

The background features a light blue gradient with a network of white lines connecting various icons. These icons include a graduation cap, a person with a plus sign, a bar chart with a dollar sign and an upward arrow, a house, a laptop, a share symbol, a mouse cursor, a scale of justice, a megaphone, a wireless signal tower, and a city skyline with various buildings.

Unmet data needs: Considerations on including sexual orientation and gender identity in administrative systems

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Overview

- **Summarize** progress of sexual orientation and gender identity (SOGI) in ongoing federal health survey data
- **Explain** value of and differences in administrative data vs. self-report survey data
- **Discuss** unique nexus of SOGI and administrative data

Disclosures

- Support from NIMH (DP2MH129967 - PI Blosnich; R21MH125360 - PI Blosnich)
- Opinions are those of the presenter and do not necessarily reflect those of the funders or institution
- Names and photographs gathered from publicly available news stories

Survey data further illuminated health risk disparities



Smoking



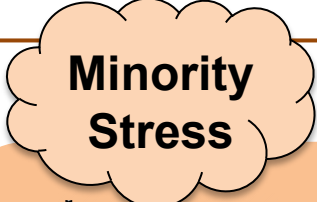
Stress



Violence



Suicidality



Minority Stress

Detect

Define outcome, populations, measures
Consider selection bias, confounding

Understand

Determinants @ individual, family, community, and system levels

Address

Intervention
Evaluation
Implementation

Considerably less on addressing disparities (3rd generation studies)

Mental Health, Drug, and Violence Interventions for Sexual/Gender Minorities: A Systematic Review

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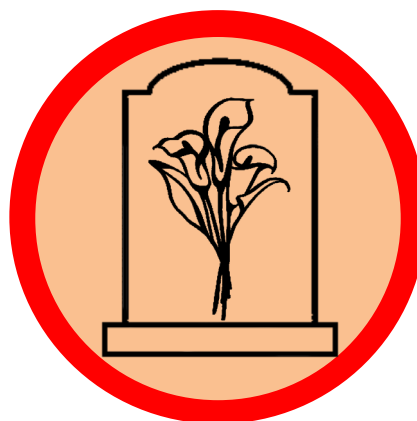
PEDIATRICS Volume 144, number 3, September 2019:e20183367

Study	Global Quality Rating	Addressed suicidality
Costa et al. 2015	Weak	No
De Vries et al. 2011	Weak	No
De Vries et al. 2014	Weak	No
Diamond et al. 2012	Weak	Suicidal ideation
Lucassen et al. 2015	Weak	No
Painter et al. 2018	Weak	No
Raifman et al. 2017	Strong	Suicide attempt
Schwinn et al. 2015	Weak	No
Seelman & Walker 2018	Moderate	Suicidal ideation & attempt

