

# VISIONS

## Reclaiming Community, Bodily, & Data Autonomy

BY  
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how your health data is used

why it's a collective problem

and how data trusts can help

the inspiration issue

THIS ZINE  
IS AN  
IMAGINATION  
EXERCISE

BONUS!

A DATA SHORT STORY  
&  
VISIONING  
WORKSHEETS

# A DATA SHORT STORY

## The scene: A Data Warehouse and a Doctor's Office, Some Suburb, U.S.A.

A bird's eye view of a warehouse building in Some Suburb, U.S.A. It's owned by a university medical center.

Inside, there are at least dozens of rows of digital hardware. This is built for data storage of medical records.

This hardware is surrounded by cables, switches, and routers to connect to the internet. This is how the warehouse is connected to a computer in a doctor's office.

You are in the office, watching an OBGYN type your pregnancy test results: 'not pregnant'.

It smells like musk and bleach.

## The character: You as a health data bit

Now imagine, you're that bit of data that says, 'not pregnant'. You were abruptly separated from your physical being and are → inside the medical record software → in the computer → in the doctor's office (where it smells like musk and bleach).

Just imagine, you've been some a physical thing all your life and now you are just two words: 'not pregnant'.

Luckily, you're still with other parts of you: height, weight, and blood pressure. You're waiting to see what happens.

## The experience: At the whims of others

The doctor closes the software. You travel at lightning speed to the warehouse. There, you join thousands of other data bits from thousands of other people. All memory of your physical self has been forgotten and you become one of the masses. You're frantic; you can't find height, weight, and blood pressure.

You have no say in who you live with or who looks at you from now on. Your physical self probably signed some documents that stated

they have no control over you. They had no choice because they needed to know if they were pregnant.

Sometimes, you rest in the warehouse.

Sometimes, copies of you are sent to researchers.

Sometimes, copies of you are sold to data brokers.

Sometimes, copies of you are shared with the Some Suburb, U.S.A public health department.

Your physical self has no clue where you are.

Perhaps there are times that you're recalled back to that musky office and reunited with height, weight, and blood pressure. Sometimes you're reunited at the insurance offices.

Reuniting isn't always a good thing. You've heard stories of other data bits being reunited in a lawyer's office to persecute abortions. You pray that will never be you.

At any moment, you might be forced to join forces with other information to model some phenomenon you have no say in. Maybe you'll be used to predict whether some other person can get pregnant. Maybe you'll be used to show that a pregnancy test no longer works. Maybe the public health department of Some Suburb, U.S.A. will use you to say they have a fertility crisis. Maybe that means we must prohibit abortions in Some Suburb, U.S.A.

You are used at the whim of others forevermore because there is basically no way for anyone to stop it. You wish you had more say in how you were used but you can't blame your physical being, this is just what it means to get formal medical care.

## The alternative: Community decisions

If only you had a say in how your future and in how you were used. You could find height, weight, and blood pressure, and help your physical being on your own terms. You could find other 'pregnant' and 'not pregnant' data, maybe even environmental or water quality data, and get to the bottom of the fertility issues in Some Suburb, U.S.A.

**ADD YOUR OWN SCENERY**

**WHAT IF WE TREATED DATA ABOUT OURSELVES AS AN EXTENSION OF OUR BODIES?**

**HOW WOULD YOU CHOOSE TO USE YOUR HEALTH INFORMATION?**

## **Exploring the Alternative: Community Control of Health Data**

When the COVID-19 pandemic hit, organizers and activists around the U.S. started up mutual aid and solidarity networks to help their communities survive and thrive. Approaches to controlling our personal health information can have a similar collective orientation.

This Zine seeks to introduce practices from surveillance and data studies that activists can turn to amidst their already rich tactics to promote mutual aid, self-determination, and autonomous control of health and data.

### **Who is this Zine for?**

- Grassroots organizations building spaces for community control and autonomy
- Grassroots organizers for health justice
- Grassroots organizers concerned with digital tech injustices
- Decision makers + tech designers looking to align with values of community autonomy

### **For example, you might be:**

- Creating spaces for community-based healing and want to know how best to store your information
- Involved with harm reduction and concerned about surveillance of people who use drugs
- Looking to protect the electronic health records of people seeking abortions or gender-affirming care
- Collecting data on a community's health experience for policy advocacy and don't want that data in the wrong hands

## Building Trust and Shared Ties for Community Autonomy

Choosing your approach to collective data autonomy will be informed by the size of your grassroots organization, the types of ties that group members have to each other, and the groups' material resources.

