# Learning Community 12: Data for Health Equity

Health Equity Assessment and Resource Team (HEART)
Office of Policy Practice and Alignment (OPPA)
3.14.24





#### Land Back Movement



**Home - NDN COLLECTIVE** 

### Today's Agenda

- Meeting objectives
- Guest presentations
  - Renold JeanLouis: Qualitative Data Coordinator, OPPA
  - Melissa Moore: Public Health Coordinator, Taylor County Health Department
  - Emile Gunovich: Data and Evaluation Manager, National LGBT Cancer Network
- Questions and answers
- Resource provision and overview
- Conclusion and Zoom survey

### Meeting Objectives

- Review qualitative methods and its importance to research.
- 2. Learn an approach to applying qualitative data to address health disparities from Taylor County Health Department.
- 3. Cover the principles of data equity and data decolonization.

# What is Qualitative Research and Why it Should Matter



Renold JeanLouis, Qualitative Data Project Manager 3.14.24

#### What Is Qualitative Research

Qualitative research is a methodology designed to collect, analyze and interpret non-numerical data to better understand people's beliefs, attitudes, experiences and interactions.

#### What Is Qualitative Research

Qualitative research relies on data that explore thoughts, and answer questions primarily centered on "why" and "how."

Qualitative data comes in narrative form.

# Why Conducting Qualitative Research Matters

- It can be used to explore topics where little information is available, offering insight and understanding by identifying key concepts and ideas.
- It has power to generate new hypotheses from inductive method.
- It has power to investigate deeper into a subject for greater understanding.
- It allows the researcher go beyond the words of the participants.

# Why Conducting Qualitative Research Matters

 Not everything that can be counted counts and not everything that counts can be counted (William Bruce German).

• It encourages us to ask questions.

• It is a way to understand what is happening locally.

• It helps explain and complement quantitative data.

# How Qualitative Data Helps Quantitative Data

 Qualitative methods can help quantitative research prioritize what to investigate.

 Qualitative researchers can explore subjects that are poorly studied with quantitative methods.

# How Qualitative Data Helps Quantitative Data

 Qualitative methods can be used to provide depth into quantitative data.

 Qualitative methods can help refine quantitative hypothesis research for future research.

#### Approach vs. Method

 An approach is a general way of thinking about a problem or situation.

 A method is the specific way of putting that approach into action.

## Approaches to Qualitative Research

• **Ethnographic** research involves incorporating yourself into the participants cultural or social group to understand their behaviors, beliefs, and practices. It focus on understanding cultures.

 Grounded Theory generates hypotheses from existing data. It focuses on collecting and analyzing data to construct new hypotheses, letting it emerge from the data itself.

## Approaches to Qualitative Research

 Phenomenological method focused on understanding individuals lived experience and how a particular phenomenon impact belief, attitudes and behavior. It seeks to understand the meaning that people give to their experiences.

• **Narrative** approach allows stories to be told to understand how participants perception and make sense of their experiences.

#### Data Collection Method

• **Focus group** consists of a group interview consisting of 6-8 people of similar characteristics or experiences to explore a topic of interest.

 Observation draws on the researcher subjective interpretation, using their senses to take detailed notes as they observe participants in their natural environment.

#### Data Collection Method

• **Survey** is a questionnaire of open-ended topic question that seek detail response in the participant's own words.

- **Interviews** focus on a personal 1 on 1 interaction and intend to dig deeper into one's experience, understanding, opinions, and motivation.
  - Structural
  - Semi- structural
  - Unstructured

#### Advantages and Disadvantages

- Surveys
  - Convenient for reaching large audience
  - Not the best for opened-ended questions
- Focus groups
  - Offers in-depth insight and rich experiences
  - Carries greater risk of disproportionate speaking

#### Advantages and Disadvantages

- Interviews
  - Better rapport and trust building
  - More time-consuming
- Observation
  - Most genuine data collection
  - Greater risk for misinterpretation/bias

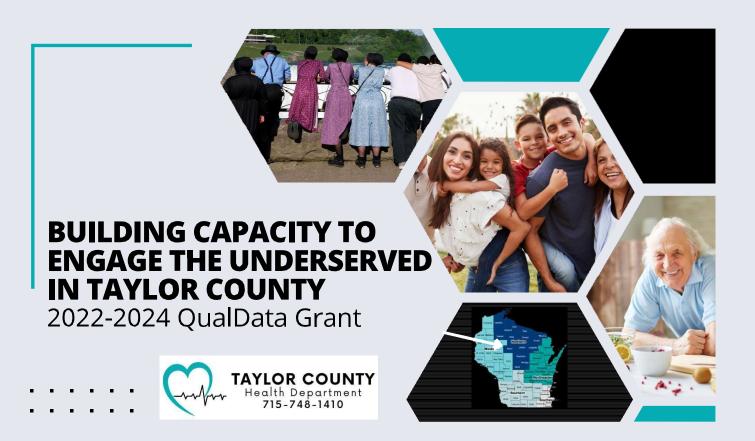
# Challenges with Qualitative Research

- Potential low credibility
- Difficult to generalize
- More difficult and more time consuming to analyze
- Research bias
- Data overload or too little data