Some key differences between administrative and research data

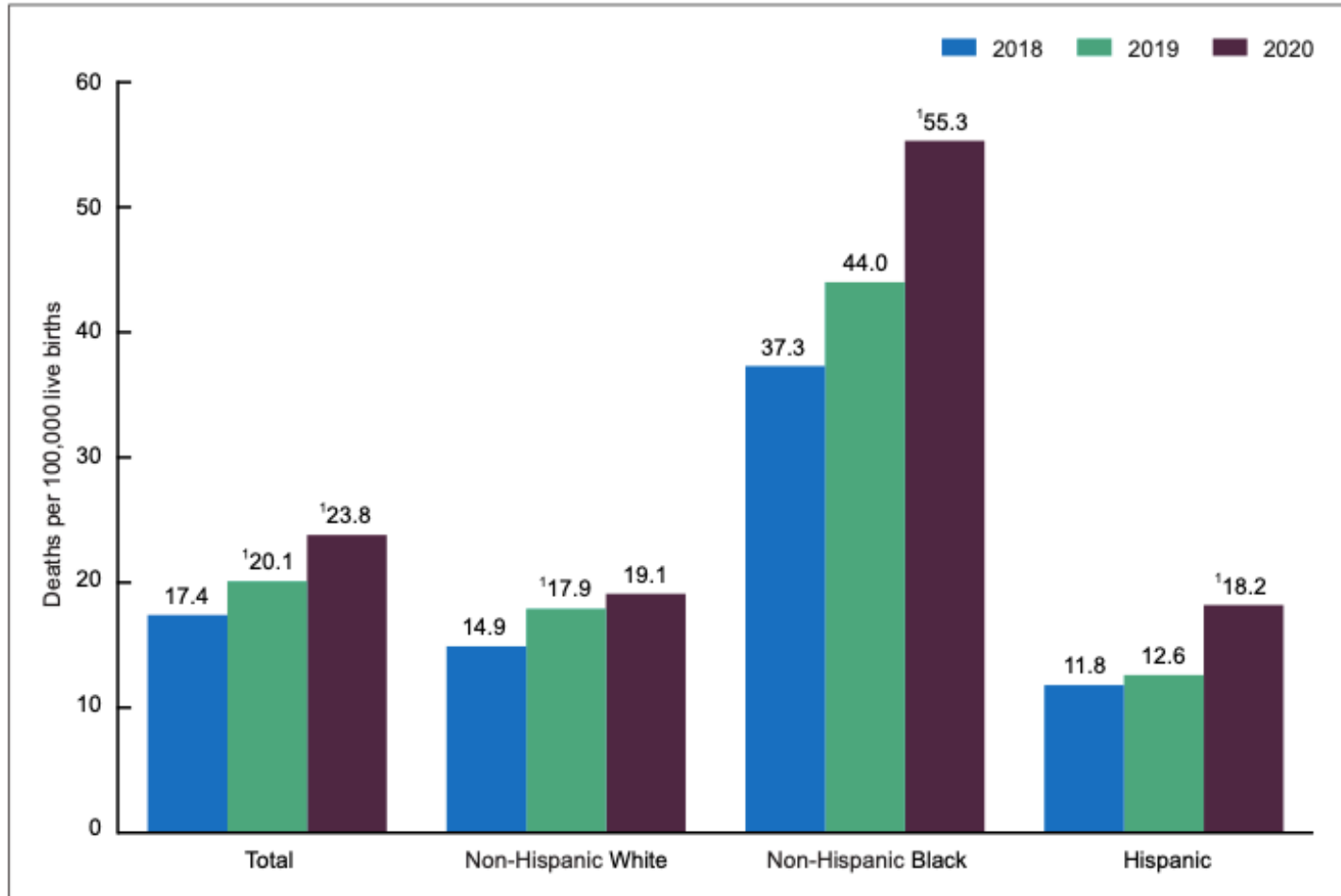
Administrative	Research
Universe of users, not a sample	Relies on sampling
Used for process (e.g., record-keeping, billing, volume)	Used for generalizable knowledge
Measurement often limited to business/agency operations	Measurement flexible
Data populated in near real-time	Studies can take years for data collection
Data often represent use of some service or deliverable	Participant may receive an incentive (or treatment in case of RCTs)

Administrative data systems



Without data about race, we'd never know disparities in maternal mortality

Figure 1. Maternal mortality rates, by race and Hispanic origin: United States, 2018–2020



¹Statistically significant increase in rate from previous year ($p < 0.05$).

NOTE: Race groups are single race.

SOURCE: National Center for Health Statistics, National Vital Statistics System, Mortality.

We need to catch up

Currently, about **3 million** Americans die each year, but because SOGI isn't collected, those data **cannot** be used to answer questions about LGBT health.

