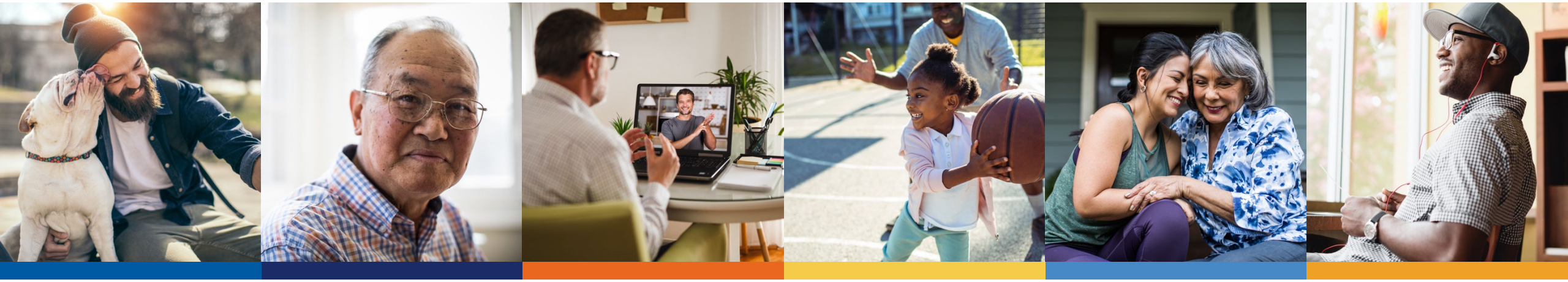
W O R K I N G T O A C H I E V E H E A L T H E Q U I T Y



Collecting Demographic and SDOH Data Elements

April 11, 2024

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CMS Office of Minority Health

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CMS Office of Minority Health

The Centers for Medicare & Medicaid Services (CMS) is the largest provider of health insurance in the United States, responsible for ensuring that more than 150 million individuals supported by CMS programs (Medicare, Medicaid, Children's Health Insurance Program, and the Health Insurance Marketplaces).

The Centers for Medicare & Medicaid Services Office of Minority Health (CMS OMH) is one of eight offices of minority health within the U.S. Department of Health and Human Services. CMS OMH works with local and federal partners to eliminate health disparities while improving the health of all minority populations.

What Drive Our Data Initiatives?

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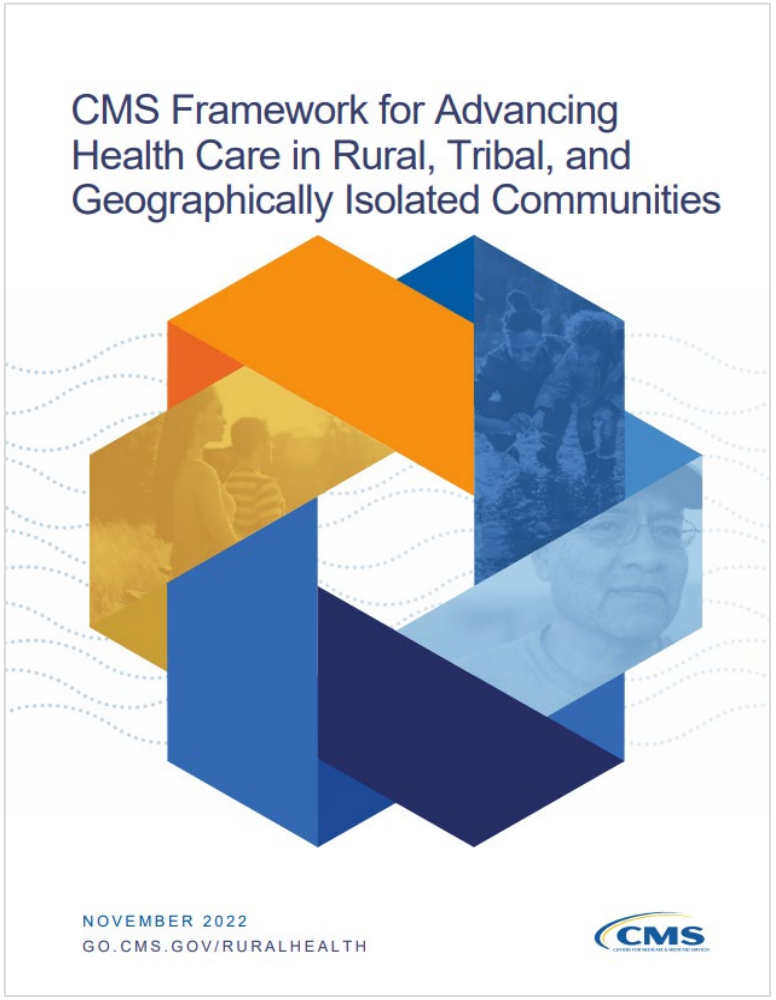
CMS Frameworks

