



DATA DISAGGREGATION
FOR THE STATE OF MICHIGAN

DO YOU SEE US?

CAMPAIGN GUIDELINES

CAMPAIGN GUIDELINES: HOW TO USE THIS PACKET



Understand the New Standards

Review Changes: Familiarize yourself with the updated OMB guidelines for race and ethnicity data collection.

Use the Case Study

Use It as a Tool: Incorporate the case study in your discussions and presentations to illustrate the tangible benefits of disaggregated data

Leverage Talking Points

Craft Your Message: Use the talking points to explain:

- Improved Accuracy: How disaggregated data provides a clearer picture of community needs.
- Targeted Interventions: Benefits for tailoring programs and services to specific groups.
- Civil Rights Protections: How detailed data helps address disparities and ensures equitable access to resources.
- Informed Policy Making: The role of accurate data in shaping effective policies and securing funding.

Share Social Media Content

Customize and Share: Use the social media to:

- Customize Graphics: Select and personalize social media graphics to align with your organization's branding and messaging.
- Share Strategically: Post the graphics and video content on your social media channels to raise awareness and support for data disaggregation.
- Tag and Share: Engage with other organizations and stakeholders by tagging them and sharing the content to broaden your reach.

Promote Video Content

Feature Voices: Share videos from nonprofit leaders and community members to highlight the impact on diverse communities.

Evaluate and Adjust

Track Success: Monitor the impact of your advocacy efforts and gather feedback to refine your approach.

ABOUT THE CAMPAIGN

The Johnson Center is leading a campaign to enable communities to see themselves in state data — data that researchers, nonprofit organizations, foundations, policymakers, and others use to direct resources to reach the areas of greatest need.

This campaign is supported by the Leadership Conference Education Fund.

ABOUT THE JOHNSON CENTER

The Dorothy A. Johnson Center for Philanthropy at Grand Valley State University was established in 1992 with support from the W.K. Kellogg Foundation. Our mission is to be a global leader in helping individuals and organizations understand, strengthen, and advance philanthropy, resulting in a smart, adaptive sector that helps create strong, inclusive communities.

We put research to work with and for professionals across the country and the world. Through professional education offerings; research, evaluation, and consulting services; and bold thinking to advance the field, we support a philanthropic ecosystem defined by effective philanthropy, strong nonprofits, and informed community change.

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CAMPAIGN GUIDELINES: THE FEDERAL RACE AND ETHNICITY DATA COLLECTION STANDARDS

Our campaign specifically encourages all state agencies to adopt uniform race and ethnicity data collection standards — including adding a “Middle Eastern or North African” category, and putting all categories in a single question with the option to “select all that apply.” We also urge the state to make this data publicly available at a community level across Michigan.

METHODOLOGY NOTES

In addition to the guidance on what question to ask, the Office of Management and Budget (OMB) made the following notes on how to ask it.

First, “wherever possible, race and ethnicity data should be collected through self-report.” In other words, the OMB recommends allowing the person under study to select their race and/or ethnicity for themselves, rather than having a researcher/observer make that judgment for them, whether by sight or other data sources.

Next, “for statistical survey reporting, agencies are required, rather than encouraged, to transparently describe whether race and ethnicity data are self-reported or collected by proxy, along with any imputation or coding procedures.” That is, federal agencies must tell us how they collect race and ethnicity data.

“With respect to collection, the seven minimum race and ethnicity categories shall be treated co-equally, except if a program or collection effort focuses on a specific racial or ethnic group, as approved by OIRA. Collection forms may not indicate to respondents that they should interpret some categories as ethnicities and others as races, or otherwise indicate conceptual differences among the minimum categories.” By this, the OMB is telling us they don’t want us to muddy the question for respondents by highlighting which categories are technically races and which are ethnicities.

Advocates and researchers generally want people to know that “Hispanic/Latino” and “Middle Eastern or North African” are ethnicities, and that also selecting a race is important to fully identify communities.