If 5% are LGBT:
150,000

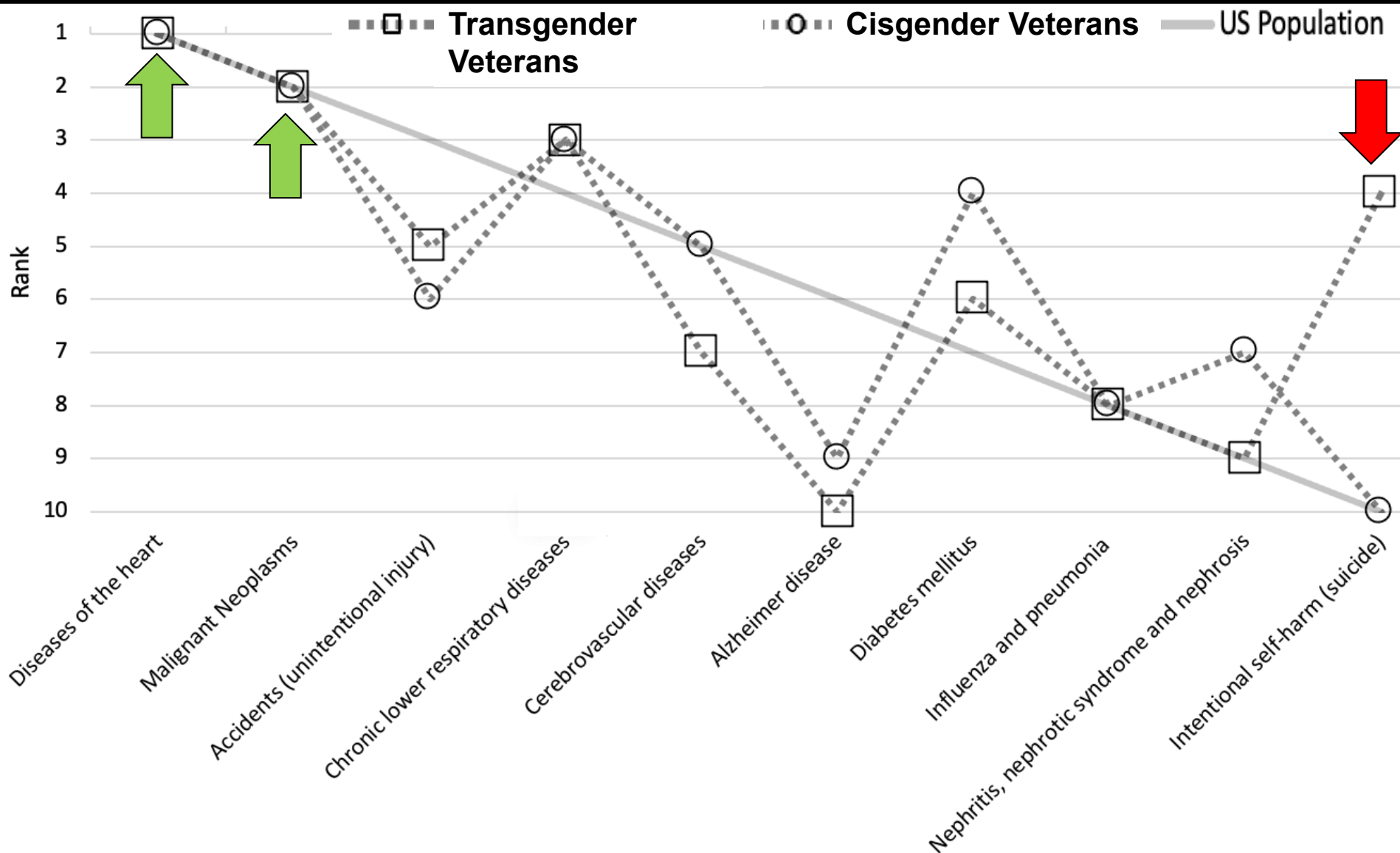
If 1.2% are T:
36,000