## Thank you!!

## Qualitative Data Grantee

Melissa Moore, Taylor County Health Department





Source: https://www.tamarackcommunity.ca/hubfs/2022\_engage\_april\_story2\_finalv2.pdf





#### Incomplete or contradictory information

# of people and opinions

Large economic burden

Interconnected or symptoms of the solutions

Source: https://hbr.org/2008/05/strategy-as-a-wicked-problem lmage: https://archive.discoversociety.org/2018/07/03/why-i-amstaying-optimistic-about-the-world-and-its-wicked-problems/



#### **OUR 'SIMPLE' GOAL...**

...to reengage communities that have been isolated or underserved during the COVID-19 pandemic.



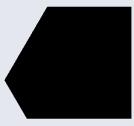
#### **OUR MOTTO...**

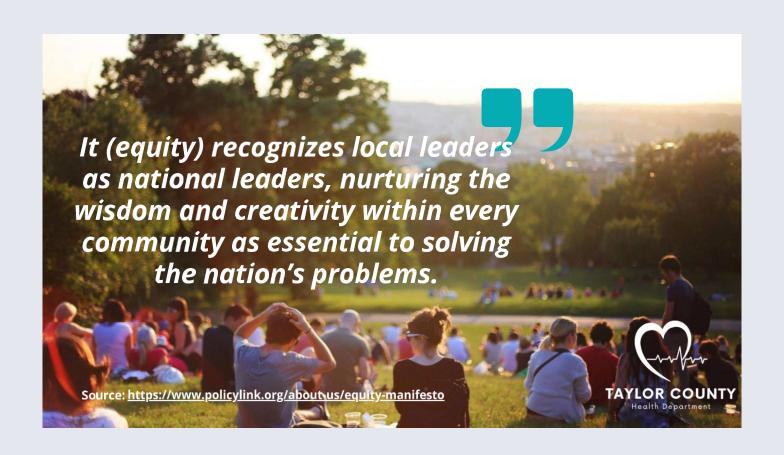
Never doubt that **a small group of thoughtful, committed citizens can change the world**; indeed, it's the only thing that ever has.

~ Margaret Mead, Anthropologist

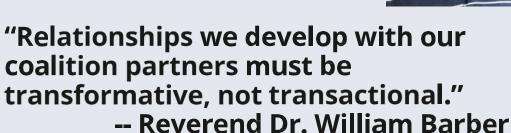








## Authentic Community Engagement



Source: https://www.health.state.mn.us/communities/practice/resources/phqitoolbox/docs/AuthenticPrinciplesCommEng.pdf

#### **OUR FOCUS AREAS**

Building Capacity to Engage the Underserved in Taylor County



. . . .



Plain Communities



Latino Residents



Older Adults & Caregivers





#### **OUR GAME PLAN...**

- > Strategies *internally* to address diversity and inclusion concerns > Strategies *externally* to address diversity and inclusion concerns







INTERNAL FOCUS
Activities within the health department & county as a whole.





**Materials** 



**Providers** 



Capacity



Orientation



Trainings



# PRINCE RESS PERFECTION

#### EXTERNAL FOCUS Activities within the health

department & county as a whole.





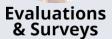
**Outreach** & Events



Contractual Help



Coalition Creation



Resources & Promotion



## Move People from where they are at





### The Reasoner Heads

Data, outcomes, & evaluation is the way to build investment in efforts



#### The Feeler Hearts

Stories, testimonials, analogies or other images build empathy for cause



#### The Doer Hands

Giving your audience a 'call to action' is one of the MOST important steps

#### **OUR SUCCESSES**



NEW COALITIONS & PARTNERSHIPS



**BUILDING MOMENTUM TO MOVE COMMUNITY** 

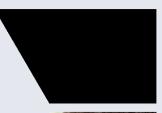


IDENTIFIED LEADERSHIP
IN FOCUS AREAS





COMMITMENT ACROSS SECTORS







General Session will provide an everview of the faith and culture of Plain groups in Wisconsin, which has the fourth largest Amish population among US states, and clarify a number of misunderstandings and stereotypes about them.

Health Care Session will address the health culture of Plain groups, that is, how they view health and well-being and health majntenance and restoration. We will ask explore hew Plain people access health grare within and outside their communities and consider common challenges for Plain patients and the providers who care for them.