Priority 1: Expand the Collection, Reporting, and Analysis of Standardized Data



Priority 2: Increase Collection and Use of Standardized Data to Improve Health Care for Rural, Tribal, and Geographically Isolated Communities

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CMS OMH's Data White Paper

- Describes the current state of health equity data collection and consolidation across CMS programs
- Details progress to date
- Defines CMS's future actions to continue the improvement of health equity data and achieve a future vision of health equity data at CMS

https://www.cms.gov/files/document/path-forwardhe-data-paper.pdf

Executive Orders Focus on Data

- **EO 13985: Advancing Racial Equity and Support for Underserved Communities Through the Federal Government**
  - Section 4(a) - Identify Methods to Assess Equity
    - *"Assist agencies in assessing equity with **respect to race, ethnicity, religion, income, geography, gender identity, sexual orientation, and disability**…"*
    - Emphasizes the need to take actions to collect demographic data in order to fully assess impact of health equity responses and extent of existing health disparities
  - Section 9(a) - Establishes a workgroup to gather necessary data
    - *"Many Federal datasets are not disaggregated by **race, ethnicity, gender, disability, income, veteran status, or other key demographic variables**. This lack of data has cascading effects and impedes efforts to measure and advance equity."*
    - Emphasizes the need to gather data to promote equity

- **EO 14031: Advancing Equity, Justice, and Opportunity for Asian Americans, Native Hawaiians, and Pacific Islanders**
    - Expand the collection and use of disaggregated data at the Federal, State, and local level on AA and NHPI communities, and facilitate improved research on policy and program outcomes for AA and NHPI communities

EO – 13985 - https://www.federalregister.gov/documents/2021/01/25/2021-01753/advancing-racial-equity-and-support-for-underserved-communities-through-the-federal-government
EO 14031 - https://www.federalregister.gov/documents/2021/06/03/2021-11792/advancing-equity-justice-and-opportunity-for-asian-americans-native-hawaiians-and-pacific-islanders

Demographic & SDOH Data Collection

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Race and Ethnicity Data Standards

OMB 1997 Standards*	2011 HHS Data Standards*
Race • White • Black • American Indian or Alaska Native • Asian • Native Hawaiian or Other Pacific Islander	**Race** • White • Black • American Indian or Alaska Native • Asian Indian • Chinese • Filipino • Japanese • Korean • Vietnamese • Other Asian • Native Hawaiian • Guamanian or Chamorro • Samoan • Other Pacific Islander
Ethnicity • Not Hispanic or Latino • Hispanic or Latino	**Ethnicity** • Not Hispanic or Latino • Mexican • Puerto Rican • Cuban • Another Hispanic Origin

Race	• The Office of Management and Budget Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity,

USCDI United States Core Data for Interoperability Version 1 (July 2020 Errata)

The Office of the National Coordinator for Health Information Technology

DATA ELEMENT	APPLICABLE STANDARD(S)
	Statistical Policy Directive No. 15, as revised, October 30, 1997 (https://obamawhitehouse.archives.gov/omb/fedreg_1997standards) • CDC Race and Ethnicity Code Set Version 1.0 (March 2000) (https://www.cdc.gov/phin/resources/vocabulary/index.html)
Ethnicity	• The Office of Management and Budget Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity, Statistical Policy Directive No. 15, as revised, October 30, 1997 (https://obamawhitehouse.archives.gov/omb/fedreg_1997standards) • CDC Race and Ethnicity Code Set Version 1.0 (March 2000) (https://www.cdc.gov/phin/resources/vocabulary/index.html)

