Report to Congress: Improving Medicare Post-Acute Care Transformation (IMPACT) Act of 2014 Strategic Plan for Accessing Race and Ethnicity Data

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EXECUTIVE SUMMARY

As the U.S. health care system, and the Medicare program in particular, moves toward delivery system reform, understanding systematic differences in the quality of care is critical to developing policies that promote efficient and appropriate care delivery for all people. This transition will require a robust approach to defining and collecting information on race and ethnicity and other socio-economic factors to detect health and health care differences in a meaningful and actionable way.

Section (2)(d)(3) of the Improving Medicare Post-Acute Care Transformation Act of 2014 (the IMPACT Act), requires the Secretary[1] to develop and report to Congress on a strategic plan for collecting or otherwise accessing data on race and ethnicity. Subsections 1899B(c) and (d) of the Act additionally mandate that the data be used for purposes of specifying quality measures and resource use and other measures and, as the Secretary determines appropriate, for other similar provisions of, including payment adjustments under, the Medicare program.

This report to Congress is being submitted in fulfillment of the requirement of Section (2)(d)(3) of the IMPACT Act for a strategic plan for accessing race and ethnicity data. Specifically, this report first summarizes the principles and uniform data collection standards adopted by the U.S. Department of Health and Human Services (HHS) in response to section 4302 of the Patient Protection and Affordable Care Act (ACA).[2] This report then reviews current Medicare race and ethnicity data categories and sources and assesses these categories against the Office of Management and Budget 1997 standards, as well as the Section 4302 data standards promulgated for major population based surveys. In addition, this report reviews the literature on the validity of current race and ethnicity data sources in the Medicare program. In response to evidence of gaps and validity concerns with existing data sources, this report then outlines potential new options for collecting and using data on the race and ethnicity of Medicare beneficiaries. Some of these options would require new data collection efforts and, in some cases, may require Congressional action. For each option, this report presents information on whether the option would collect data on all or some and current or future beneficiaries, what race and ethnicity categories would be used, whether new data collection is required, and also notes any limitations and anticipated barriers to collecting or accessing the data.

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[1] References to "the Secretary" are to the Secretary of the U.S. Department of Health and Human Services.

[2] Section 4302(a) of the Affordable Care Act added section 3101 to the Public Health Service Act, which contains provisions to strengthen federal data collection efforts by requiring that any federal health care or public health data collection efforts include information on race, ethnicity, sex, primary language and disability status to the extent practicable.

1. INTRODUCTION: IMPROVING MEDICARE POST-ACUTE CARE TRANSFORMATION ACT OF 2014

The Improving Medicare Post-Acute Care Transformation Act of 2014 (the IMPACT Act) (Public Law 113-185), enacted on October 6, 2014, amended title XVIII of the Social Security Act by, among other things, adding section 1899B, which imposes new data reporting requirements on certain post-acute care (PAC) providers, including the reporting of data on quality and resource use and other measures (IMPACT Act measures). The IMPACT Act mandates that the Secretary of the Department of Health and Human Services (HHS) conduct a study that examines the effect of individuals' socioeconomic status on quality measures, resource use and other measures under the Medicare program. The goal of that study, currently underway with the Office of the Assistant Secretary for Planning and Evaluation, is: (1) to assess whether adjustments to Medicare's quality measures, resource use measures, and other measures are appropriate based on socioeconomic status and, if so, (2) to assess and implement appropriate adjustments to PAC and other Medicare payment systems to improve payment accuracy. A related section of the IMPACT Act (Section (2)(d)(3)) is concerned specifically with the collection of race and ethnicity data and is the focus of the remainder of this report:

> *STRATEGIC PLAN FOR ACCESSING RACE AND ETHNICITY DATA. Not later than 18 months after the date of the enactment of this Act, the Secretary shall develop and report to Congress on a strategic plan for collecting or otherwise accessing data on race and ethnicity for purposes of specifying quality measures and resource use and other measures under subsections (c) and (d) of section 1899B of the Social Security Act, as added by subsection (a), and, as the Secretary determines appropriate, other similar provisions of, including payment adjustments under, title XVIII of such Act (42 U.S.C. 1395 et seq.).*

This report to Congress complies with this section of the IMPACT Act by reporting on a strategic plan for collecting or otherwise accessing data on race and ethnicity for purposes of specifying IMPACT Act measures and, as the Secretary determines appropriate, other similar provisions under title XVIII. This report is organized into the following sections:

Section 2. HHS Collection Standards for Race and Ethnicity Data. This section describes current Office of Management and Budget Directive 15 federal data collection standards for race and ethnicity, Section 4302 Standards for collecting granular race and ethnicity data, and HHS data collection guidance on race and ethnicity for major population-based surveys and provides an approach to effectively assessing the quality of race and ethnicity data.

Section 3. Currently Available Data on Race and Ethnicity in the Medicare Program. This section reviews current CMS data sources based on the standards discussed in Section 2.