For example:



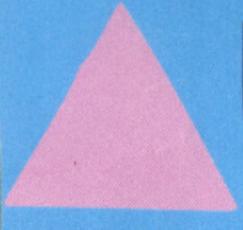
The Black Panther Party opened Free People's Health Clinics that pushed back on medical discrimination, leveled power hierarchies in the medical system, and facilitated political education.



Indigenous researchers in the U.S. have created the first Native BioData Consortium to control how genetic data is used in medical research.



HIV/AIDS activists in the 1990's created responsible needle exchanges in their communities.



# FIGHT AIDS ACT UP



They were tied by shared experiences as Black Americans, shared political beliefs, and shared ownership of spaces for clinics

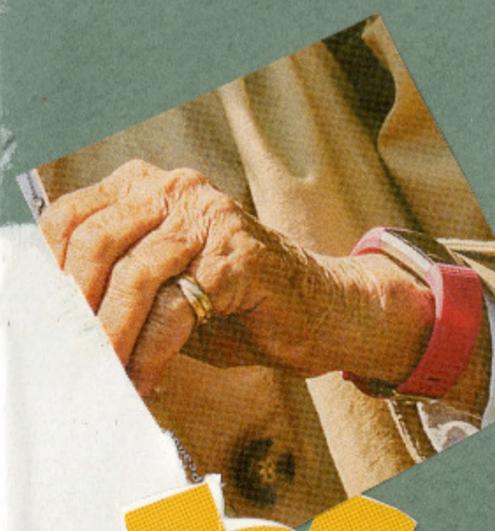
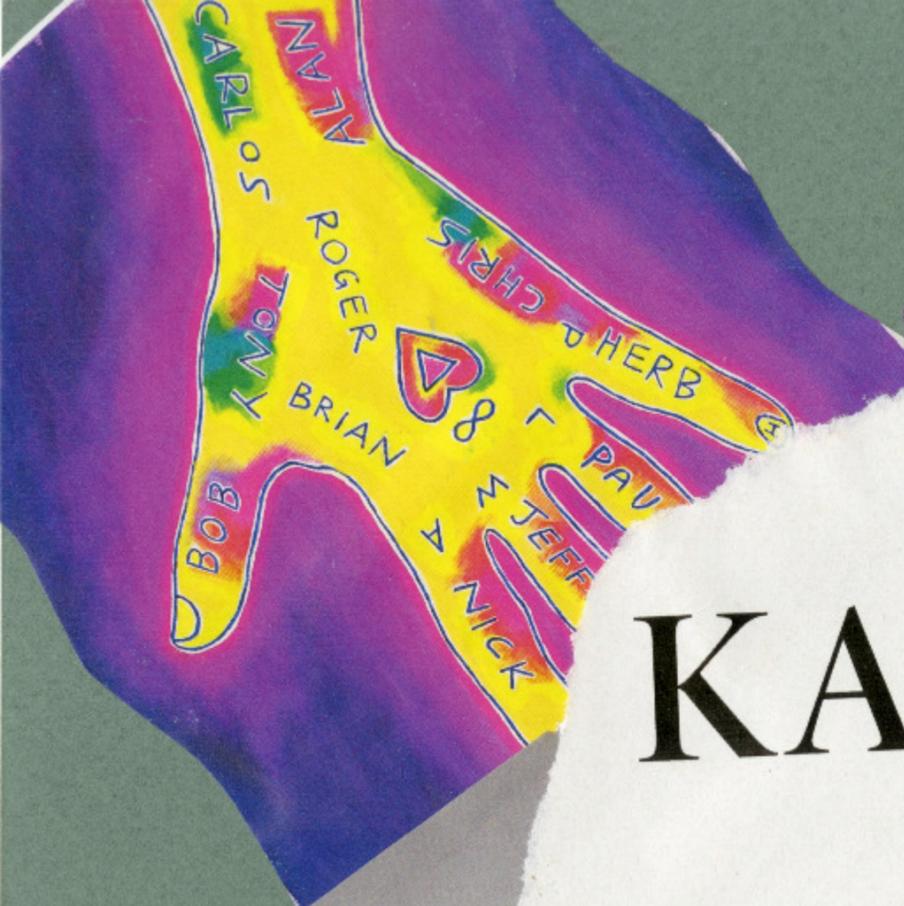