**OMB recommends that when self-identification is used, a method for reporting more than one race should be adopted, and that when a list of races is provided to respondents, the list should not contain a "multiracial" category.*

2011 HHS Data Standards - https://aspe.hhs.gov/reports/hhs-implementation-guidance-data-collection-standards-race-ethnicity-sex-primary-language-disability-0

USCDI Standards - https://www.healthit.gov/isa/sites/isa/files/2020-10/USCDI-Version-1-July-2020-Errata-Final_0.pdf

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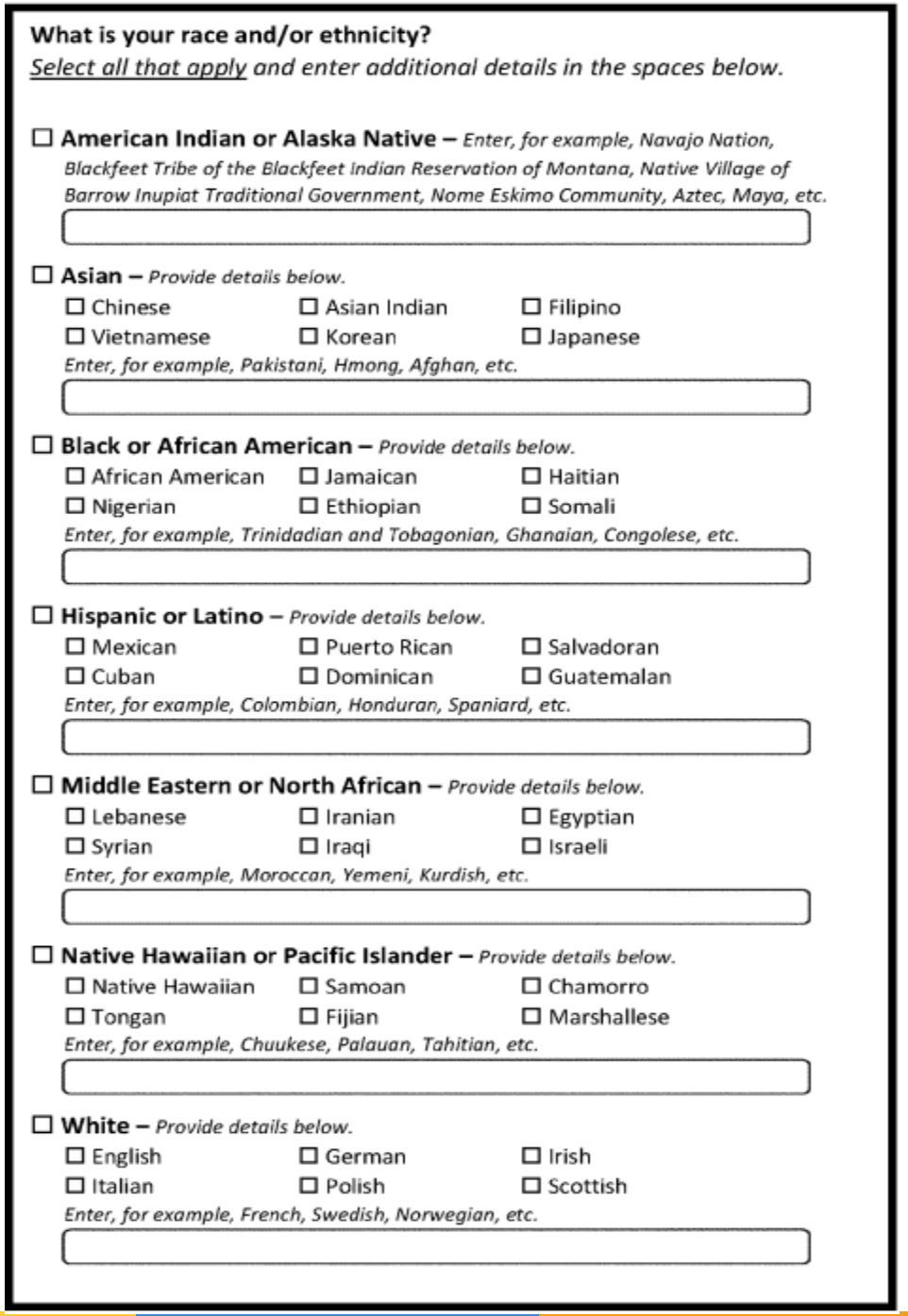
Race & Ethnicity Data Collection at Disaggregated Level