Service Provider Session will focus on interactions between Plain people and a range of service providers (including social and CPS workers, law enforcement, and the legal system) dealing with a range of issues including mental health, abuse, and road safety.

Register for these free events online https://bit.ly/PlainCommunities2022 or by calling 715-748-1420.

Presented by Mark Louden

This program was supported by funds made available from the Centers for Disease Control and Prevention, Center for State, Fribal, Local and Territorial Support, index COL-PA-4-CIZI-2005. National Initiative to Address COVID-PA-4-each Disportiess Among Populations received by the Center of the Center of the Color of the Color of the Center of the Cent



From the Getting to Know Your Community series...

#### SUPPORTING **HEALTHY AGING**

Attend to learn more about the local services and programs available for you and your loved ones as we age.

Tuesday, May 2, 2023 NTC-Medford or Online Repeated sessions held at 11AM and 1PM. Free lunch will be served at noon. RSVPs requested to 715-748-1420.

ought to you by Commission on Aging, Health Dept., Aspirus Medford C, Human Services, Stepping Stones, Extension Taylor County, & NTC









Free event | Attend virtually or in-person RSVPs requested, but not required NTC-Medford Campus 1001 Progressive Drive, Medford Light refreshments will be available

REGISTER AT BITLLY/GTKYCAUG29 OR BY CALLING 715-748-1420

ANDREA

OYUELA

-	-	•	-	-	•	•
-	•	•	-	•	-	-



August 4, 2023

Dear Michelle -

The Center for Special Children (CSC) is a program within the La Farge Medical Clinic-VMH. The focus of our work is the diagnosis and management of inherited disorders and complex medical issues in the Plain community (Amish, Mennonite, Hutterite). Early identification and treatment of these conditions may lead to complete prevention of the consequences of the disorder, with healthy children as a result. In other cases, the child's health can be improved, and disability lessened by knowledge and appropriate treatment. Some children are found to have lethal disorders, for which there is no cure and early death is certain. In this difficult situation, children and families can be spared painful and expensive diagnostic evaluation and hospital stays. Knowledge of the diagnosis can allow the child to be lovingly cared for in the comfort of their home and community.

We are a collaboration of many to include; UW-Madison specialties (cardiology, neurology, metabolic, ophthalmology); a team of research scientists assisting in identifying unknown conditions based in Exeter, England; newborn screening and targeted disease testing at the Wisconsin State Lab of Hygiene; and one of eight clinics collaborating on research studies, unknown cases, testing, family education through the Plain Community Health Consortium.

CSC has grown exponentially in the last few years with families located throughout WI, MN, IA, II, and MI. As our enrollment has grown so has our opportunity to collaborate with more providers. We are facilitating Community Days in various locations throughout Wisconsin as an opportunity for connection; families to come together, for us to re-connect with families, and to meet all who care for these special children.

On behalf of the CSC team and our families, we hope you can join us so we all can learn more. We will be in your area on:

#### Thursday, September 21, 2023 - 10 AM to 3 PM The Christian Aide Ministry Sorting Center

W8872 Pine Road, Thorp, WI At 11 AM, Dr. Katie Williams will provide an educational talk on genetics and genetic testing. Lunch will be potluck if you are interested. Please share this information with others who may be interested in attending

If you would please complete and return the enclosed response card, it would be appreciated. We realize schedules are busy, but we hope you can stop by as we look forward to meeting you.

If you have any questions about the Community Day or the services we provide, please reach out to us at (608) 625-4039 or shammond@vmh.org. We hope you can join us!

Sincerely, Sheri Thamose Sheri Hammond Program Manager

> Center for Special Children 206 North Mill Street, La Farge WI 54639



aylor Co Health Dept aylor Co Comission on Aging aylor Co Veteran's Service Resource Room



From our Getting to Know Your Community Series

# Preparedness & Seniors Emergencies happen! Are YOU ready?



Join us to learn more about what you and your loved ones can do to prepare for the unexpected and each household will receive a free gift!

### Tuesday, March 26

NTC, 1001 Progressive Avenue, Medford Lunch\* starting at 11:30AM, with the free presentation to follow at 12PM Noon

\*Lunch reservations required by March 22 to either 715-748-1491 or 715-748-2157. Meal [chicken breast, cream sauce w/mushrooms, mashed potatoes, carrots, peaches & cookie) as part of the Taylor County Nutrition Program. \$5 suggested contribution.

Transportation available for \$1 round trip within the City of Medford.











Hosted by the Supporting Healthy Aging Coalition





















# **LESSONS LEARNED**At least so far...









66

...Recognize and address the power dynamics in a partnership...giving equal opportunity to define the issues, create strategies, implement solutions and make decisions...

