physical physique but they don't want to help you." - Bee (Charlotte)

"When you go to the DPSS [Department of Public Social Services] office they want to know all your information, if you own a house, if you own a car, if you own storage, if you own stocks...I mean how much money do you got in the savings account or do you have any money under your bed." - Amy Black (Los Angeles)

"For their benefit they do communicate. But for my benefit, no." - Assata (Charlotte)

"In my experience, even if you don't want to interact with them, law enforcement will find ways to stop you and collect your data."  
- Janet (Los Angeles)

"The beauty of social media is to be able to express yourself without ramifications, to have a platform to speak to people you love. But that's not necessarily what's happening. Social media is really polarizing individuals."  
- Chloe (Charlotte)

**Data Sharing and its Consequences.** Interviewees have expressed fear, anxiety, and dread around the material consequences of data sharing.



Systems in our lives. Photo: The Stop LAPD Spying Coalition.

"Everything you do in this country, good or bad, it's used against you. Does it have an impact on your family? Of course it does! A very negative impact. Those who suffer most are always the children. What are we creating? Panic, fear, sadness." - Guadalupe (Los Angeles)

"I see why people fake their identity. This is a circle, the DMV, the department social services, credit, jobs, probation, I mean...Come on, how you going to get out?" - Jack (Charlotte)

**Solutions, Survival, and Self-Defense.** Despite feeling tracked and trapped by data collection, interviewees share innovative strategies for survival and data self-defense. They've talked about blocking, avoiding data collection, expungement, FOIA requests of their records, and building alternative communication systems that support human dignity and self-determination. They offer compelling policy prescriptions: minimize the amount of data that is collected, for example, or use a level of data privacy common to healthcare in other settings.

"What's the price of me having my records expunged? After that, where do we go from here? You going to still neglect to forgive me, or you going to not forgive me? Is it going to count against other things I'm going to do in life to get ahead?" - Hatman (Los Angeles)

“My cell phone is a prepaid cell phone. I don’t have a contract, so there is no true tie back to my identity. Wherever I can minimize me giving someone any of my information, I will. I avoid as many contracts as possible. I do a lot of direct channel transactions if I can. I don’t think there is anything that you can really do to secure yourself.” - Renita Gray (Detroit)

“Each institution [should] deal only with the information it needs. ... Collection systems should only capture data that’s necessary. They should not intimidate people. They should not violate their human rights.” - Angélica (Los Angeles)

Although the impacts of data collection are significant, we are finding that our communities still have a great deal of hope, creativity and resilience. Those we have spoken to have also expressed promising visions for building a future based in social justice, material abundance, and open and free communication.

## THE POLITICAL MOMENT

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Prior to the Trump administration, we were already hearing some mention of surveillance and insecurity around data collection. Under the Trump administration, communities have been expressing greater concern.

“The work feels even more relevant now that the Trump presidency took the reins of the system we were already mapping out.”  
- Mariella Saba, Data Justice Researcher (Los Angeles)

Because participants are more readily open to have

these discussions, the O.D.B. Project team has been afforded an opportunity to engage in conversations around proposed solutions.

“Before Trump, it feels like people hadn’t really thought about how their information is connected to how they live. Now, people are quick to mention surveillance, monitoring, or tracking. It feels like they come in thinking about it. We can actually be part of the conversation and the solution, and that makes the difference.” - Tawana Petty, Data Justice Researcher (Detroit)



# WHAT'S NEXT

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Our next steps include gathering the self-defense and survival strategies we've learned so far and sharing them out to a broader audience. We want to start from the everyday experiences of marginalized people in our communities, but we also want to remain visionary, and to contribute to a body of knowledge and practice that will help our communities be safe, just, and abundant in the digital age.

It is important to remember that data systems can also lead to positive outcomes.

"Systems can be created for good things. Systems are forms of communication; they can sustain life. I've also been thinking about

alternatives, and what has worked. ... The state is trying to study our patterns, our movement patterns or our shopping patterns or interest patterns. The way we break away from patterns feels like defense to me, how we become unpredictable, which is natural." - Mariella Saba, Data Justice Researcher (Los Angeles)

"There are advanced new technologies doing very harmful things, but there are also new technologies that are more advanced at doing humane things. We can't always be thinking from a deficit. We've got to think about the things that we create and be proactive as well." Tawana Petty, Data Justice Researcher (Detroit)

**Each institution [should] deal only with the information it needs. Collection systems should only capture data that's necessary. They should not intimidate people. They should not violate their human rights.**

# MORE ABOUT THE PROJECT

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## What We've Done So Far

- Sixty-one interviews across three cities
- Analysis of the data we've gathered so far, using a collective “code book” that helps us identify themes and patterns
- Our first reflective focus group, a gathering of interviewees and interested community members that will help us analyze the information we've collected so far
- Two convenings of the full research team, one in Charlotte and one in Los Angeles, where we developed new skills, tools, and understandings
- A very simple skeleton website—much more to come! See it here: <http://odbproject.org>

## On the Horizon

Over the next six months, the team will mostly be focused on completing interviews. Our community-led research approach is enormously time-consuming. We focus on building relationships, reciprocity and trust. We also take the time to connect research participants to resources for survival, self-defense and organizing. We think this approach produces richly textured interviews that grow from mutual accountability. By the end of July, we hope to have completed 50 interviews in each city.

Team members are also beginning to plan a series of reflective focus groups in their communities. These meetings will invite research participants and other key community members to get together and look over some of the research results so far. They will help us analyze our data, identify themes and patterns, and plan next steps. The first reflective focus group will be held in April in Los Angeles.

Mariella, Tamika and Tawana are inviting community members into the research process, speaking to them about their experiences with data collection, and analyzing the results. At the same time, Seeta and Virginia are busily working in the background to keep the project vigorous and sustainable in the long-term.

## What to Look Forward to

- A national representative telephone survey of low-income households.
- The build out of our website (<http://odbproject.org>) to report results and build a community of activists, academics, policy-makers and others interested in human rights and data justice.
- A popular education guide and academic and popular writings.



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