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# Unlocking Race and Ethnicity Data to Promote Health Equity in California Proposals for State Action

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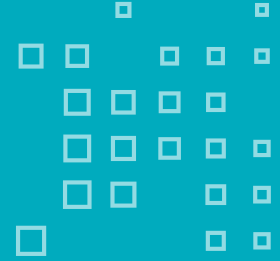
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# Unlocking Race and Ethnicity Data to Promote Health Equity in California

## Proposals for State Action



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## Introduction

COVID-19 has illuminated systemic racial and ethnic inequities in our healthcare system and catalyzed an unprecedented call to action to address their root causes.<sup>1</sup> It has also revealed the dearth of reliable and standardized race and ethnicity (R/E) data available to identify multidimensional contributors to disparities, design effective initiatives to drive improvement, and measure progress. R/E data gaps limit the ability of healthcare stakeholders—including states, plans, consumer organizations, and providers—to meaningfully advance equitable healthcare delivery, obscuring the line of sight as to where disconnects are present and reforms are needed while leaving a persistently clear view of the system’s failures: higher rates of chronic disease, higher infant mortality rates, and lower life expectancies for many racial and ethnic populations.<sup>2</sup>

Health plans are well-positioned to collect R/E data and then use this information to promote health equity. However, health plans face several data collection challenges that result in significant gaps in reporting. In fact, two-thirds of commercial health plans, half of Medicaid plans, and more than a quarter of Medicare plans have race data missing for more than half of their membership, with ethnicity data sparser still.<sup>3</sup> This paper discusses common health plan R/E data collection challenges, and how California can help mitigate these barriers and equip all health system stakeholders with crucial information to promote health equity.

**Better data on race and ethnicity is necessary to guide policymakers, plans, consumer organizations, and health systems in their development of targeted reforms to promote health equity.**

## Why States Need Payer Data to Identify Inequities and Address Disparities

In California and around the country, the repercussions of limited R/E data have been felt throughout the COVID-19 public health crisis. Race and ethnicity data gaps initially masked the disproportionate toll COVID-19 took on the health of on Black or African American (Black), Hispanic or Latino (Latinx), Asian, Native Hawaiian or other Pacific Islander, and American Indian or Alaska Native communities and slowed public health responses to the pandemic.<sup>4</sup> As state and federal R/E reporting requirements were introduced, reporting improved, highlighting the role targeted data collection mandates and standards can play in improving data quality and use in support of responsive program action.<sup>5</sup>

States, plans, consumer organizations, and providers can use R/E data to identify barriers to health care access and monitor the impact program reforms have on health inequities. State Medicaid managed care programs and state-based health insurance marketplaces have pioneered such requirements, leaning on plans to collect and use R/E data—often through quality improvement programs—to identify and address disparities.<sup>6</sup> California’s Department of Health Care Services (DHCS), for example, analyzes Medi-Cal

Managed Care Plan (MCP) quality data received through its External Quality Review Organization (EQRO) process to assess potential differences in health outcomes between population groups, and shares those analyses with plans to guide interventions.<sup>7</sup> DHCS has also emphasized the importance of increased data collection to reduce disparities and inequities, through its broader California Advancing & Innovating Medi-Cal (CalAIM) proposal.<sup>8</sup> Louisiana similarly requires plans to collect and use R/E data to drive population health program improvement and develop targeted interventions for subpopulations facing disparate outcomes.<sup>9</sup>

Meanwhile, Covered California continues to increase R/E data reporting and use expectations by contracted Qualified Health Plans (QHPs).<sup>10</sup> For 2022, Covered California has proposed:

- Increasing plan R/E data completeness requirements to include an 80% threshold for “self-identification” of enrollees;
- Requiring plans to receive National Committee for Quality Assurance (NCQA) Multicultural Health Care (MHC) Distinction (which includes R/E and language data collection standards); and
- Requiring plans to work with Covered California to reduce identified disparities.<sup>11</sup>

States may also consider using health plan R/E data as part of cross-departmental efforts to better understand and monitor cross-payer population inequities, though such reporting has been limited to date. By assembling available data from state Medicaid, Marketplace, and public health departments—as well as state data resources (e.g., All Payer Claims Databases, hospital discharge databases)—state regulators and healthcare stakeholders would be better equipped to understand where health system disconnects are occurring and where specific reforms may be warranted. Potential health equity measures could comprise indicators with race and ethnicity segmentations of:

- Population health and well-being (e.g., physical and behavioral health condition prevalence, premature death rates, preventable hospitalizations);
- Access to coverage and care (e.g., uninsured rates, premiums, high-deductible health plan adoption);
- Service utilization (e.g., physical and behavioral health screening rates, immunizations, behavioral health provider utilization for preventive care); and
- Drivers of health (e.g., homelessness rates, food benefit prevalence, physical safety, access to broadband internet).

