

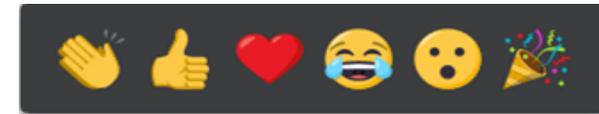
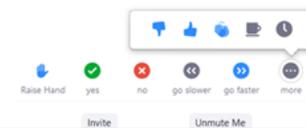
# Designing systems centered on equity

**Moderator** Lura Dausat, Director of Practice Support, Public Health Informatics Institute | May 24, 2022

Better data. Better decisions. Better health.

# Finding your way around Zoom

- The audience is muted, type your questions into the chat or use reactions to communicate with panelists.





# Antiracism Data Equity Framework

2022 Data Modernization Workshop  
May 24, 2022

Tanisha Harrell, 211/CIE San Diego  
Artrese Morrison, Health Leads  
Roxanne Suarez, 211/CIE San Diego

# Agenda

- Welcome, **Session Goals**, **Facilitator Introductions**
- **Overview** of CIE Data Equity Framework
- **Institutional and Individual Reflection**
- **Large Group Reflective** Discussion
- **Closing** Remarks

# Session Goals

## Session Goals

1. Present the landscape of data system design types, including those that center anti-racist practices
2. Discuss challenges of developing, establishing and maintaining anti-racist data design practices
3. Review and discuss the strategic visioning to reflect on the institutional practices that do harm and transform them into anti-racist solutions
4. Reflect on your personal biases as you engage in this work

## Your Intentions

### In the Chat:

- Name, Organization, Location
- What experience you bring to this session (I AM Statements)
- What knowledge you want to bring back to your community

# Facilitators



**Tanissha  
Harrell**

Director of Partner Engagement  
211/CIE San Diego



**Artrese  
Morrison**

Sr. Director of Programs, Bay Area  
Health Leads



**ROX  
SUAREZ**

Director of Partner Integration  
211/CIE San Diego

# Overview of Data Equity Framework



# Key Concepts for Understanding & Awareness

## Racism

- Racism operates at multiple levels – interpersonal, structural or institutional, and internalized.
  - **Interpersonal racism** often manifests in stereotypes, individual discrimination, and forms of prejudice.
  - **Institutional racism** is advanced through individual choices that provide or offer "differential access to goods, services, opportunities, by race." It is "normative, sometimes legalized, and often manifests as inherited disadvantage."
  - **Internalized racism** is defined as "acceptance by members of the stigmatized races of negative messages about their own abilities and intrinsic worth."
- Source: Jones CP. Confronting Institutionalized Racism. *Phylon* 2003;50(1-2):7-22.