However, the OMB seems to be erring on the side of simplicity here, at the risk of ambiguity.

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.

Figure 1: New federal standard question for race and ethnicity data collection as of March 29, 2024 – OMB



For more information on the data disaggregation campaign in Michigan, scan this QR code or visit johnsoncenter.org/doyouseeus



For more information on the OMB standards, scan the code or visit spd15revision.gov/

MESSAGING FRAMEWORK: GOALS AND APPROACH



OUR GOAL IS TO ENCOURAGE COLLECTIVE ACTION AND KNOWLEDGE SHARING

We want organizations and their communities to know about the new OMB data standards, so they can expect it, advocate for it, and make the change. This is ongoing work. The ability to count, or not count certain populations is an often underrated power held by state and local organizations. Many communities have advocated for these changes for a long time, which is a big step forward.

WHO ARE YOU TALKING TO?

Whether you're sharing the rich history of advocacy behind the OMB standards or explaining the changes themselves, your audience should be informed of the type of messages you choose to share. Your messaging will likely have different goals depending on whom you're trying to reach.

Your Friends, Family, and Colleagues

Orgs + Leaders Who Collect Data

EMOTIONAL

Why should I care about this?

- This is about representation.
- Data inclusion shows us that our experiences matter.
- When we don't collect, we aren't able to make the best choices for our communities.

ACTIONABLE

What can I do?

- As an organization, update your standards. Add the checkbox.
- As an individual, advocate for change. Share these posts. Celebrate change where you see it.

FUNCTIONAL

What are the standards?

- We're adding the MENA category.
- We're making sure you can check multiple race and ethnicity categories.
- We're continuing to prioritize self reporting.

UTILIZING CAMPAIGN THEME - DO YOU SEE US?

The "Do You See Us" theme is an introduction to a conversation. As an organization, you are providing an answer to this question. You're saying, "Yes, we hear and recognize our communities. We're taking action and updating our data standards to better understand the needs of the communities we serve."

After the introduction, shift the focus from the theme to the specific impacts that inclusive data has on your work. This approach helps the audience understand the practical benefits of the new standards, rather than just the theoretical concept.

MESSAGING FRAMEWORK: GUIDELINES + CONSIDERATIONS

This messaging framework outlines a few guiding points on how to speak to data disaggregation and the OMB changes. These are not meant to be hard rules, they are considerations that can help guide your organization and teams when crafting messaging.

LEAD BY EXAMPLE

Let your audience know this is a big deal. Raising awareness for new data standards resonates more when you share your commitment to the change.

BE CLEAR AND SHARE DIGESTIBLE INFORMATION

Focus your posts - don't dance around the point. **The way we measure race and ethnicity is improving.** We share this because we want other organizations to adopt the change.

THIS IS ABOUT REPRESENTATION, NOT SURVEILLANCE

The prevailing mental model of "data collection" is negative. Anticipate a fear of surveillance, but don't prioritize that conversation. When concerns arise, use the opportunity to share what a lack of data means for decision-making (uninformed decisions, poorly resourced programming, stalled decisions, etc.).

MAKE IT PERSONAL; TIE THIS BACK TO YOUR ORGANIZATION

This toolkit includes pre-built posts and imagery. Using these can save time, and unifies the greater collective action. However, it's just as impactful to share about this work using your organization's own voice, tone, and imagery.

ATTENTION-GRABBING IMAGES WITH INFORMATIVE CAPTIONS:

People will only spend a little time reading text in an image but will look to the caption for details. The image should introduce the idea, and the caption should summarize the point.

REPEAT YOURSELF, AND VARY THE PRESENTATION:

Most digital media is designed to be short-form, so we can't expect the audience to spend much time engaging. So repeat your information and present it in new ways. You might celebrate the change, then educate about the change, and then show your commitment to the change.