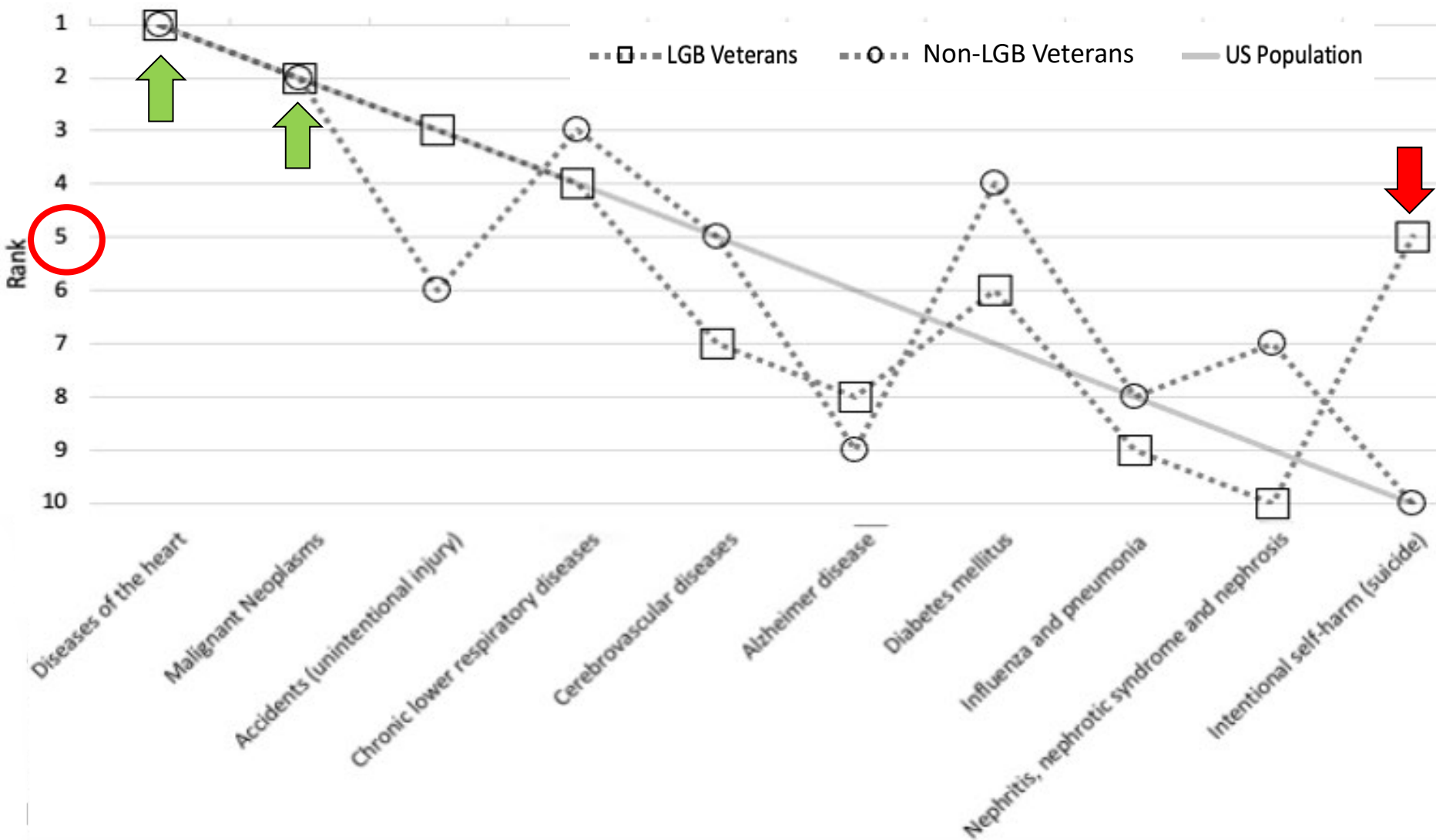
Dr. Judy Bradford

“If you're not counted, you don't count.”