With improved R/E data collection, California could establish data-driven health reporting that measures health disparities across the state. Improving R/E data acquisition on administrative (claims/encounter) data would provide both payers and the state with more detailed and actionable insights on health disparities.

Such reporting could also help guide policymakers, plans, consumer organizations, and health systems in their development of targeted reforms to promote health equity.

# Challenges in Race and Ethnicity Data Collection

Health plans may more effectively address health inequities by acquiring more consistent self-identified R/E data upon member enrollment. However, plans face several challenges with collection, including:

- Member reluctance to voluntarily provide R/E information;
- Limited and uneven regulations that govern and incentivize R/E data collection across all lines of business (e.g., Medi-Cal, Covered California, small group, large group); and
- Inconsistent use of R/E data standards, impacting data integrity and analytic use.

These challenges, individually and collectively, impact plan R/E data acquisition and its efficacy for use.<sup>12</sup>

## Reluctance to Self-Identify



Individuals are the source of truth regarding their race and ethnicity information, and many choose to not voluntarily share it with their health plan.<sup>13,14</sup> State payers and plans frequently report that a minority of their members share their R/E information upon enrollment, and those that do tend to skew White.<sup>15</sup> Reluctance to self-identify may stem from long-standing concerns about privacy and discrimination. States, plans, and providers have improved self-identification rates by providing members with context for why information is being collected and how it will be used (and will not be used) and by adjusting questionnaires to require members to “actively opt out” of responding (i.e., forcing a “choose not to respond” option). Confusion about self-classification among provided race and ethnicity categories may also result in a lack of responses.

## Limited and Uneven Regulatory Requirements



Health plans are often not required by federal or state authorities to collect R/E data for significant portions of their members; and where they are, requirements can vary considerably by state and line of business. Limited and uneven regulatory requirements weaken plans’ abilities to develop comprehensive strategies for R/E data collection and use, which can require significant process changes and health information technology (HIT) system and analytic investments.

In California, plan R/E data collection and use requirements are largely limited to Medi-Cal and Covered California.<sup>16</sup> DHCS requests R/E data as part of its Medi-Cal enrollment process and shares collected data with Medi-Cal plans.<sup>17</sup> Covered California similarly collects R/E data in its joint Medi-Cal application, which it shares with its QHPs.<sup>18</sup> QHPs are expected to obtain additional race and ethnicity data, acquiring such data for 80% of their Covered California enrollees, with financial penalties and incentives tied to meeting the threshold.<sup>19</sup> Covered California has seen a significant improvement in the acquisition of R/E data since implementing this requirement.<sup>20</sup>

California has placed the expanded collection and use of R/E data at the center of its strategy to improve health equity. In the SFY 2022 budget proposal, priorities were set to:

- Promote quality measures for full-service and behavioral health plans that include health equity benchmarks;
- Advance new contract requirements for Medi-Cal, Covered California, and California Public Employees' Retirement System (CalPERS) plans that focus on health disparities and cultural and language competency; and
- Invest in the California Health and Human Services (CHHS) agency to "further reorient the administration of its programs through the use of data and the development of an equity dashboard."<sup>21</sup>

## Inconsistent Use of Standards



While a federal standard for R/E data categorization was first established in 1977 by the U.S. Office of Management and Budget (OMB) with Statistical Policy Directive No. 15 and updated in 1997 with Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity, other federal agencies (e.g., U.S. Health Resources & Services Administration, Census Bureau), health plans, and providers have retained alternative classifications or use their own codes.<sup>22,23</sup> Variation in the collection and reporting of R/E data prevents accurate comparisons of the quality of care being delivered to different population groups across multiple entities. Having common reporting requirements and standards across the healthcare industry would greatly enhance uniform data collection, reporting accuracy, and ultimately equitable care delivery.