MESSAGING FRAMEWORK: GUIDELINES + CONSIDERATIONS

SAMPLE SOCIAL MEDIA LANGUAGE

This page contains ideas and starting points for social media captions. These can be utilized alongside social media images or videos from the campaign, or with original content from your organization. This language is meant to provide a starting point — these are not required content.

We've heard our communities advocating to see themselves represented in data, asking "Can you see us?" Now with the federal government's improved race and ethnicity data standards, we're doing our part to make sure we can give a resounding yes!

It's time for more representative data standards.

We use data to make critical decisions for our communities. And when communities aren't counted, their stories can become invisible. That's why we're joining other Michigan organizations and leaders to push for a more representative data standard.

On our surveys and forms, you'll see improvements to the way we ask race and ethnicity questions. These changes help us understand whom we're currently serving and what communities we're missing, and helps us plan for a stronger future.

Do you see us? Our answer is a resounding YES!

We hear and recognize our communities. With the new OMB race and ethnicity data standards, we're updating our practices to ensure more communities are represented.

Data drives key decisions, from our housing systems to program funding. Encourage your local organizations to update their data collection standards and include categories like American Indian or Alaska Native, Middle Eastern or North African, and the other OMB standard categories.

Social media algorithms do consider hashtags as a factor in determining the reach and engagement of posts, but their importance varies across platforms and is just one of many factors these algorithms use. If they are standard in your organization, these can help boost and unify the campaign.

#DoYouSeeUs #OMBStandards #InclusiveData #MichiganLeads #DataForAll #DiverseData #EquityInData

Data shape our communities, but what happens when we aren't counting correctly? That's why we're championing new, inclusive data standards in Michigan! 🇺🇸🌟

Our updated surveys and forms now feature improved race and ethnicity questions, ensuring every story is counted. These changes help us see whom we're serving, identify gaps, and build a brighter, more inclusive future for all.

Join us on this journey to make every community visible and valued!

Our communities have advocated for more representative data, and we're listening!

With the federal government's new race and ethnicity data standards, we're ensuring everyone is seen and heard. 🇺🇸

These updates help us paint a clearer, more inclusive picture of our diverse community, making sure no one is left invisible. We're updating the way we collect race and ethnicity data, and we call on other Michigan organizations to do the same.

"Do you see us?" Yes, we do! We're committed to hearing and recognizing the diverse stories within our communities. By adopting the new OMB data standards, we're taking action to better understand and serve your needs. Community voices drive us to make better decisions, so we're making the change toward better data.

CASE STUDY: THE MICHIGAN CORONAVIRUS TASK FORCE ON RACIAL DISPARITIES AND DISAGGREGATED DATA



On April 7, 2020 — roughly one month after the first cases of COVID-19 were reported in Michigan — the Washington Post highlighted the widely disproportionate impact of the virus on Black/African American people: while only 14% of the state’s total population identified as Black/African American, this community comprised 41% of the 845 people who had died (Thebault, et al., 2020). Just two days later, Gov. Gretchen Whitmer established the Michigan Coronavirus Task Force on Racial Disparities. “This virus is holding a mirror up to our society,” said Gov. Whitmer, “and reminding us of the deep inequities in this country” (Executive Order 2020-55, 2020).

The task force — with appointees from state government, universities, and the private, nonprofit, and philanthropic sectors — was charged with “improving data collection on racial and ethnic demographic information, and greatly enhancing the sharing and analysis capabilities of equity-related data” (Michigan Coronavirus Racial Disparities Task Force, 2023). In fact, it was only due to the efforts of Michigan and a few other states to collect and publish this type of information that racial disparities were known at all in those first weeks of the pandemic (Thebault, et al., 2020). Without knowledge of these disparities, the task force and its partners in communities across the state would not have been equipped to direct resources to the communities that needed it most.

“UNDERFUNDED AND INADEQUATE”

Joneigh Khaldun, Michigan’s chief medical executive from 2019–2021, was an early champion of race and ethnicity data disaggregation. “Whether it’s the opioid crisis and deaths, maternal deaths, I always encouraged our team,” she said in a 2022 interview, “when you’re looking at data sets, make sure you’re looking at race and ethnicity” (University of Michigan, 2022).