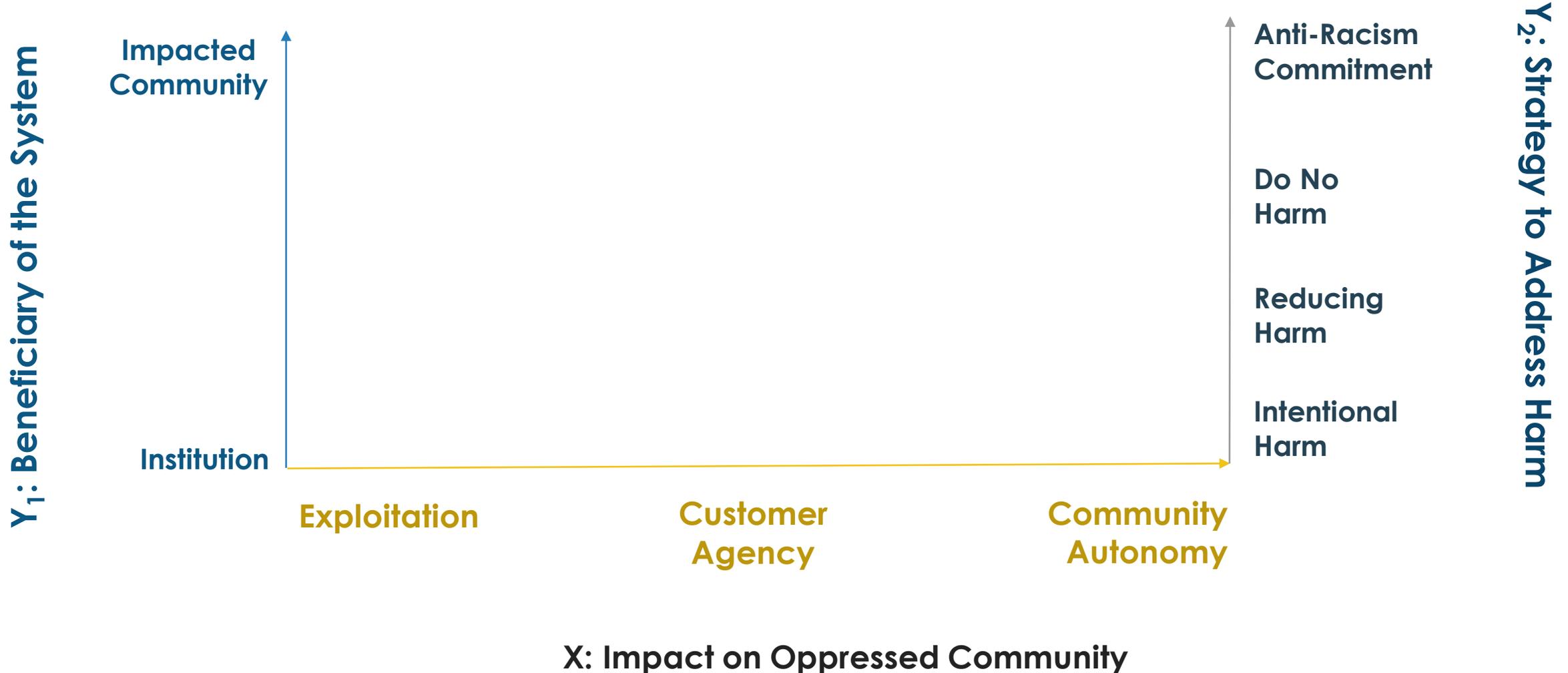
## Do No Harm

- Recognizes that the realities of poverty, class, racism, past trauma, sex/identity based and other social inequities affect people's ability to live a thriving life experience.
- Institutions that practice Do No Harm will:
  - Acknowledge and address the real and tragic harm and danger that can be associated with the results of racial and social inequity experiences;
  - Ensure that community members with said experiences have a real voice in the creation of programs and policies designed to serve them;
  - Practice civic engagement and shared leadership within institutions and boards that are reflective of communities served; and
- Promote more inclusive and equitable data practices.

## Anti-Racism

- A set of actions that respond to the systemic nature of racism.
- Anti-racism is a process that includes both unlearning and learning, abolition and building, divesting and reinvesting to create systems that advance racial justice.
- Practicing anti-racism offer opportunities to reimagine ways of understanding and addressing human needs without re-entrenching a hierarchy of needs in society.
- It also offers opportunities for intersectional solidarity between individuals facing other systems of oppression and individuals, systems, and communities.

# Landscape of Data System Design: Axes



# Landscape of Data System Design: System Types

Each system's approach is differentiated by how it centers the community.

Every system or intervention has the ability to produce harm, but **the response to the harm is what creates the lasting effect on the individual and the community.**