Nationally, NCQA's Multicultural Health Care Distinction certification has also provided state payers, plans, and healthcare providers with standard approaches to R/E data collection, although adoption is nascent.<sup>24</sup>

## In recognition of and response to R/E self-identification challenges, many health plans are increasingly relying on indirect or proxy methodologies to collect R/E data for their membership.



Indirect data sources may include patient experience surveys (e.g., CAHPS), clinical data from providers or health information exchanges (HIEs), or other external administrative data resources.<sup>25</sup> Plans may also use advanced analytics or probabilistic matching algorithms to approximate a member's race and ethnicity based on information the plan does have about the member (e.g., surname, address) and how those characteristics correlate with the race and ethnicity of others.<sup>26</sup>

While indirect data acquisition can substantially improve R/E data collection and reporting, its accuracy can vary based on its source and how the plan integrates the data into its HIT systems.<sup>27</sup> Healthcare stakeholders should consider the following limitations in assessing indirect data source use:

- Data obtained through indirect methods will typically be less accurate than self-identified data;<sup>28</sup>
- Acquired data may be coded against different standards than what the organization already has in place, impacting the ability to consistently aggregate, compare, and analyze the combined data without a concerted cross-walking or harmonization process;

- Estimated or imputed data, while providing helpful population-level information, may result in individual-level inaccuracies and should be used with caution to inform assessments;
- The more indirect data sources used, the greater the potential loss of analytic integrity; and
- Maintaining data fields that capture R/E data source notes are important to allow organizations to establish a “hierarchy of truth” for collected data and ensure that indirect data does not replace self-identified data.

Organizations seeking to use indirect data sources to improve their R/E data collection should establish a governance process for its consistent application over time.

Indirect data can be invaluable in helping plans assess where subpopulations face health system disconnects. Their utility can be enhanced when paired with member verification processes, where broader R/E data collection standards are established (e.g., partnering plans and providers agreeing to common R/E classifications).

Addressing the process, technical, and regulatory hurdles for R/E data collection will be critical to ensuring healthcare stakeholders have access to the information they need to identify health disparities and promote health equity.

## Recommendations for Improving Race and Ethnicity Data Collection and Reporting

California, through actions by the state government—including DHCS, the Department of Managed Health Care (DMHC), Covered California, CalPERS, and the Department of Insurance (CDI)—and the legislature, can advance standards and requirements for R/E data collection that could support stakeholders’ understanding of, and ability to address, our most pressing health equity issues. These actions should include:

### 1. Developing HIE capacity as a centralizing source of R/E data for plans and providers.

HIEs are uniquely positioned and functionally equipped to securely collect, link, and share R/E data among health plans, providers, and public and private payers. Building on their existing connections and processes, HIEs can use the data they receive from participants to create centralized R/E records for all members, improving data acquisition for healthcare providers and plans; apply a centralized, standardized method of R/E estimation or collection to fill R/E data gaps while minimizing the impact on overall data integrity; and facilitate R/E data standardization among participants. The Connecticut Office of Health Strategy, for example, recommended that the state HIE play a primary role in improving R/E data collection, developing standards, and requiring connecting health systems, organizations, and agencies to collect and report R/E data.<sup>29</sup> HIEs can also provide plans and providers with clinical data that can strengthen population health programs and disparity interventions.<sup>30</sup>



## 2. Requiring health plans to collect standardized R/E data across all regulated lines of business.

Consistent data standards are critical for identifying and monitoring responses to health ecosystem inequities. A cross-agency workgroup should be convened to establish R/E data collection standards and acquisition targets for contracted and regulated health plans, potentially building on work planned to support the Annual Health Care Service Plan Health Equity and Quality Reviews.<sup>31</sup> Requirements should be embedded in regulations (e.g., DMHC and CDI regulations for fully insured HMO and PPO plans) and state-administered contracts (e.g., DHCS, Covered California, and CalPERS for Medi-Cal plans, QHPs, and state-employee plans, respectively). Acquisition requirements should elevate R/E data collection as a plan priority, ensuring the data is available to guide interventions. The state should also facilitate sharing of industry best practices for maximizing member self-identification (e.g., active non-response protocols) and optimal use of indirect data.<sup>32</sup>

These actions may be advanced through an executive order, leveraging the state's role as a regulator and administrator and allowing for a quick and direct impact on all non-self-insured California health plans and regulated providers.