Without sufficient resources and a broad commitment to collect this data at the state level, however, information on race and ethnicity can be hard to come by. As Khaldun outlined the state of Michigan’s public health data system in the first weeks of the pandemic,

[I]n the early days, I believe people probably didn’t understand just how underfunded and inadequate the public health data infrastructure really is. ... In the beginning, the way we were able to identify demographic information about cases was if someone actually wrote it on the lab requisition form that was shipped, literally shipped physically to the state lab in Lansing (University of Michigan, 2022).

It is no surprise, then, that authorities in early April 2020 could not determine the race of 28% of the people who had died in the state (Quesnelle, 2020a). The reporting on ethnicity was even more threadbare — later that same month, the organization Data Driven Detroit pointed out that Hispanic/Latino identity was not reported in 27% of total deaths, and Arab identity was unknown in three-quarters of all deaths (Quesnelle, 2020b).

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INTERVENTIONS AND IMPROVEMENTS ON DATA COLLECTION AND TRANSPARENCY

Over the next year, then, the task force supported efforts to improve demographic data collection. One such effort included a collaboration between the Dearborn-based nonprofit ACCESS (Arab Community Center for Economic and Social Services) and Oakland University. In this initiative, researchers disaggregated COVID-19 case and mortality data by Middle Eastern or North African descent (MENA) in order to better understand how the pandemic impacted those communities, long ignored in federal and state data collection (Michigan Coronavirus Racial Disparities Task Force, 2020). The task force also drew on other indicators — such as the Social Vulnerability Index, which uses race and ethnicity information among other data — to target efforts like public health campaigns and testing sites.

In addition, the task force also guided partnerships between the Michigan Department of Health and Human Services (MDHHS) and others to develop the Michigan Safe Start Map, a public, interactive online dashboard that could filter COVID-19 data by race and ethnicity for the user (Michigan Coronavirus Racial Disparities Task Force, 2022).

FEDERAL CHANGE AT THE STATE LEVEL

The work supported by the task force continues today, in recent efforts by MDHHS to change its data collection policies, and engage different racial and ethnic groups in “community conversations” on those proposed changes. Specifically, the MDHHS Office of Equity and Minority Health (OEHM) has proposed changes that largely align with new federal race and ethnicity data standards (Michigan Department of Health and Human Services, 2024). In March 2024, the federal Office of Management and Budget updated Statistical Policy Directive no. 15 for the first time in more than 25 years (OMB, 2024). Among other changes, all federal agencies that collect race and ethnicity data must now combine their separate race and ethnicity questions into a single question, add “Middle Eastern or North African” to their categories, and seek more detailed race and ethnicity data by default.

As MDHHS explained in a public notice, “currently, there is no standard way for MDHHS to collect race and ethnicity data for residents receiving services,” or for “comparing the quality of MDHHS service delivery for different race and ethnicity groups between programs” (Michigan Department of Health and Human Services, 2024). The OEHM’s proposed changes, if adopted, would make MDHHS the first agency in Michigan to formally recognize Middle Eastern and North African communities in the state.

It would also signal that the agency intends to grapple with the “consequences of longstanding structural inequalities with respect to access and utilization of health care” in underserved populations (Michigan Coronavirus Racial Disparities Task Force, 2023).

We applaud these proposed changes and look forward to their enactment — not just within MDHHS, but across all state agencies. The COVID-19 pandemic offered just one horrifying example of how systemic racism can manifest in society. Without data disaggregated by race and ethnicity, much of the work of the Michigan Coronavirus Racial Disparities Task Force may have bypassed the communities most in need. Michigan stands on the cusp of transformative change, and investing in robust data systems and prioritizing standardized data collection and reporting will greatly aid Michigan’s efforts in eliminating racial disparities in the state.