Administrative data - US Dept of Veterans Affairs



Administrative data - US Dept of Veterans Affairs



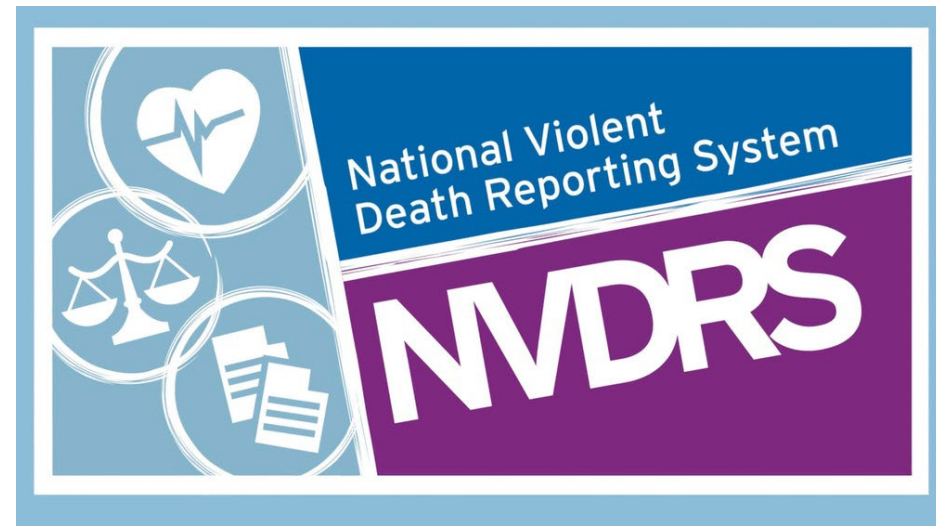
Example to improve administrative data quality: Postmortem SOGI Project

History: May 2014 meeting to develop consensus plan

Goal: Getting more complete SOGI data in mortality surveillance

Focus: Decedents of suicide and other violent or investigated deaths

Audience: Medicolegal death investigators (MDIs), medical examiners, coroners



Despite suspecting LGBT cases, most investigators are not asking about SOGI

Death investigators (n=113; Nevada, Colorado, New York)