Payers, health plans, and providers should also continue refining their methods for collecting standardized R/E data directly from members. Proven tactics to increase data acquisition and accuracy include improving member communication about why such information is needed (e.g., "to ensure all patients receive the highest quality care"); enhancing enrollment staff training on how to consistently and appropriately solicit this information; and tailoring electronic applications and forms to include "active opt-out" options (e.g., "decline to state") instead of allowing questions to be skipped.<sup>33</sup>

## Conclusion

Addressing the barriers to R/E data collection is imperative for all healthcare stakeholders as we work together to address the historical and deeply entrenched structural and programmatic barriers to better care and health for all Californians. Through actions by the state leadership and entities, and the legislature, California can advance health equity with standardized requirements for R/E data collection that will support stakeholders' understanding of and ability to address our most pressing health equity needs.

<sup>1</sup> “Something Must Change: Inequities in U.S. Policy and Society,” U.S. House Committee on Ways & Means. Jan. 2021. Available at [https://waysandmeans.house.gov/sites/democrats.waysandmeans.house.gov/files/documents/WMD%20Health%20and%20Economic%20Equity%20Vision\\_REPORT.pdf](https://waysandmeans.house.gov/sites/democrats.waysandmeans.house.gov/files/documents/WMD%20Health%20and%20Economic%20Equity%20Vision_REPORT.pdf).

<sup>2</sup> “California Health Care Almanac – Health Disparities by Race and Ethnicity: The California Landscape,” CHCF. Oct. 2019. Available at <https://www.chcf.org/wp-content/uploads/2019/10/DisparitiesAlmanacRaceEthnicity2019.pdf>.

<sup>3</sup> “Data on Race, Ethnicity, And Language Largely Incomplete For Managed Care Plan Members,” Health Affairs. Mar. 2017. Available at <https://www.healthaffairs.org/doi/full/10.1377/hlthaff.2016.1044>.

<sup>4</sup> New data on national vaccine distribution was similarly found to be missing race and ethnicity values for nearly half of all vaccinations, making it difficult to determine the depth of inequities in vaccine distribution and emphasizing the chronicity of missing critical data. “Race and Ethnicity Data Missing for Nearly Half of Coronavirus Vaccine Recipients, Federal Study Finds,” Washington Post. Feb. 2021. Available at <https://www.washingtonpost.com/health/2021/02/01/covid-vaccine-race-ethnicity-data/>.

<sup>5</sup> “Racial Disparities in COVID-19: Key Findings from Available Data and Analysis,” KFF. Aug. 2020. Available at <https://www.kff.org/report-section/racial-disparities-in-covid-19-key-findings-from-available-data-and-analysis-issue-brief/>.

<sup>6</sup> Federally, CMS’ Medicare Advantage Chronic Care Improvement Program (CCIP) similarly seeks to guard against potential health disparities by requiring population analyses to target care interventions. See “Medicare Advantage CCIP,” CMS. 2020. Available at <https://www.cms.gov/Medicare/Health-Plans/Medicare-Advantage-Quality-Improvement-Program/5CCIP>.

<sup>7</sup> The EQRO aggregates results to allow for statewide interpretation. Results are shared back with MCPs to guide intervention through their performance improvement projects. For more information, see “Health Disparities Data as a Driver of Quality Improvement in Medi-Cal,” RWJF State Health Value Strategies. Feb. 2021. Available at <https://www.shvs.org/wp-content/uploads/2021/02/Analyzing-Health-Disparities-in-Medicaid-Managed-Care.pdf>.

<sup>8</sup> “California Advancing & Innovating Medi-Cal (CalAIM) Proposal,” DHCS. Jan. 2021. Available at <https://www.dhcs.ca.gov/provgovpart/Pages/CalAIM.aspx>.