They are tied together by shared cultural, identity, land ownership, and legal recognition of the right to self-governance



They were tied together by shared queer identities and political beliefs

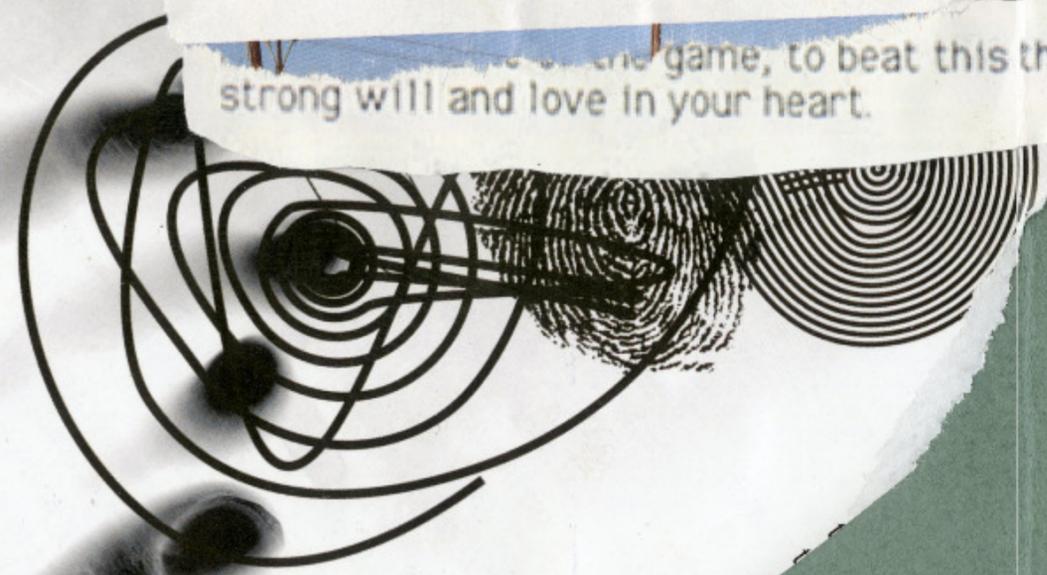




# KARMA *of the* CROWD

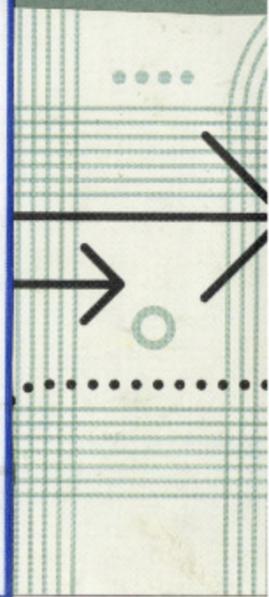


...the game, to beat this thing you got to do your part, have a strong will and love in your heart.



*flip to see what you can do!*

Remember this?  
'If only you had a say in how your future and in how you were used. You could find height, weight, and blood pressure, and help your physical being on your own terms. You could find other 'pregnant' and 'not pregnant' data, maybe even environmental or water quality data, and get to the bottom of the fertility issues in Some Suburb, U.S.A.'



## What are your options? Community Data Trusts

Data trusts create a way for groups of people to store their information with a trusted third party which then mediates how and if data is shared with outsiders.

### Imagine a data trust where you could:

- Collect the data you need
- Decide where the data are stored
- Move your data to a location of your choosing
- Decide who has access to your data and for what purpose
- Provide or withdraw consent for your data use at any moment

### In a data trust, you can make data decisions by:

- Choosing a health or technology institution you trust to make decisions about your data
- Electing leaderships to make decisions
- Voting on each data decision
- Creating a system where people who don't want to share data opt out while others chose to share
- Engaging in consensus-based decision making
- Shifting data management to your local government
- Or anything else you choose!

### In a data trust, you'll have to have some access to physical storage infrastructure:

- You can build your own data infrastructures
- You can piggyback off existing data infrastructures

### To make data trusts possible, we must pressure institutions to change:

You should be allowed to move or withdraw your health records and put them in a data trust with a guarantee that they will be deleted from their old storage location – this can be called data portability. The General Data Protection Act has started the process for this in the European Union.