Contributions | Resources | Expertise

99

# **MORE COMMUNITY**

...cultivate and build on relationships; identify and utilize everyone's skills, passions and knowledge; work collaboratively with other agencies in focusing on whole places rather than separate functions; and give people a sense of ownership by empowering them to determine their own priorities and plan or co-design their own responses...



Source: https://www.cdc.gov/nccdphp/dch/pdf/healthequityguide.pdf, https://www.linkedin.com/pulse/we-need-fewer-volunteers-more-community-jim-diers/



# THE BIG ???

What makes our efforts sustainable?













Reverse your thinking! Live in the hub, but make your efforts the wheel!

Not everyone will have the time or capacity to come to your table. What opportunities are you taking to go to theirs? How do you keep the channels open? Spokes are OK, silos are not!

# WHAT DO WE NEED?

**Meet Our Fabulous** 

**PUBLIC** HEALTH TEAM!









Melissa PH Coordinator Coordinador de PH



Karen Community Nurse

**Community Nurse** 



Michelle Health Officer Oficial de Salud



Gina Account Specialist Especialista en Cuentas

Rhianna **PH Program Specialist** 

Especialista en Programas



Environmental Health Specialist Especialista en Salud Ambiental





.AND CONTINUED CONNECTIONS TO THE QUAL DATA LEARNING COMMUNITY







# Melissa Moore PH Coordinator 715-748-1420

melissa.moore@co.taylor.wi.us

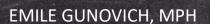




# Data Equity Emile Gunovich, National LGBT Cancer Network



# Data Equity



Data and Evaluation Manager National LGBT Cancer Network The history of data collection is rooted in racism, colonization, ableism, and homophobia.

# The 1860 Census Had Three Race Categories: White, Black and Mulatto

	the jon.	po.			SCRIPT		
	Dwelling Hous numbered in order of visitat	Families numbered in the order of visitation.	The name of every person whose usual place of abode on the first day of June, 1860, was in this family.	Age.	Ser.	Color, Sieck, or Mulen.	Profession, each peri over 15 ye
	1.	2	3	4	5	6	
1							
2							
3			,*				

Source: U.S. Census Bureau

### Instructions to 1930 Census Takers on Counting People by Race

#### PERSONAL DESCRIPTION

149. Column 11. Sex.—Write "M" for male and "F" for female, as indicated in the notes at the bottom of the schedule.

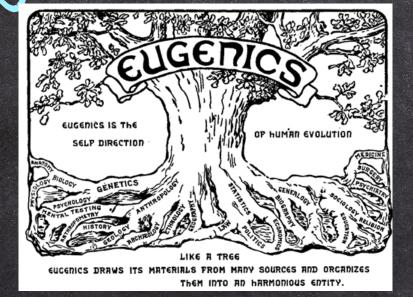
150. Column 12. Color or race.—Write "W" for white; "Neg" for Negro; "Mex" for Mexican; "In" for Indian; "Ch" for Chinese; "Jp" for Japanese; "Fil" for Filipino; "Hin" for Hindu; and "Kor" for Korean. For a person of any other race, write the race in full.

151. Negroes.—A person of mixed white and Negro blood should be returned as a Negro, no matter how small the percentage of Negro blood. Both black and mulatto persons are to be returned as Negroes, without distinction. A person of mixed Indian and Negro blood should be returned a Negro, unless the Indian blood predominates and the status as an Indian is generally accepted in the community.

152. Indians.—A person of mixed white and Indian blood should be returned as Indian, except where the percentage of Indian blood is very small, or where he is regarded as a white person by those in the community where he lives. (See par. 151 for mixed Indian and Negro.)

153. For a person reported as Indian in column 12, report is to be made in column 19 as to whether "full blood" or "mixed blood," and in column 20 the name of the tribe is to be reported. For Indians, columns 19 and 20 are thus to be used to indicate the degree of Indian blood and the tribe, instead of the birthplace of father and mother.

Source: U.S. Census Bureau



#### UNFIT HUMAN TRAITS

EPILEPSY, CRIMINALITY,
INSANITY, ALCOHOLISM,
PAUPERISM AND MANY OTHERS,
RUN IN FAMILIES AND ARE
INHERITED IN EXACTLY THE
SAME WAY AS COLOR IN
GUINEA-PIGS. IF ALL
MARRIAGES WERE EUGENIC
WE COULD BREED OUT
MOST OF THIS UNFITNESS
IN THREE GENERATIONS.

## THE TRIANGLE OF LIFE



YOU CAN IMPROVE YOUR EDUCATION, AND EVEN CHANGE YOUR ENVIRONMENT; BUT WHAT YOU REALLY ARE WAS ALL SETTLED WHEN YOUR PARENTS WERE BORN.