- CMMI Models - Started January 1, 2023 – All CMMI model participants will be required to report race and ethnicity data at the USCDI standards
- 2011 HHS Data Standards
  - —Post-Acute Care Settings
    - October 2022 – Started to collect race and ethnicity data in long term care and inpatient rehabilitation facilities.
    - January 2023 – Started to collect race and ethnicity data in home health agencies.
    - October 2023 – Started to collect race and ethnicity data in skilled nursing facilities.
  - —Medicare Part C/D Enrollment Form
  - —Surveys conducted by CMS

Revisions to Statistical Policy Directive No. 15: Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity

- Using **one combined question for race and ethnicity**, and encouraging respondents to select as many options as apply to how they identify.
- **Adding Middle Eastern or North African as a new minimum category**. The new set of minimum race and/or ethnicity categories are:
  - American Indian or Alaska Native
  - Asian
  - Black or African American
  - Hispanic or Latino
  - Middle Eastern or North African
  - Native Hawaiian or Pacific Islander
  - White
- **Requiring the collection of additional detail beyond the minimum required race and ethnicity categories** for most situations, to ensure further disaggregation in the collection, tabulation, and presentation of data when useful and appropriate.
- The updated standards also include several additional updates to definitions, terminology, and guidance to agencies on the collection and presentation of data.

https://www.govinfo.gov/content/pkg/FR-2024-03-29/pdf/2024-06469.pdf



What is your race and/or ethnicity?

Select all that apply and enter additional details in the spaces below.

☐ **American Indian or Alaska Native** – *Enter, for example, Navajo Nation, Blackfeet Tribe of the Blackfeet Indian Reservation of Montana, Native Village of Barrow Inupiat Traditional Government, Nome Eskimo Community, Aztec, Maya, etc.*

☐ **Asian** – *Provide details below.*

☐ Chinese ☐ Asian Indian ☐ Filipino
☐ Vietnamese ☐ Korean ☐ Japanese

Enter, for example, Pakistani, Hmong, Afghan, etc.

☐ **Black or African American** – *Provide details below.*

☐ African American ☐ Jamaican ☐ Haitian
☐ Nigerian ☐ Ethiopian ☐ Somali

Enter, for example, Trinidadian and Tobagonian, Ghanaian, Congolese, etc.

☐ **Hispanic or Latino** – *Provide details below.*

☐ Mexican ☐ Puerto Rican ☐ Salvadoran
☐ Cuban ☐ Dominican ☐ Guatemalan

Enter, for example, Colombian, Honduran, Spaniard, etc.

☐ **Middle Eastern or North African** – *Provide details below.*

☐ Lebanese ☐ Iranian ☐ Egyptian
☐ Syrian ☐ Iraqi ☐ Israeli

Enter, for example, Moroccan, Yemeni, Kurdish, etc.

☐ **Native Hawaiian or Pacific Islander** – *Provide details below.*

☐ Native Hawaiian ☐ Samoan ☐ Chamorro
☐ Tongan ☐ Fijian ☐ Marshallese

Enter, for example, Chuukese, Palauan, Tahitian, etc.

☐ **White** – *Provide details below.*

☐ English ☐ German ☐ Irish
☐ Italian ☐ Polish ☐ Scottish

Enter, for example, French, Swedish, Norwegian, etc.