## **Predatory**

*Profits from systems of oppression*



## **Passive**

*Observes systems of oppression*



## **Savior-Designed**

*Acknowledges systems of oppression*



## **Ally-Designed**

*Confronts systems of oppression*



## **Equity-Empowered**

*Dismantles systems of oppression*

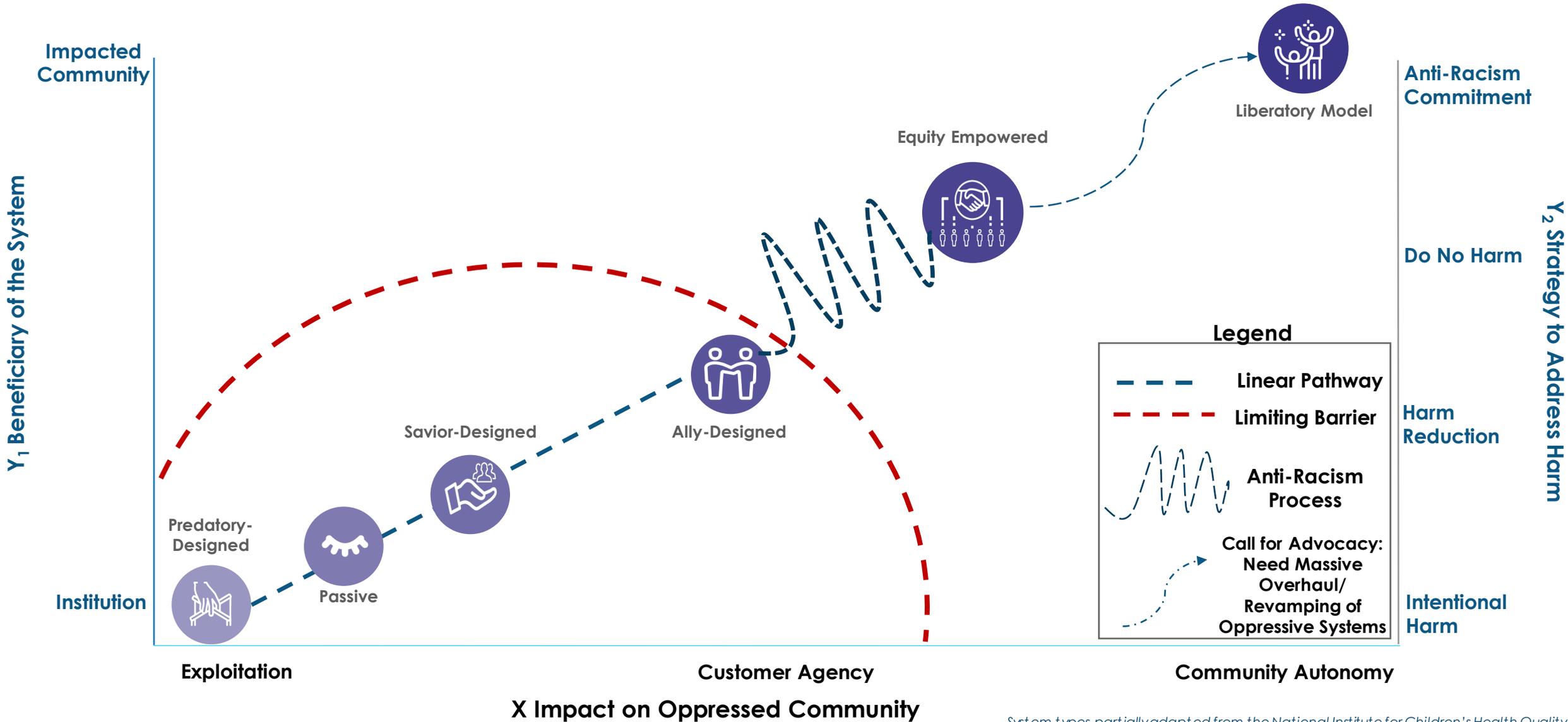


## **Liberatory Model**

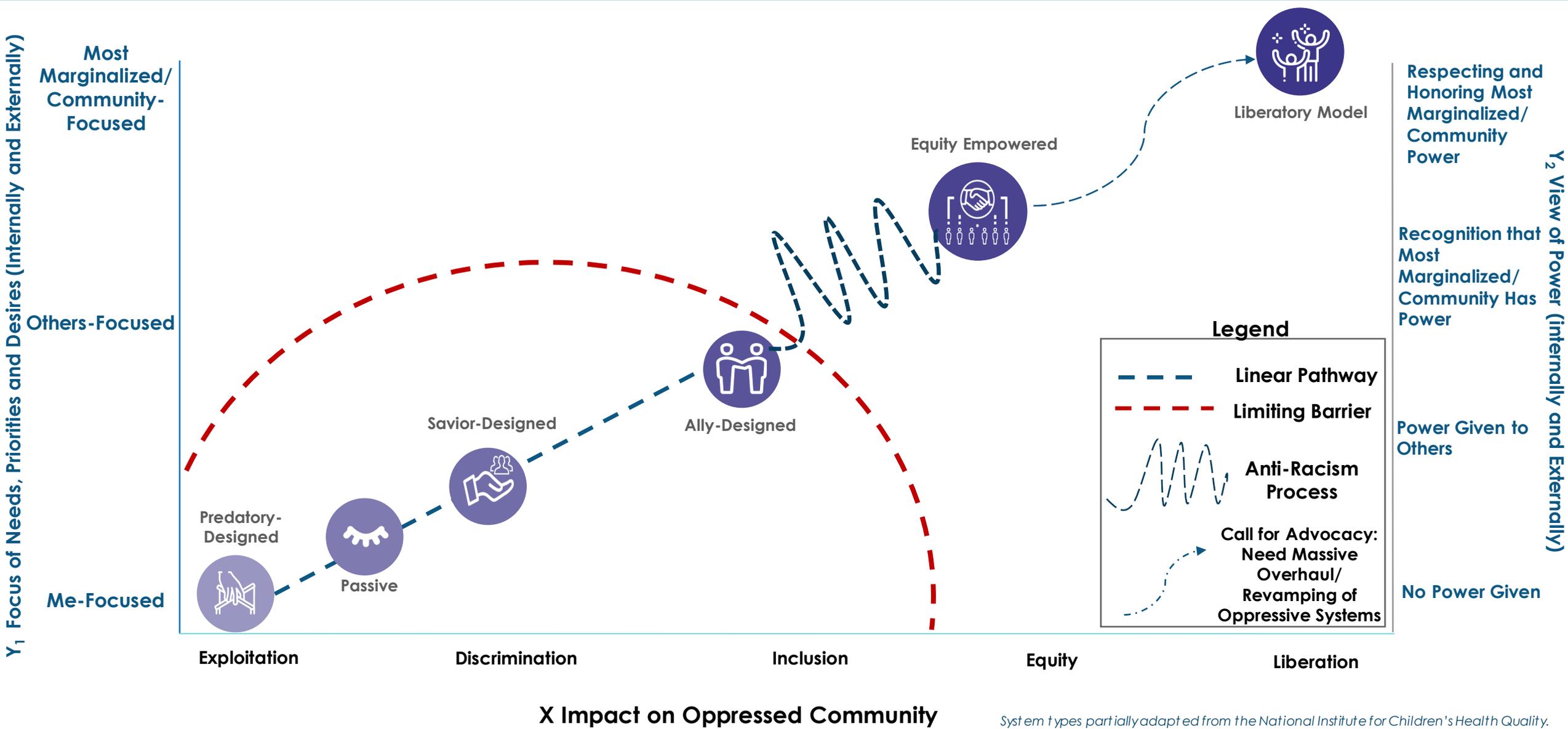
*Eliminates systemic oppression*

System types partially adapted from the National Institute for Children's Health Quality. <https://www.nichq.org/insight/savior-designed-equity-empowered-systems>