Health data protection laws must also change to limit un-consented access to health records. As it stands now, people can buy your data anonymously and you may never know. Law enforcement might access your data and you will never know. And health researchers might use your data anonymously and you won't know.

### An Example: Māori Data Sovereignty in New Zealand

Māori-run health and housing programs in New Zealand work with the Metro Auckland Data Stewardship group to center the needs of Māori people and hold the New Zealand health system accountable to health equity.

The Metro Auckland Data Stewardship Group uses a set of guidelines to decide how data gets shared with healthcare systems while protecting patient confidentiality. These guidelines are set by a combination of negotiation by leaders and members of the trust.

## Your Data Autonomy Planning Space

### Taking the lead from grassroots projects

What if your group has similar politics or identities but isn't legally recognized to self govern?

Owning land and data infrastructures can help facilitate health data autonomy.

Look up the Black Panther Party's Free People's Medical Clinics as an example of infrastructural control

What if you don't have the resources for ownership?

Multiple grassroots groups can create alliances to share ownership of infrastructures.

*↳ P.S. Social Movement Scholars also study activist media as a possible coordinator for "swarm intelligence."*

Check out the Anti-Eviction Mapping Project for an example of policy change. They have been running a campaign that demands access to eviction data and repurposes that data to call for changes in rental practices

Check out the Philadelphia-based Alliance for a Just Philadelphia as an example of a coalition

What if you're less aligned through politics or identity?

Maybe the best paths of action is through policy action rather than through owning physical infrastructures.

Some of the most coherent approaches to data autonomy are pioneered by indigenous groups largely because tribes have cultural, infrastructural, and legal ties between their members.

Check out the Native BioData Consortium, the first indigenous-owned infrastructure for the storage of genetic data in the U.S. that seeks to keep storage and decision-making power local.

What does your funding look like?

A well-funded group may be able to support the cost of a digital infrastructure whereas a volunteer-based organization may not. Also, who do you trust to fund a data trust (it's in the name!).

## Your Data Autonomy Planning Space

WHO IS IN YOUR SQUAD OR ORGANIZATION  
AND WHAT TIES YOU TOGETHER?  
(WHO ELSE WOULD YOU BRING IN?)

WHO WON'T YOU INVITE IN?  
(WHO DO YOU NOT TRUST WITH YOUR HEALTH DATA)  
→ For example, do you trust  
your public health department?

DO YOU HAVE ANY SHARED LAND / INFRASTRUCTURE  
(DO YOU WANT IT? HOW DO YOU GET IT?)

HOW WOULD YOU MAKE DECISIONS?  
(BALANCING THE INDIVIDUAL / COLLECTIVE)

**DREAM IT, DO IT!**

## ABOUT ME

THIS ZINE IS MADE BY ME, LEAH, A RESEARCHER AND (DANCE) ARTIST.

I AM A PHD CANDIDATE RESEARCHING HOW TECHNOLOGY AND HEALTH SOCIAL MOVEMENTS ORGANIZERS VISION AND ENACT COMMUNITY AUTONOMY IN THE CURRENT LANDSCAPE OF DIGITAL SURVEILLANCE TECHNOLOGIES.

I'M FROM THE PHILADELPHIA AREA WHERE I WORKED, DANCED, WENT TO SCHOOL, LIVED LIFE, ETC., AND WHERE I CURRENTLY VOLUNTEER AS A RESEARCHER WITH COMMUNITY ORGANIZATIONS WORKING TOWARDS TECHNOLOGY JUSTICE.

I'M INTERESTED IN HOW AUTONOMY AND AGENCY MANIFEST IN THE BODY AND HOW THEY ARE TRANSLATED TO RELATIONSHIPS WITH THE STATE, EACH OTHER, AND TECHNOLOGY. IN MY WORK, I COMMIT MYSELF TO THE PURSUIT OF AGENCY, AUTONOMY, AND FREEDOM IN THE BODY AND IN COMMUNITY.

To reference Lilla Watson,  
Muri artist/activist/academic:

IF YOUR LIBERATION

IS BOUND UP WITH MINE

SO IS YOUR DATA

This Zine would not be possible  
without legacies of Indigenous, Black,  
disabled, and queer folks pushing  
against surveillance and  
creating resources for survival.