Marketplace Sexual Orientation & Gender Identify (SOGI) Questions

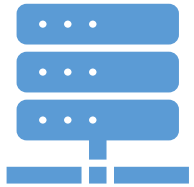
Since November 1, 2023 the Marketplace has asked three new SOGI questions on all applications starting with Plan Year 2024

Purpose:

- Identifying health disparities in access to coverage
- Improve Marketplace consumer experience by allowing consumers to attest in a way that better reflects and affirms their identities

Category	Question	Responses
Sex Assigned at Birth	**What was [First Name]'s sex assigned at birth?** *You can find this on an original birth certificate or similar document. (optional, single select)*	**•Female •Male •A sex that's not listed: [free text] •Not sure •Prefer not to answer**
Gender Identity	**What's [First Name]'s gender identity?** *(optional, single select)*	**•Female •Male •Transgender female •Transgender male •A gender identity that's not listed: [free text] •Not sure •Prefer not to answer**
Sexual Orientation	**What's [First Name]'s sexual orientation?** *(optional, single select)*	**•Lesbian or gay •Straight •Bisexual •A sexual orientation that's not listed: [free text] •Not sure •Prefer not to answer**

Social Determinants of Health (SDOH) Data



New SDOH Data Element Submission to USCDI Standard

-CMS OMH submitted a new SDOH data element through the ONC New Data Element and Class system, currently in draft v5 for comment

-Proposed new element: “Do you need or want an interpreter to communicate with a doctor or health care staff?”

-This data element can add important context about the supports a particular patient requires to address literacy or language barriers

Post-Acute Care Settings

Started October 2022

-Preferred Language

-Need for an Interpreter

-Health Literacy

-Social Isolation

-Transportation

CMMI Models

Started January 1, 2023 – All CMMI model participants are to provide SDOH data based on USCDI standards

SDOH Measures

Both SDOH measures finalized for adoption into Hospital IQR program from the fiscal year (FY) 2023 IPPS rule.

Voluntary reporting in 2023
Mandatory reporting beginning in CY2024 reporting period (FY 2026 payment determination).

Screening for Social Drivers of Health

- Assesses the total number of patients, aged 18 years and older, screened for social risk factors during an inpatient facility stay, or during established care in the case of dialysis facilities.
- Focused specifically on food insecurity, housing instability, transportation needs, utility difficulties, and interpersonal safety

Screen Positive Rate for Social Drivers of Health

- Structural measure
- % of patients admitted for an inpatient facility stay or received established care in the case of dialysis facilities, and 18+ years on the date of admission or established care who:
  - Were screened for all five HSRNs, **and**
  - Screen positive for one or more of the following five HRSNs: food insecurity, housing instability, transportation problems, utility difficulties, or interpersonal safety.

End Stage Renal Disease Quality Incentive Program (ESRD QIP), Inpatient Psychiatric Facility Quality Reporting Program (IPF), and PPS- Exempt Cancer Hospital Quality Reporting Program (PCH)

Opportunities to Use CMS's Data

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Tribal Data Learning Community (TDLC) Program

- A new one-year pilot program for researchers at Tribal Epidemiology Centers (TECs) to conduct research that is meaningful to Tribal communities using CMS data.
- Sponsored by the CMS Office of Minority Health in partnership with the CMS Division of Tribal Affairs.
- Provide participating TECs with data resources to assess the needs of their communities and develop appropriate interventions.
  - Peer learning network;
  - CMS Medicare and Medicaid program data access for 1 year; and
  - Technical support in conducting analyses.
- Objectives:
  - Promoting development of research, analytic methods, and dissemination practices relevant to tribal communities;
  - Creating opportunities for participants to network and develop meaningful, sustainable connections with each other;
  - Providing timely and tailored technical assistance that enhances participants' capacity to carry out their research; and
  - Providing a forum for CMS to engage with TECs along their research lifecycle.

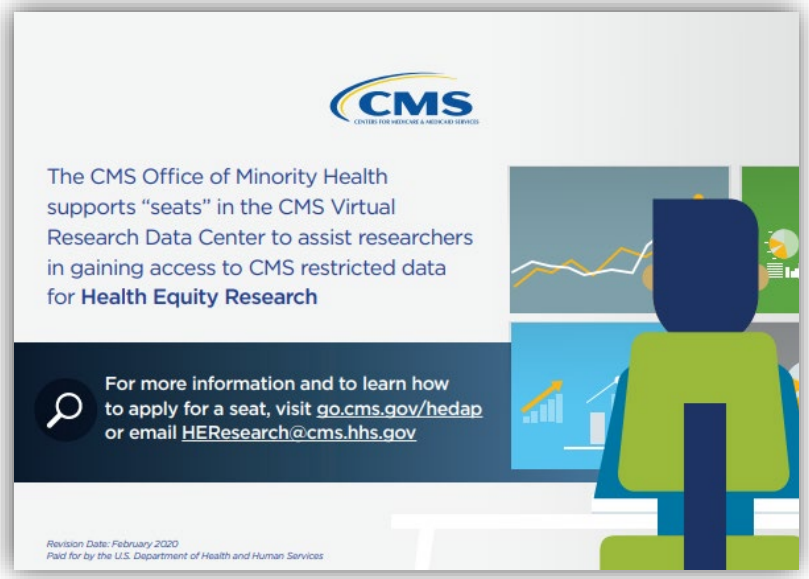
Health Equity Data Access Program (HEDAP) Grant