SELECTED PARENTS WILL HAVE BETTER CHILDREN THIS IS THE GREAT AIM OF EUGENICS

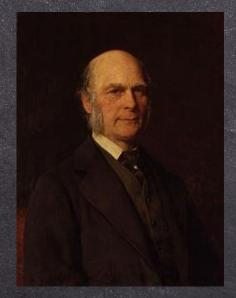


# What is Eugenics?

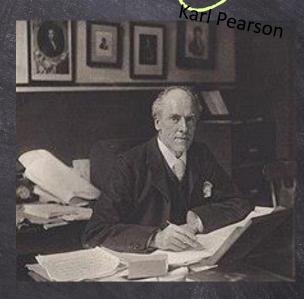
the study of how to arrange reproduction within a human population to increase the occurrence of <a href="https://example.com/heritable">heritable</a> characteristics regarded as desirable. Developed largely by Sir Francis Galton as a method of improving the human race, eugenics was increasingly <a href="https://example.com/discredited">discredited</a> as <a href="https://example.com/unscientific">unscientific</a> and racially biased during the 20th century, especially after the adoption of its doctrines by the Nazis in order to justify their treatment of Jews, disabled people, and other minority groups.

/VVVVV

## Francis Galton



major contributions to mathematical statistics included the initial development of quantiles and linear regression techniques.

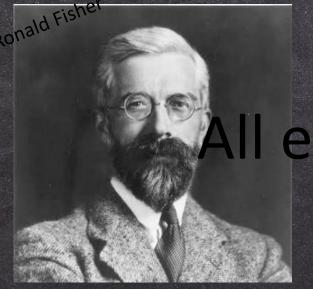


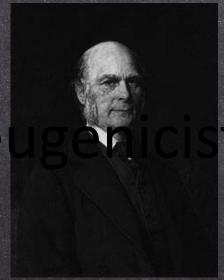
introduced probability values, or pvalues, and founded the first ever university statistics department and the first academic journal focused on the field

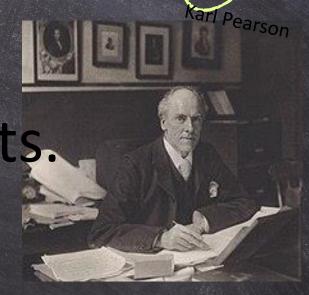


laid the foundation of statistical inference, invented experimental design, randomization, ANOVA, Ftests, concept of null hypothesis

## Francis Galton



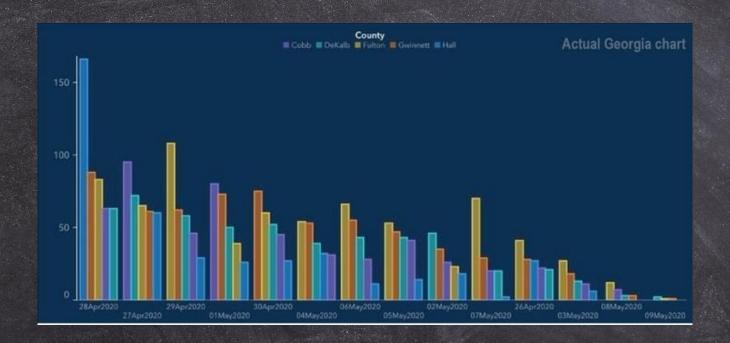


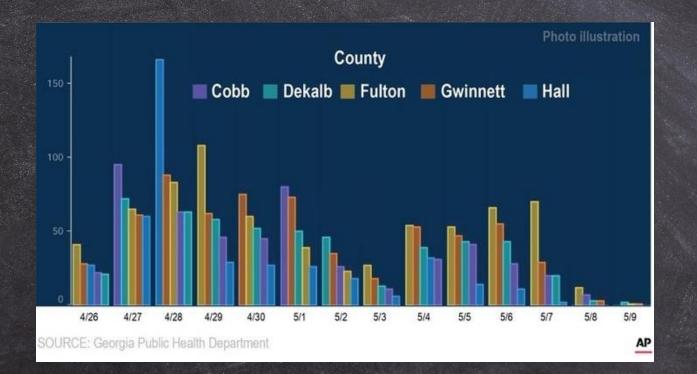


laid the foundation of statistical inference, invented experimental design, randomization, ANOVA, Ftests, concept of null hypothesis

major contributions to mathematical statistics included the initial development of quantiles and linear regression techniques.