<sup>9</sup> “Medicaid Managed Care Organization Model Contract,” State of Louisiana. Available at [https://ldh.la.gov/assets/medicaid/RFP\\_Documents/RFP3/AppendixB.pdf](https://ldh.la.gov/assets/medicaid/RFP_Documents/RFP3/AppendixB.pdf). (Accessed Mar. 2021)

<sup>10</sup> “Draft Attachment 7 to Covered California 2017 Individual Market QHP Issuer Contract: Quality, Network Management, Delivery System Standards and Improvement Strategy,” Covered California. Jan. 2021. Available at [https://hbex.coveredca.com/stakeholders/plan-management/library/Attachment-7-2022-Draft-Jan-2021\\_Clean.pdf](https://hbex.coveredca.com/stakeholders/plan-management/library/Attachment-7-2022-Draft-Jan-2021_Clean.pdf).

<sup>11</sup> Ibid.

<sup>12</sup> For example, Oregon’s All Payer All Claims database, which collects data across plans and lines of business, has race and ethnicity data missing for 59% and 72% of member records, respectively. “Data User Guide, 2011-2018 Claims & Insurance Coverage Release: APAC 2020,” Oregon Health Authority. May 2020. Available at <https://www.oregon.gov/oha/HPA/ANALYTICS/APAC%20Page%20Docs/APAC-Data-User-Guide.pdf>.

<sup>13</sup> Such information may be solicited at enrollment, during a health screening, or when a member is engaged in a care management program.

<sup>14</sup> Despite one plan’s concerted effort to maximize direct R/E data acquisition, the plan obtained R/E data for only a third of its members, emphasizing that while significant direct collection is possible, it may have upper limits. “Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement,” Institute of Medicine U.S. Subcommittee on Standardized Collection of Race/Ethnicity Data for Healthcare Quality Improvement. 2009. Available at <https://www.ncbi.nlm.nih.gov/books/NBK219747/>.

<sup>15</sup> “Patients’ Attitudes Toward Health Care Providers Collecting Information About Their Race and Ethnicity,” Journal of General Internal Medicine. Oct. 2005. Available at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1490236/>.

<sup>16</sup> CalPERS also aims to collect R/E information, although it has faced challenges from employees in attempting to do so, with only 9% of newly hired employees self-identifying their ethnicity. “CalPERS Demographics,” Sept. 2016. Available at <https://www.calpers.ca.gov/docs/board-agendas/201609/financeadmin/item-6a-02.pdf>.