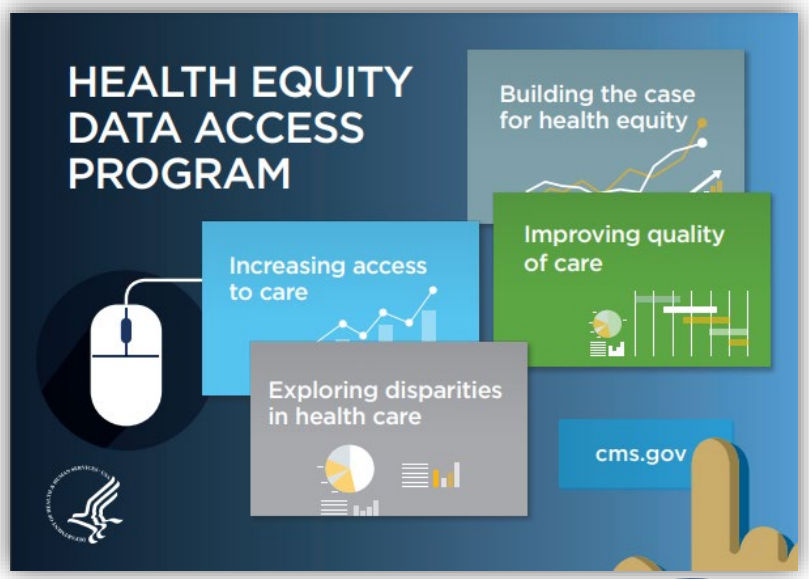
CMS OMH supports three “seats” in the CMS Virtual Research Data Center (VRDC) to assist researchers in gaining access to CMS restricted data for minority health research.

Awardees gain access to CMS data to conduct health services research focusing on, but not limited to, minority populations, including race, ethnicity, language, sexual orientation, gender identity, and disability status.

Learn more:

- Visit: go.cms.gov/hedap
- Email: HEResearch@cms.hhs.gov





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Minority Research Grant Program (MRGP)

- Administered by CMS OMH to support researchers at minority-serving institutions that explore how CMS can better meet the health care needs of the populations we serve.
- Supports CMS's efforts to advance health equity by increasing understanding and awareness of health disparities, developing, and disseminating solutions, and implementing sustainable actions.
- Health equity researchers with suitable projects from the following types of minority serving institutions may apply:
  - Historically Black Colleges and Universities
  - Hispanic-Serving Institutions
  - Asian American and Native American Pacific Islander-Serving Institutions
  - Tribal Colleges and Universities
  - Predominantly Black Institutions
  - Native American Serving Non-Tribal Institutions and
  - Alaska Native and Native Hawaiian-Serving Institutions

- Notice of Funding Opportunity for 2024 was just released – up to 5 grantees award totaling $1.275 million
- Application deadline is June 3, 2024
- Email questions to OMHGrants@cms.hhs.gov

https://www.cms.gov/priorities/health-equity/grants-awards/minority-research

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Contact Us

OMH@cms.hhs.gov

Visit Our Website

go.cms.gov/omh

Listserv Signup

bit.ly/CMSOMH

Coverage to Care

CoverageToCare@cms.hhs.gov

Health Equity Technical Assistance Program

HealthEquityTA@cms.hhs.gov

Rural Health

RuralHealth@cms.hhs.gov

Slides and Recordings from Previous ELS Sessions

https://cmsintranet.share.cms.gov/ER/Pages/CMSEquityLearningSeries.aspx

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Thank You!

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