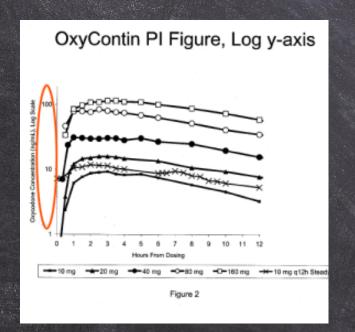
introduced probability values, or pvalues, and founded the first ever university statistics department and the first academic journal focused on the field Data is biased.



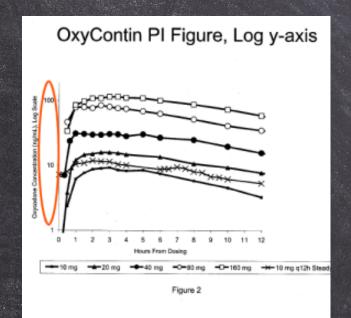


Data has consequences.

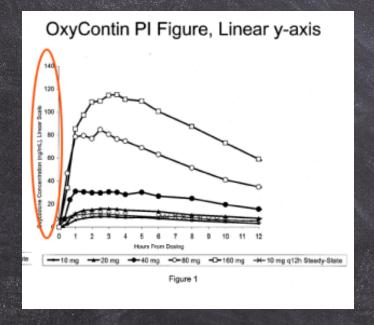
This chart, which was approved by the FDA at the time, appears to show that OxyContin doses peak quickly and then plateau in the blood stream, providing constant levels of pain relief.



This chart was used by Purdue as a marketing tool to convince doctors that OxyContin was less addictive than it actually was.



The reality is that levels of the drug drop off sharply in users, triggering withdrawal symptoms and addiction.



# OxyContin PI Figure, Log y-axis

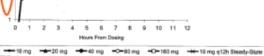


Figure 2

## OxyContin PI Figure, Linear y-axis

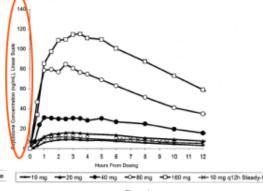


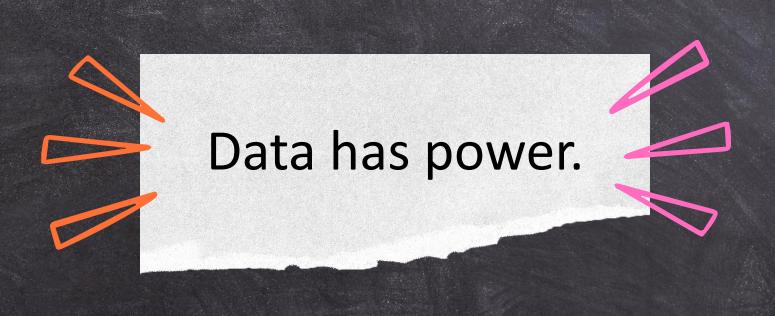
Figure 1

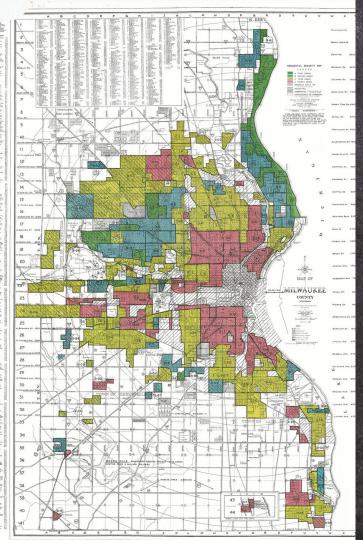


OxyContin was developed and patented in 1996 by Purdue Pharma L.P. and was originally available in 10 milligram (mg), 20 mg, 40 mg, and 80 mg tablets.

Figure 3. National Overdose Deaths Involving Any Opioid\*, Number Among All Ages, by Gender, 1999-2021 100,000 Total Female 80,411 Male 80,000 68,630 60,000 40,000 20,000 2008 2009 2010 2011 2006 2012 \*Among deaths with drug overdose as the underlying cause, the "any opioid" subcategory was determined by the following ICD-10 multiple cause-of-death codes; natural and semi-synthetic opioids (T40.2), methadone (T40.3), other synthetic opioids (other than methadone) (T40.4), or heroin (T40.1). Source: Centers for Disease Control and Prevention, National Center for Health Statistics. Multiple Cause of Death 1999-2021 on CDC WONDER Online Database, released 1/2023.

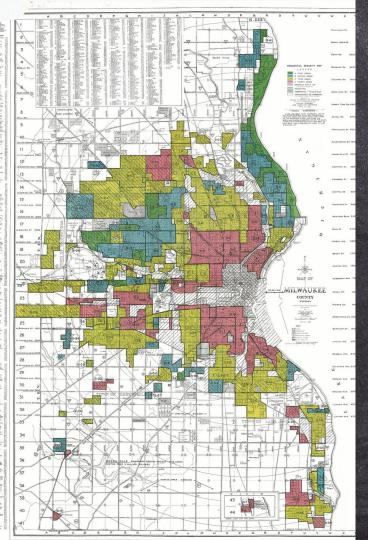
A 160 mg tablet became available in July 2000.