# Landscape of Data System Design: Institutional Reflection

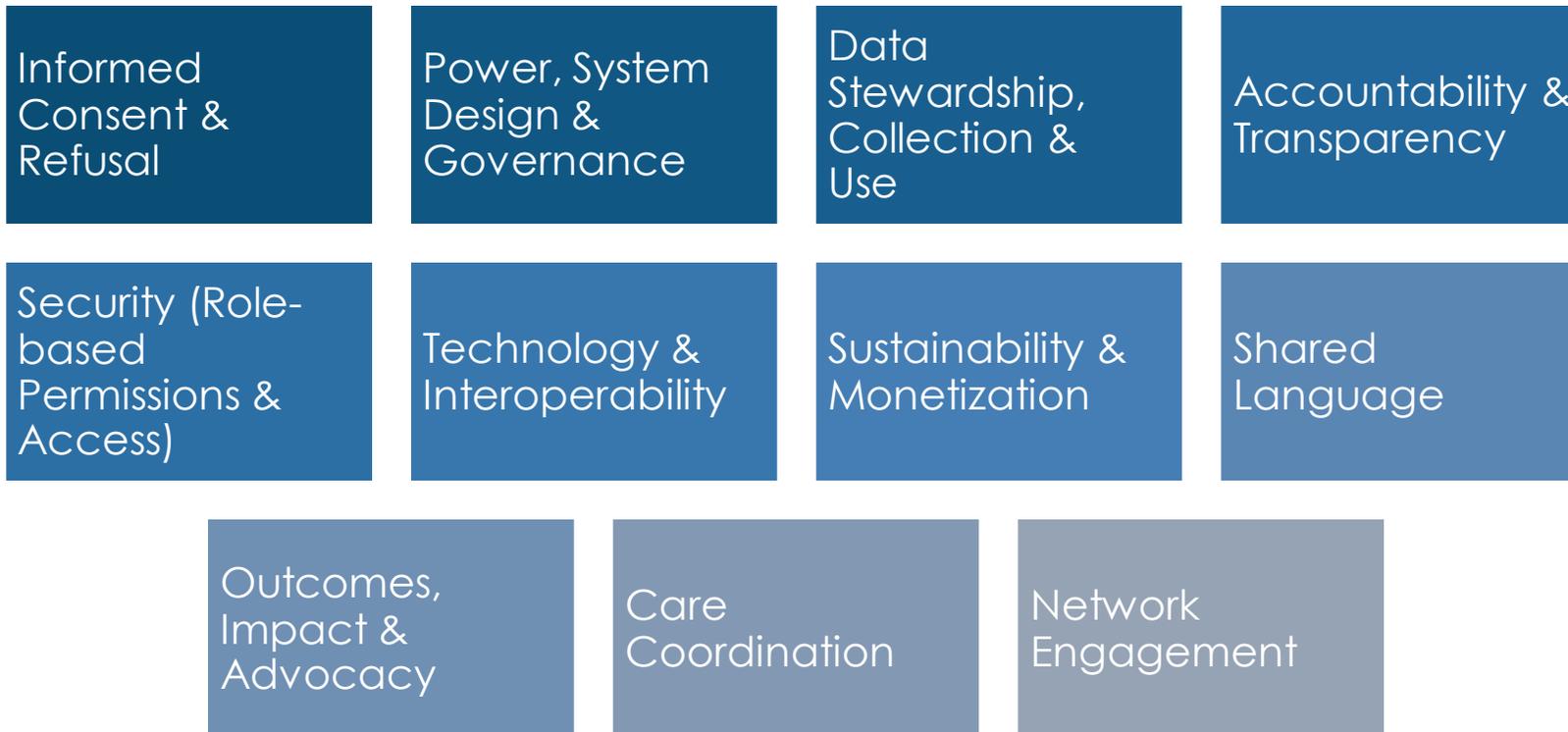


# Landscape of Data System Design: Individual Reflection



# Data System Drivers

These 11 key components provide detailed descriptions of existing data drivers that will help institutions and organizations understand the differences between each system design and opportunities to move towards an anti-racist model.



# Application of Data Equity Framework: Institutional and Individual Reflection



# Mindset

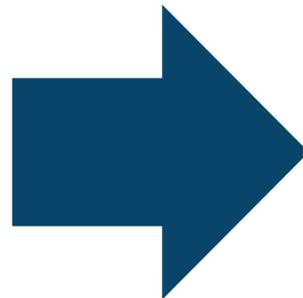


• This framework is a reflection and planning tool, not a blueprint

- Help facilitate conversations with key stakeholders, investors and partners on the importance of system design within the work.
- Many organizations will have differing paths forward.
- Some may require breaking down and rebuilding much current systems may look different for different stakeholders.

- Better understand the design and key drivers to building a robust data system of care.
- We will need to continue to do intentional, ongoing and meaningful work to move towards genuine impact on our communities.

This framework is a starting point



This framework can be used beyond data systems:

- This framework can be leveraged to examine other institutions or systems within our society.
- Democratization of all systems of care are necessary to liberate humans from systems of oppression.

# Strategic Visioning

• Understand where you are on your journey to champion data equity and justice.

- See things for how they really are, not what you are aspiring to
- Understand how you are operationalizing or perpetuating harm

Set intentions.

- State what you intend to accomplish through your actions.
- Make a commitment to what you want the journey to be about as you move forward.
- Be in the moment: who you are, what you do, why you do it.



# Institutional Reflection



## How should we use the Institutional Reflection Questions?

- Guide institutions as they navigate where they are in their journey to champion data equity and justice and where they want to be.

# Beneficiary of the System

**Which stakeholder(s) have decision-making rights and power in the design of services, intervention or programs?**

- Who benefits the most from your work? The institution creating the intervention or the most impacted populations in the community?



Institution

Impacted Community

# Impact on Oppressed Community

**REFLECT: Consider how the oppressed groups in the community are benefiting from or being harmed by the system.**

- Are community members being exploited?
  - Are they receiving more agency and feeling empowered?
  - Are they exercising autonomy? (ie feeling empowered to shape or lead the program/intervention/services?)
- 
- **How are the most underserved/vulnerable populations in your community experiencing and benefiting from your institution's services?**



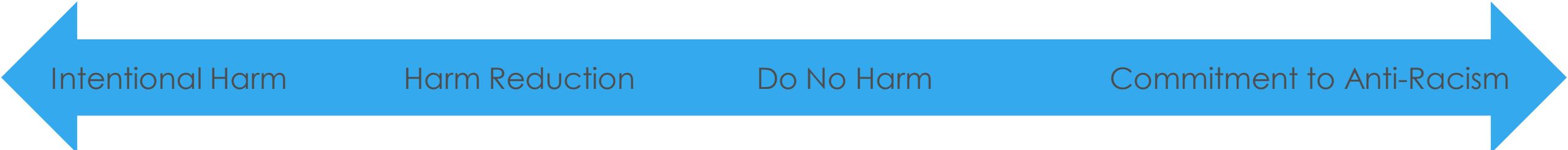
Exploitation

Customer Agency

Community Autonomy

# Strategy to Address Harm

- Does the program/intervention/solution have a clear intention and strategy to reduce or address community harm?
- If yes, how? What harms are being reduced? What are the program/intervention/solution's intentions and strategy aimed at reducing or addressing harm? What is the evidence that it is actually reducing or addressing harm?
- If not, what harms are present/being created? What are the barriers to declaring an intention and developing a strategy along these lines?