- <sup>17</sup> During Q2 2020, nearly a third of newly Medi-Cal-eligible individuals did not report R/E information. “Race/Ethnicity of Newly Medi-Cal Eligible Individuals,” CHHS Open data. Available at <https://data.chhs.ca.gov/dataset/race-ethnicity-of-newly-medi-cal-eligible-individuals/resource/156a3a30-b86e-441a-bc9a-d4105a43df3c>. (Accessed Mar. 2021)
- <sup>18</sup> Covered California’s application is the same as Medi-Cal’s. See “Application for Health Insurance,” Covered California. Available at [https://www.dhcs.ca.gov/services/medi-cal/eligibility/Documents/2014\\_CoveredCA\\_Applications/ENG-CASingleStreamApp.pdf](https://www.dhcs.ca.gov/services/medi-cal/eligibility/Documents/2014_CoveredCA_Applications/ENG-CASingleStreamApp.pdf). (Accessed Mar. 2021)
- <sup>19</sup> “Covered California Holding Health Plans Accountable for Quality and Delivery System Reform,” Covered California. Dec. 2019. Available at [https://hbex.coveredca.com/data-research/library/CoveredCA\\_Holding\\_Plans\\_Accountable\\_Dec2019.pdf](https://hbex.coveredca.com/data-research/library/CoveredCA_Holding_Plans_Accountable_Dec2019.pdf).
- <sup>20</sup> Ibid.
- <sup>21</sup> “California Budget 2021-22, Budget Summary, Health and Human Services,” CA Governor’s Office. Jan. 2021. Available at <http://www.ebudget.ca.gov/2021-22/pdf/BudgetSummary/HealthandHumanServices.pdf>.
- <sup>22</sup> OMB Standards, OMB. Available at <https://orwh.od.nih.gov/toolkit/other-relevant-federal-policies/OMB-standards>. (Accessed Mar. 2021) “The Patient Protection and Affordable Care Act,” U.S. Congress. 2010. Available at <https://www.govinfo.gov/content/pkg/PLAW-111publ148/pdf/PLAW-111publ148.pdf>. ACA § 4302 requires the Department of Health and Human Services (HHS) to establish data standards for collecting ethnicity, race, sex, primary language, and disability status data. The HHS Office of Minority Health developed and finalized R/E data standards in partnership with the Census Bureau and OMB.
- <sup>23</sup> CDC Race and Ethnicity Code Set expands on and may be combined to match OMB standards. Available at <https://www.cdc.gov/phih/resources/vocabulary/documents/cdc-race--ethnicity-background-and-purpose.pdf>. LOINC codes are another commonly used race/ethnicity standard. Available at <https://loinc.org/46463-6#:~:text=LOINC%2046463%2D6%20E2%80%94%20Race%20or%20ethnicity%20%5BOASIS%5D>. (Accessed Mar. 2021)
- <sup>24</sup> As of November 2020, 57 organizations have been MHC certified. See “Plotting a Course to Address Disparities,” NCQA. Nov. 2020. Available at <https://www.ncqa.org/videos/plotting-a-course-to-address-disparities/>.
- <sup>25</sup> “Collection of Race and Ethnicity Data by Health Plans Has Grown Substantially, But Opportunities Remain To Expand Efforts,” Health Affairs. Oct. 2011. Available at <https://www.healthaffairs.org/doi/full/10.1377/hlthaff.2010.1117>.
- <sup>26</sup> One example is RAND Corporation’s Bayesian Improved Surname Geocoding (BISG) indirect estimation method, discussed at <https://www.rand.org/pubs/periodicals/health-quarterly/issues/v6/n1/16.html>. (Accessed Mar. 2021)
- <sup>27</sup> “Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement,” Institute of Medicine Subcommittee on Standardized Collection of Race/Ethnicity Data for Healthcare Quality Improvement. 2009. Available at <https://www.ncbi.nlm.nih.gov/books/NBK219747/>. (Accessed Mar. 2021)
- <sup>28</sup> “Race and Ethnicity Data Quality and Imputation Using U.S. Census Data in an Integrated Health System: The Kaiser Permanente Southern California Experience,” Medical Care Research and Review. 2012. Available at [https://www.researchgate.net/publication/233738822\\_Race\\_and\\_Ethnicity\\_Data\\_Quality\\_and\\_Imputation\\_Using\\_US\\_Census\\_Data\\_in\\_an\\_Integrated\\_Health\\_System\\_The\\_Kaiser\\_Permanente\\_Southern\\_California\\_Experience](https://www.researchgate.net/publication/233738822_Race_and_Ethnicity_Data_Quality_and_Imputation_Using_US_Census_Data_in_an_Integrated_Health_System_The_Kaiser_Permanente_Southern_California_Experience).
- <sup>29</sup> “Health Equity Data Analytics, Policy Recommendations,” CT Office of Health Strategy. Sept. 2020. Available at [https://portal.ct.gov/-/media/OHS/docs/HEDA-Recommendations\\_-Sept2020.pdf](https://portal.ct.gov/-/media/OHS/docs/HEDA-Recommendations_-Sept2020.pdf).
- <sup>30</sup> “Beyond Racial Bias: Rethinking Risk Stratification in Health Care,” Health Affairs. Jan. 2020. Available at <https://www.healthaffairs.org/doi/10.1377/hblog20200109.382726/full/>.
- <sup>31</sup> “Budget Change Proposal Annual Health Care Service Plan Health Equity and Quality Reviews (4150-022-BCP-2021-A1 and 4260-177-BCP-2021-A1),” State of California. Apr. 2021. Available at [https://esd.dof.ca.gov/Documents/bcp/2122/FY2122\\_ORG4150\\_BCP4552.pdf](https://esd.dof.ca.gov/Documents/bcp/2122/FY2122_ORG4150_BCP4552.pdf).
- <sup>32</sup> Plans and providers may also discuss whether a new data field (e.g., “R/E Source”) would be beneficial and may be instituted to allow for assessments of data reliability and member confirmation as the data is exchanged.
- <sup>33</sup> “Exploring Strategies to Fill Gaps in Medicaid Race, Ethnicity, and Language Data,” State Health & Value Strategies. Oct. 2020. Available at <https://www.shvs.org/exploring-strategies-to-fill-gaps-in-medicare-race-ethnicity-and-language-data/>.

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