## The Racist Legacy of Redlining

- In the 1930's the U.S. government implemented several policies to counteract the economic fallout of the Great Depression
   Led to the creattion of the Federal Housing Administration.
- The FHA worked with the Home Owners' Loan Corporation, a government-sponsored lending agency, to issue bonds for homeowners struggling to keep up.
- HOLC also created "residential security" maps that identified specific neighborhoods as high or low risk for investment. These maps were used by bank and finance entities in making lending and other investment decisions.
- The resulting grading system categorized neighborhoods on maps, reflecting the prejudices of the evaluators and the ingrained biases of the system as a whole



## Redlining in America's Most Segregated City

Green = Grade A; exemplary neighborhoods for lenders

Blue = Grade B; desirable, older but still worthy of investment

Yellow = Grade C; "definitely declining"

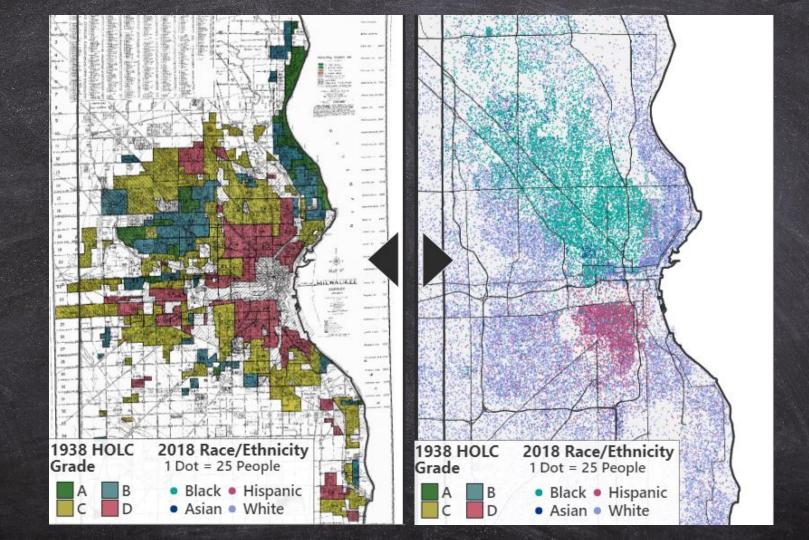
Red = Grade D; "hazardous" for investment

In contemporary Milwaukee, the Halyard Park, Hillside and Haymarket neighborhoods, located just north of the city's downtown, were given a red rating. The rating was explained in the assessment with notes: "This is the Negro and slum area of Milwaukee. It is old and very ragged. Besides the colored people, a large number of lower type Jews are moving into the section."

5. CLARIFYING REMARKS: This is the Negro and slum area of Milwaukee. It is old and very ragged. Besides the colored people, a large number of lower type Jews are moving into the section. This section housed Milwaukee's wealthiest families seventy years ago.

FORM	8
10-1-	-37

10-	1-37	AREA DESCI	RIPTION - SECURITY MAP OF MILWAUKEE AREA	
1.	***	CHARACTERISTICS: Description of Terrain.	Level with a pitch north.	9
	b. ]	Favorable Influences.	All utilities — schools — transportation	790
	c. I	Detrimental Influences.	Negro and slum area — condemnation proceedings going on.	
	d. 1	Percentage of land impro	oved 0 %; e. Trend of desirability next 10-15 yr	s.Down
2.	INHA a. (	BITANTS: Laborers and OccupationNe'er-do-wells	; b. Estimated annual family income \$	
				o Yes 65 %
	e. :	Infiltration of Russian J	ews ; f. Relief families Many	
	g. ]	Population is increasing	Yes ; decreasing — ; static —	<del>-</del>



# Remember:

Behind every data point is a person, a community, a story.





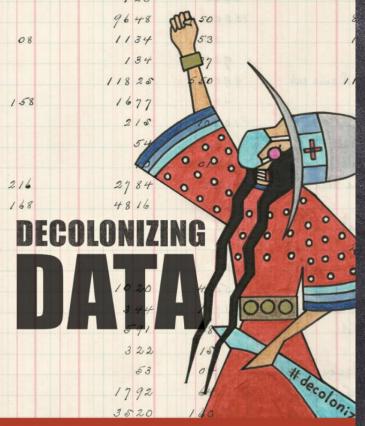
# What is Data Genocide?