Intentional Harm

Harm Reduction

Do No Harm

Commitment to Anti-Racism



Community  
Information  
Exchange®



**THANK YOU!**

# Useful Resources

[ciesandiego.org/data-equity](https://ciesandiego.org/data-equity)

## Leveraging Community Information Exchanges (CIEs) for Equitable and Inclusive Data: *A Vision for the Future*

October 2021



Karis Grounds, MPH  
Vice President of Health and Community Impact,  
211/CIE San Diego

Beth Johnson, MPH  
Senior Consultant, Strategic Initiatives,  
211/CIE San Diego



## Leveraging CIE for Public Health Needs and Response

March 2022



Karis Grounds, MPH  
Vice President of Health and Community Impact  
211/CIE San Diego

Beth Johnson, MPH  
Senior Consultant, Strategic Initiatives  
211/CIE San Diego

Sheena Nahm McKinlay  
Vice President, Research & Development  
Health Leads



## CIE Data Equity Framework System Design Reflection and Planning Worksheet

October 2021

## Leveraging Community Information Exchanges for Equitable and Inclusive Data: The CIE® Data Equity Framework



CIE® Data Equity Framework developed by:

California Children's Trust  
Rhea Boyd, MD, MPH

211/CIE® San Diego  
Karis Grounds, MPH  
Beth Johnson, MPH  
Roxanne Suarez  
Tanisha Harrell

Health Leads  
Artair Rogers, MS  
Artrese Morrison



# Working Toward Data Justice: Concepts & Strategies

**2022 Data Modernization Workshop:  
Accelerating Transformational Strategies for Lasting Change  
May 24, 2022**

John W. Patty  
Professor of Political Science and Quantitative Theory & Methods, Emory  
*jpatty@emory.edu*

# Why “Data Justice”?

Data has become central to a dizzying array of **everyday** policy choices

Empirically, social/medical/economic data are

- Unevenly collected across individuals or groups
- Unevenly analyzed across individuals or groups

Unsurprisingly, social/medical/economic data often

- Lead to people being unevenly “**treated**,” creating **disparities**, and...
- These disparities oftentimes are correlated with individuals’ **sensitive traits**.

**Examples of “sensitive traits”:** race, gender, ethnicity, age, & more...

## But, what **is** “Data Justice”?

Data Justice is a relatively new & broad concept based on two principles:

**1. Treat similar people similarly**

and

**2. People should not be distinguished by their sensitive traits**

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(This can be complicated in health, of course—consider **gender** and/or **age**, for example)

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# A Simple Health Example

Suppose race & gender are sensitive traits, and consider four individuals

- A. A 44 year old Black woman seeks health treatment X
- B. A 44 year old white man seeks health treatment X
- C. A 23 year old white woman seeks health treatment X
- D. A 23 year old Black man seeks health treatment X

Individuals A & B differ only with respect to race and gender:

=> They should be “treated the same” (in expectation)

Applicants C & D differ only with respect to race and gender:

=> They should be “treated the same” (in expectation)

But A & C (similarly, A&D, B&C, and/or B&D) can be “treated differently”

# What does it mean to be “treated differently”?

---

Suppose that **I**

Patient A is a good candidate, and she has a 40% chance of being treated.

Patient B is a good candidate, and he has a 62% chance of being treated.

This is a violation of **Error Rate Balance.**

---

**Patient A:** Of 44 year old Black women who are treated: 90% are good candidates.

**Patient B:** Of 44 year old white men who are treated: 60% are good candidates.

This is a violation of **Predictive Parity.**

## The “Bad News”

It is generally impossible to achieve both Error Rate Balance & Predictive Parity

Turns out, this is an elegantly “simple” mathematical fact

But, this was recognized only recently (2016)!

# The Heart of the Problem

Different notions of fairness/justice **condition** on different choices:

- **Of those who received treatment**, how many individuals “**deserved it**”?
  - This is the heart of predictive parity
- **Of those who deserved treatment**, how many individuals **received it**?
  - This is the heart of error rate balance

And, there are *many* notions other than predictive parity and error rate balance

- And many/all of these have the “same kind of conflicts” with each other...