78%

Had investigation when they **suspected** decedent was LGBT

59%

Did not ask about decedent's sexual orientation

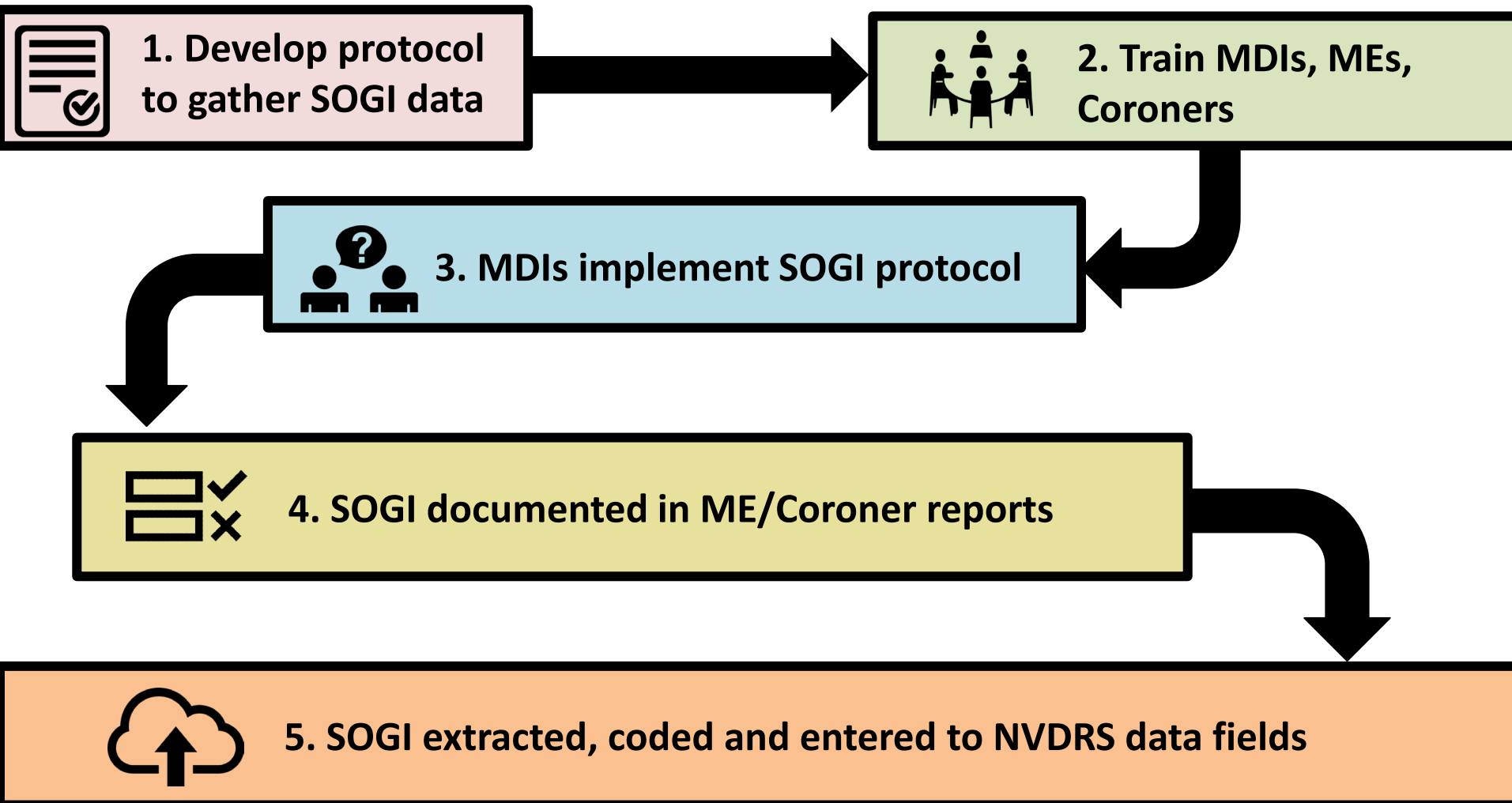
75%

Did not ask about decedent's gender identity

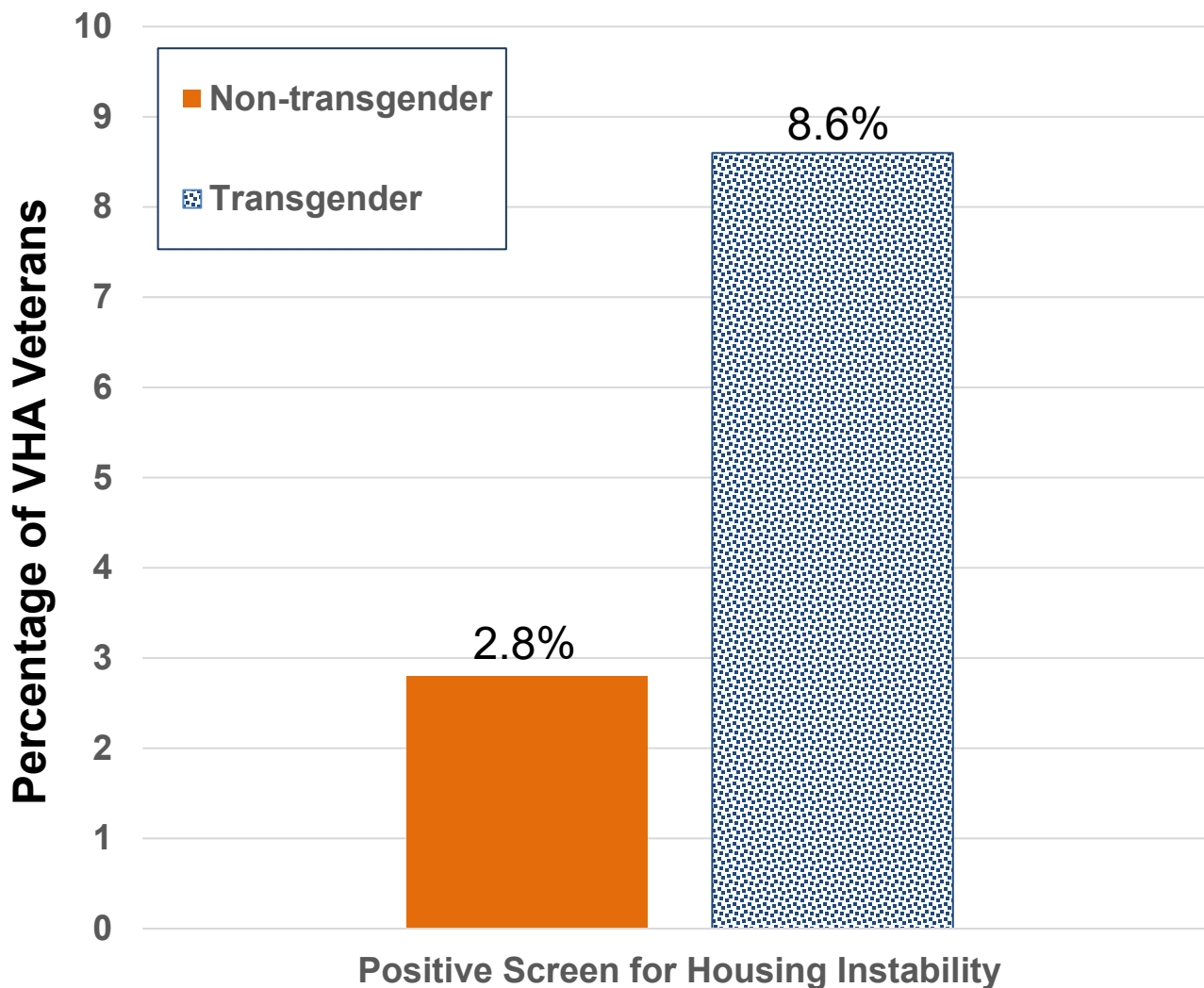
0%

Had training about how to collect SOGI data

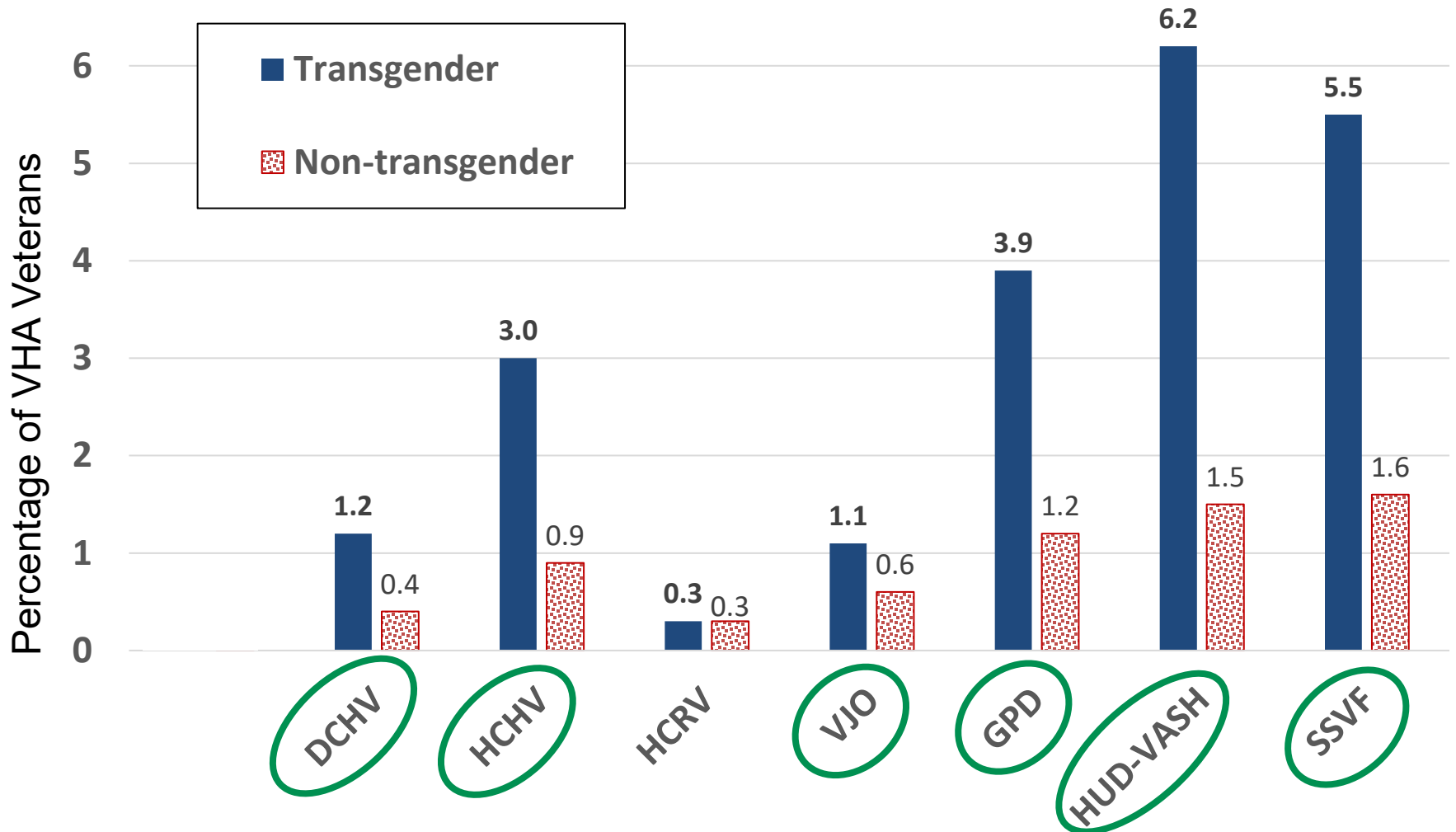
Envisioning a data pipeline



Example from VA administrative data - housing instability greater for transgender veterans (1st generation study)



But are they accessing supportive housing services? (3rd generation study)



DCHV=Domiciliary Care for Homeless Veterans; HCHV=Health Care for Homeless Veterans; HCRV= Health Care for Re-entry Veterans; VJO=Veterans Justice Outreach; GDP=Grant and Per Diem; HUD-VASH=VA Supportive Housing; SSVF=Supportive Services for Veteran Families

Lack of representation in administrative datasets means we:



Cannot measure ultimate burdens of disease and risk



Cannot estimate service utilization



Cannot direct resources



Cannot evaluate interventions at scale



Lose time waiting for survey data



Keep falling further behind

But questions remain

Would adding these measures create a chilling effect on services?

- Increase fears of discrimination and outing
- Visibility can cost

Field of Dreams - "If you build it, they will come"...not exactly.

- Need to train gatekeepers of data
- Quality assurance and evaluation of inputs

Reify problematic social constructions?

- AMA recommendation to remove sex from birth certificate
- State Dept "X" on Passports

Who's on first?

- Missing data cannot be assumed to be cisgender, heterosexual or "non-SGM"
- Responses that agency/user understand and accept
- Accommodate developmental nature of SGM identities



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Thank you!

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