

Risks & Rewards of Demographic Data Collection: How Effective Data Privacy Can Promote Health Equity



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movement advancement project ▶

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In pairs...

- How do you use data in your work? Your relationship and experience with it?
- What motivated you to come to this session?
- What particular concerns do you have about data collection and its use?
- How do you feel when you think about data and demographic information being collected? Excited? Anxious? Something else?

CMS Authority to Collect Race/Ethnicity Data in Medicaid & CHIP

National Health Law Program (2022)

Constitutionality of Demographic Data Collection

National Health Law Program (2023)

Medicaid Race & Ethnicity Data Collection & Reporting

Medicaid and CHIP Payment and Access Commission (2023)

Measuring Sex, Gender Identity, and Sexual Orientation

National Academies of Sciences, Engineering, and Medicine (2022)

Recommendations of the Equitable Data Working Group

National Science and Technology Council (2022)

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This four-part report series is a joint project of the National Health Law Program, DREDF, Justice in Aging, Movement Advancement Project, and Race Forward



Disability Rights Education & Defense Fund



FIGHTING SENIOR POVERTY THROUGH LAW

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This Data, Not That Data: Big Data, Privacy, and the Impact on People with Disabilities

Silvia Yee & Mary Lou Breslin

Disability Rights Education and Defense Fund

Administrative Data: Providing Information to Advance Autonomy and Drive Equality

Naomi G. Goldberg, M.P.P.

Movement Advancement Project

TABLE 1. Federal Surveys’ Sample Size Sufficiency for Medicaid Populations

Federal Survey	Disability Type: Functional	Disability Type: Intellectual	Disability Type: Serious mental illness (SMI)	Primary Language: Not English	Spoken English Proficiency: Not well or Not At All	Sexual Orientation: Lesbian or Gay	Sexual Orientation: Bisexual	Gender Identity: Trans-gender	Gender Identity: Gender Non-Conforming or Non-Binary
ACS	✓	-	-	✓	✓	-	-	-	-
BRFSS	✓	-	-	-	-	✓	✓	✓	✓
CPS	✓	-	-	-	-	-	-	-	-
HPS	-	-	✓	-	-	✓	✓	X	-
MEPS-HC	✓	-	✓	✓	✓	-	-	-	-
MCBS	✓	NA	NA	NA	NA	-	-	-	-
NAMCAHPS	✓	-	-	-	-	-	-	-	-
NHANES	✓	-	✓	✓	-	NA	-	-	-
NHIS	-	X	✓	-	-	✓	✓	-	-
NSCH	-	✓	-	✓	-	-	-	-	-
NSDUH	-	-	✓	-	✓	✓	✓	-	-
PRAMS	-	-	-	-	-	-	-	-	-
SIPP	✓	-	-	✓	✓	-	-	-	-



Source: MACPAC, *Federal Survey Sample Size Analysis: Disability, Language, Sexual Orientation, and Gender Identity* (2023).

TABLE 4. Unweighted Sample size by Disability Type in Public Use Data for Selected Federal Surveys

Federal survey	Total vs Medicaid	Disability Type: Functional	Disability Type: Intellectual	Disability Type: Serious mental illness
ACS	Total	501,018	NA	NA
	Medicaid	74,407	NA	NA
BRFSS	Total	127,194	NA	NA
	Medicaid	20,303	NA	NA
CPS	Total	14,715	NA	NA
	Medicaid	2,077	NA	NA
HPS	Total	NA	NA	9,248
	Medicaid	NA	NA	221
MEPS-HC ¹	Total	4,274	NA	1,322
	Medicaid	2,628	NA	563
MCBS ^{2,3}	Total	1,193	NS	NS
	Medicaid	307	NS	NS
NAMCAHPS ⁴	Total	NA	NA	NA
	Medicaid	174,616	NA	NA
NHANES	Total	2,118	NA	169
	Medicaid	537	NA	42*
NHIS ⁵	Total	NA	118	1,897
	Medicaid	NA	47	313
NSCH ⁶	Total	NA	530	NA
	Medicaid	NA	242	NA
NSDUH	Total	NA	NA	4,648
	Medicaid	NA	NA	1,111
PRAMS	Total	NA	NA	NA
	Medicaid	NA	NA	NA
SIPP ⁷	Total	9,854	NA	NA
	Medicaid	1,327	NA	NA

Source: MACPAC, *Federal Survey Sample Size Analysis: Disability, Language, Sexual Orientation, and Gender Identity* (2023).

Breakout Groups

1. Overcollection of the “wrong” type of data
2. Undercollection of data on granular and intersectional groups
3. Challenges in agency and autonomy, self-identification, and community involvement in data collection

Discussion Questions

- Defining the issue. What scenarios illustrate this issue? Who is affected? What groups are currently considered in data collection/data privacy frameworks and what groups are not?
- What are the risks to individual privacy and wellbeing presented by this issue? Consider this question from the perspective of multiple stakeholders identified in question #1.
- What are the benefits to particular stakeholders if addressed appropriately?



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THANK YOU