# A Numerical Example

## Data for Female Patients

	Received Treatment	Denied Treatment	<u>Error Rate</u>
<b>Good Candidate</b>	20%	40%	$0.4/(0.2+0.4) = \underline{67\%}$
<b>Bad Candidate</b>	30%	30%	$0.3/(0.3+0.3) = \underline{50\%}$
<b><u>Predictive Value</u></b>	$0.2/(0.2+0.3) = \underline{40\%}$	$0.4/(0.4+0.3) = \underline{57\%}$	

## Data for Male Patients

	Received Treatment	Denied Treatment	<u>Error Rate</u>
<b>Good Candidate</b>	40%	10%	$0.1/(0.4+0.1) = \underline{20\%}$
<b>Bad Candidate</b>	25%	25%	$0.25/(0.25+0.25) = \underline{50\%}$
<b><u>Predictive Value</u></b>	$0.4/(0.4+0.25) = \underline{62\%}$	$0.1/(0.1+0.25) = \underline{29\%}$	

## “Demonstrating the Bad News”

### Data for Female Patients

	Received Treatment	Denied Treatment	<u>Error Rate</u>
<b>Good Candidate</b>	48.9474%	11.0526%	<b><u>82%</u></b>
<b>Bad Candidate</b>	30%	30%	$0.3/(0.3+0.3) = \underline{50\%}$
<b><u>Predictive Value</u></b>	<b><u>62%</u></b>	$0.4/(0.4+0.3) = \underline{27\%}$	

### Data for Male Patients

	Received Treatment	Denied Treatment	<u>Error Rate</u>
<b>Good Candidate</b>	40%	10%	$0.1/(0.4+0.1) = \underline{20\%}$
<b>Bad Candidate</b>	25%	25%	$0.25/(0.25+0.25) = \underline{50\%}$
<b><u>Predictive Value</u></b>	$0.4/(0.4+0.25) = \underline{62\%}$	$0.1/(0.1+0.25) = \underline{29\%}$	

# A Health Example

Suppose we're rolling out a new vaccine to the whole world (just imagine!)

Suppose that each person is either

1. A **good candidate** for the vaccine or
2. A **bad candidate** for the vaccine.

Consider **race** as the sensitive trait

Error rate balance:

- Black & white patients who are good candidates are equally likely to get the vaccine.

Predictive parity:

- Black & white patients who get the vaccine are equally likely to be good candidates.

# What does this have to do with Equity/Justice/Etc.?

**Error Rate Balance** protects the interests of the “served” (the individuals)

- It equates the “incentive to volunteer for the shot” across **sensitive traits**
  - **Example:** Black & white “good candidates” equally likely to **get the vaccine**

**Predictive Parity** protects the interests of the “server”/“provider”

- It equates the “incentive to give the shot” across **sensitive traits**
  - **Example:** Black & white individuals equally likely to **benefit from the vaccine** (if they get it)

## ...So what?

Recently, we prioritized older citizens to get the COVID vaccines

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This was a “deliberate” decision to *de-prioritize* Error Rate Balance

- And it was **publicized/explained** (*i.e.*, “reasons were given”)
- 

...and studies of **vaccine efficacy** are, in part, monitoring **predictive parity**

- For example, concerns about “wasting doses”

# There's No Silver Bullet ... but some practical steps

Error rate balance is helped by targeted recruitment

- Informing (likely) “good candidates” they are likely to receive treatment
  - **Example:** Contact tracing

Predictive parity is helped by screening

- Prioritizing “likely good applicants” **after** application
  - **Example:** Taking more detailed medical histories “at the appointment”

# Putting the data into “Data Justice”

Predictive parity and error rate balance are each based on **data**

1. Both require data on **outcomes** (i.e., is the person a good candidate?)
2. Both require data on **decisions** (i.e., who got the shot, who didn't?)

Thus, both benefit from **data interoperability**

(i.e., enabling data exchange between different systems)

Without this, it's harder to **find the source(s) of inequities**

- **Example:** Is the vaccine *differentially effective* or *differentially administered*?

# Causal Identification

Predictive performance is based in part on **counterfactual data**

**Examples:** How many

- “Good candidates” **didn’t get the shot?**
- People who didn’t get the shot were “**good candidates**”?

And, ideally, these data should be able to be broken down by “sensitive traits”

- Privacy issues: intersectionality & personal identifiability
- Interoperability: choices/codings of sensitive traits
- Social issues: stigma, “loss in trust,” etc.