- The elimination of Indigenous people in data resulting in the non-fulfillment of treaty and trust responsibility due to "lack" of data on urban and rural Tribal communities.
- Embedded structural racism in data systems that results in non-collection and/or non-reporting of Indigenous people's race and ethnicity.
- Lack of data being used as an excuse to not allocate appropriate resources to urban and rural Tribal communities perpetuating chronic health disparities.



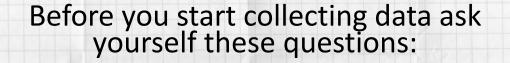






Urban Indian
Health Institute

- Acknowledgement of harmful data practices couples with healing, restoration, and reparation.
- Strengths-based data collection, analysis, and dissemination.
- Protective community and cultural factors measured and weighted against disparities and gaps.
- Community governance every step of the way (collection, analysis, dissemination).
- Accurate data reporting of race and ethnicity.
- Embedded accountability of entities for collection of race and ethnicity.
- Disaggregation of data by race, ethnicity, and multiple races.
- Undoing STEM education disparities.
- Exploring and refining small populations methodologies.
- Acknowledging community knowledge and investing in data capacity as informed by the community.



Who are you doing this for?

Why is this necessary?

How will you collaborate with community?

When will you share what you learn?





#### Characteristics of White Supremacy Culture

- Perfectionism
- Sense of Urgency
- Defensiveness
- Quantity over Quality
- Worship of the Written Word
- Paternalism
- Either/Or Thinking
- Power Hoarding
- Fear of Open Conflict
- Individualism
- Progress is Bigger, More
- Objectivity
- Right to Comfort

Reflect: How do these characteristics show up in the way you interact with and communicate about data and evaluation?

From Dismantling Racism: A Workbook for Social Change Groups, by Kenneth Jones and Tema Okun, ChangeWork, 2001



#### Emile's Hot Tips for Data Equity Champions

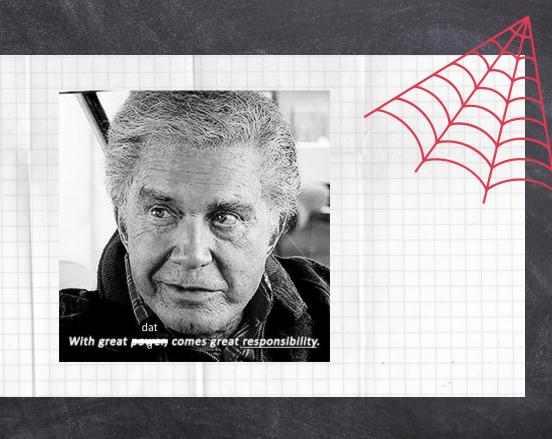
- You're going to mess up. Probably a lot. It's okay. You do not have to be the "expert" for everything.
- Don't work in silos-- equitable evaluation takes a community (see point #1)
- Disaggregate. Your. Data.
- "White" is not the standard basis for comparison!
- Say what you mean!
- Just because it's "the way we've always done things" doesn't mean it's the way things ought to be done.
- If there's a will, there is a way.
- Small sample sizes are not an excuse to withhold information.
- Qualitative data is just as valid and important as quantitative data.
- Don't ask a question if you're not going to use the information!
- Involve and include young people!

### Remember:

Data is biased.

Data has consequences.

Data has power.



# THINK ABOUT THINGS DIFFERENTLY



#### Want to learn more?

- Find and follow Indigenous evaluators, data scientists, and their organizations.
  - Urban Indian Health Institute
  - Reconciling Ways of Knowing
- (Book) Decolonizing Methodologies by Linda Tuhiwa Smith
- (Book) Becoming Kin: An Indigenous Call to Unforgetting the Past and Reimagining Our Future by Ratty Krawec
- (Website/community) We All Count
- Additional resources will be sent out after this presentation



## Questions for Presenter





### Resource Guide

Data Equity Resources		
Data Equity: What Is It, and Why Does It Matter? — Hawai'i Data Collaborative (hawaiidata.org)	Colorado Changes Data  Narrative and Incorporates Equity  Metrics – HealthEquityGuide.org	Health Equity Data Analysis - MN HD  HEDA Example (wicphet.org)
Why Am I Always Being Researched?	We All Count – Data Equity Framework	Beyond the Numbers: Incorporating Community Voice Through Qualitative Data

### Contact Us!

 Would you like more resources on a similar or different topic? Please contact the HEART team, and we will provide you with the appropriate resources.

afeefah.khan@dhs.wisconsin.gov

## Next Meeting

May 9<sup>th</sup>, 2024

Promising Practice for Health Equity 10:00 – 11:30 A.M. CST

Please remember to fill out the post-meeting survey!