CASE STUDY: THE MICHIGAN CORONAVIRUS TASK FORCE ON RACIAL DISPARITIES AND DISAGGREGATED DATA

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DOROTHY A. JOHNSON CENTER FOR PHILANTHROPY

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APPENDIX: REFERENCES

- Executive Order 2020-55 (2020, April 20). Michigan Coronavirus Task Force on Racial Disparities. <https://www.michigan.gov/whitmer/news/state-orders-and-directives/2020/04/20/executive-order-2020-55>
- University of Michigan Gerald R. Ford School of Public Policy. (2022, June 10). Lessons learned: Michigan's coronavirus task force on racial disparities. University of Michigan. <https://fordschool.umich.edu/video/2022/lessons-learned-michigans-coronavirus-task-force-racial-disparities>
- University of Michigan School of Information and University of Michigan School of Public Health. (2024, January). MI Safe Start Map: Track the risk levels of COVID-19 indicators. <https://www.mistartmap.info/active-metrics>
- Michigan Coronavirus Racial Disparities Task Force. (2020). Rapid Response Initiative: Final list of funded initiatives. Michigan Department of Health and Human Services. https://www.michigan.gov/mdhhs/-/media/Project/Websites/coronavirus/Folder22/Rapid_Response_Initiative_-_Final_List_of_funded_initiatives_2_with_Project_Column_Added.xlsx?rev=8505bf53c9d6445c902332cc04ab81e2&hash=B44F2DAA124AF0AD6258BCA9207A92C4
- Michigan Coronavirus Racial Disparities Task Force. (2022, February). Recommendations for collaborative policy, programming and systemic change. Michigan Department of Health and Human Services. https://content.govdelivery.com/attachments/MIEOG/2022/03/04/file_attachments/2094072/Racial%20Disparities%20Task%20Force_Recommendations%20for%20Collaborative%20Policy%20Programming%20and%20Systemic%20Change%20%28%29.pdf
- Michigan Coronavirus Racial Disparities Task Force. (2023, February). Recommendations for collaborative policy, programming and systemic change: Year two. Michigan Department of Health and Human Services. <https://www.michigan.gov/mdhhs/-/media/Project/Websites/mdhhs/Doing-Business-with-MDHHS/Boards-and-Commissions/Coronavirus-Task-Force-on-Racial-Disparities/RDTF-Final-Report-14Feb2023.pdf?rev=3e7b7a78f0cd4f09a7569995536d4333&hash=44C9A5F061FA2A575134518DFFA9C76C>
- Michigan Department of Health and Human Services. (2024). Race and ethnicity data collection standards. <https://www.michigan.gov/mdhhs/keep-mi-healthy/multihealth/race-and-ethnicity-data-collection-standards>
- OMB Interagency Technical Working Group on Race and Ethnicity Standards. (2024, March 28). U.S. Office of Management and Budget's Statistical Policy Directive No. 15: Standards for maintaining, collecting, and presenting federal data on race and ethnicity. <https://spd15revision.gov/>
- Quesnelle, S. (2020, April 8). Understanding data during a pandemic. Data Driven Detroit. <https://datadrivendetroit.org/blog/2020/04/08/understanding-data-during-a-pandemic/>
- Quesnelle, S. (2020, April 27). Data quality: Examining the impact of COVID-19 on the African American community. Data Driven Detroit. <https://datadrivendetroit.org/blog/2020/04/27/data-quality-impact-of-covid19-on-african-american-community/>
- Thebault, R., Tran, A., & Williams, V. (2020, April 7). The coronavirus is infecting and killing black Americans at an alarmingly high rate. Washington Post. <https://www.washingtonpost.com/nation/2020/04/07/coronavirus-is-infecting-killing-black-americans-an-alarmingly-high-rate-post-analysis-shows/>
- Michigan Department of Health and Human Services. (2024, March 12). Michigan data. <https://www.michigan.gov/coronavirus/stats>