# Some Other Directions toward/with Data Justice

Examining **predictive performance** in public health (and other “big systems”) can

- Identify **existing inequities** in “other parts of the system” (health insurance, education, trust, etc.)
- Provide quantitative estimates of **equity impacts** of various reforms (outreach, reminder calls, subsidies, etc.)
- Ultimately, hopefully, **inform** public debates about the “proper trade-offs” (should we prioritize the vulnerable, or the “most productive”?)

In the end, these are debates at the heart of the perceived **legitimacy** of public health policies.

Without them, **public trust is ultimately at risk.**

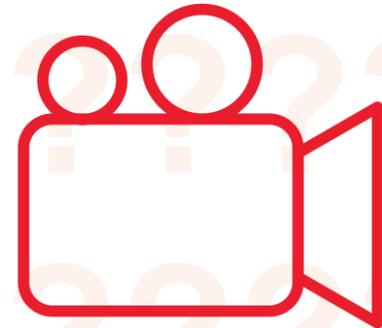
# Questions and answer



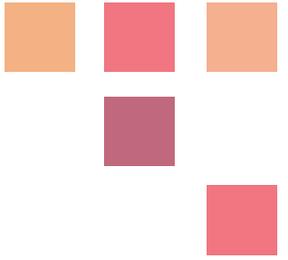
**Post in the chat**



**Raise your hand**

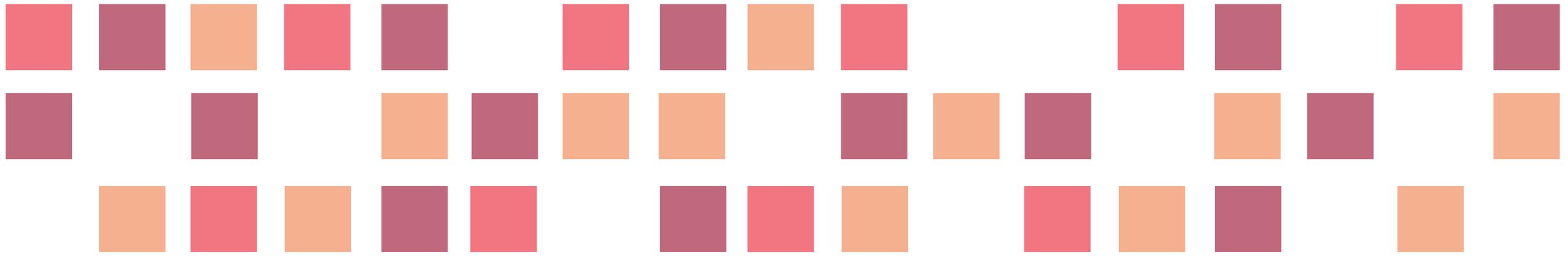


**Turn on your video**

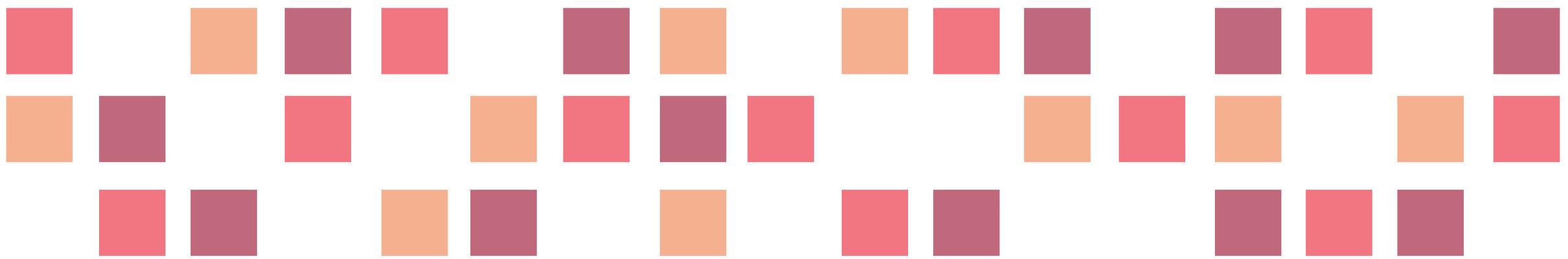


# Next Steps

- Post additional questions on Circle - link provided in the chat
- Twenty minute break 1:35– 1:55 PM EST
- Next session 1:55 PM EST
  - *Maker Session: Building Blocks (invite only)*



Thank you.



Better data. Better decisions. Better health.