Section 4. Options for Improving Race and Ethnicity Data Collection in Medicare. This section discusses possible options for collecting data on race and ethnicity, from incremental to more sweeping approaches, for the purpose of specifying IMPACT Act measures and, as the Secretary determines appropriate, under other provisions of title XVIII.

Section 5. Strategic Plan Next Steps. This section discusses the CMS's process for advancing the strategic plan, evaluating the options, and developing the implementation plan to execute the selected option.

2. HHS COLLECTION STANDARDS FOR RACE AND ETHNICITY DATA

In 1977, the Office of Management and Budget (OMB), responding to legislative, program, and administrative needs, issued OMB Directive No. 15, *Race and Ethnic Standards for Federal Statistics and Administrative Reporting*. This Directive provided standard classifications for record keeping, collection, and presentation of data on race and ethnicity in Federal program administrative reporting and statistical activities (OMB 1977). Directive No. 15 was then revised in 1997 into the current *Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity.* The 1997 standards encouraged the collection of more granular and detailed race and ethnicity categories beyond the minimum reporting categories (OMB 1997). The revised standards expanded the minimum reporting categories for data on race from four to five: American Indian or Alaska Native, Asian, Black or African American, Native Hawaiian or Other Pacific Islander, and White. The standards established two categories for data on ethnicity: "Hispanic or Latino" and "Not Hispanic or Latino" (OMB 1997).

As the U.S. health care system, and CMS in particular, moves toward delivery system reform, understanding systematic differences in the quality of care is critical to developing policies that promote efficient and appropriate care delivery for all health care consumers across settings. This transition will require a robust approach to defining and collecting information on race and ethnicity and other socio-economic factors to detect health and health care differences in a meaningful and actionable way. Section 4302(a) of the Affordable Care Act added section 3101 to the Public Health Service Act (PHSA), which contains provisions to strengthen federal data collection efforts by requiring that any federal health care or public health data collection efforts include information on race, ethnicity, sex, primary language, and disability status to the extent practicable. In accordance with section 4302 of the ACA, CMS has received delegated program authority under Section 3101 of the PHSA to collect these data. Section 4302 as described in the legislation was to address any federally conducted or supported health care or public health program, activity, or survey. HHS's implementation of the Section 4302 Standards is currently limited to surveys conducted or sponsored by HHS. The HHS Data Council, charged with developing recommendations for the Section 4302 data standards for the Secretary to adopt, determined that data collected for clinical purposes and administrative data transactions each represent a different set of circumstances and would require a separate process to develop data standards. Thus, for the purposes of this report, the current OMB Directive 15 standards will be used for assessing the quality of the race and ethnicity data currently available through administrative data collections on Medicare beneficiaries. However, given the importance and opportunity afforded by having more granular data, for purposes of this report, the Section 4302 Standards will serve as a framework for consideration for future improvements for the race and ethnicity data currently available on Medicare beneficiaries.

To ensure uniformity among data collected, Section 4302 requires the Secretary of HHS to establish data collection standards for these data elements (HHS 2011). In response, the HHS Data Council promulgated a set of principles and uniform data collection standards for inclusion in surveys conducted or sponsored by HHS (see Figure 1). The race and ethnicity categories in the right-hand column of Figure 1 (referred to throughout this report as the *Section 4302 categories*) are based on the following principles articulated in the "Implementation Guidance on Data Collection Standards for Race, Ethnicity, Sex, Primary Language, and Disability Status" (HHS 2011):

- **Self-identification preferred:** Self-reporting or self-identification is the preferred means of obtaining information about an individual's race and ethnicity. The surveyor should not tell an individual who he or she is, or specify how an individual should classify himself or herself. In cases where self-reporting or self-identification is not feasible, then observer-collection is permitted (OMB 1997).

- **Separate questions for race and ethnicity:** To provide flexibility and ensure data quality, separate questions for race and ethnicity should be used wherever feasible. Specifically, when self-reporting or other self-identification approaches are used, ethnicity is asked first, and then race, with the caveat that this standard might not work in other contexts. Regarding this caveat, when self-reporting or self-identification is not practical or feasible, then a combined race/ethnicity question may be used for observer-collection. In this case, collecting both race and ethnicity shall be collected when appropriate and feasible; however, the collection of one category in the combined format is acceptable. In the case of a combined format, there are six minimum reporting categories: American Indian or Alaska Native, Asian, Black or African American, Hispanic or Latino, Native Hawaiian or Other Pacific Islander, and White (OMB 1997).

- **Granular categories:** Section 4302 categories are to be used except when the collection involves a sample of such size that the data for the smaller categories would be unreliable or when the collection effort focuses on a specific racial or ethnic group. Where the Section 4302 categories are not feasible for these reasons, the OMB 1997 categories (referred to throughout this report as the OMB 1997 categories) are to be used (OMB 1997). Figure 1 reveals the higher degree of granularity in the Section 4302 categories compared to the OMB 1997 categories.

Figure 1. Race and Ethnicity Data Standards: OMB 1997 vs. Section 4302

OMB 1997 Standards

- **Race**
  - White
  - Black
  - American Indian or Alaska Native
  - Asian
  - Native Hawaiian or Other Pacific Islander
- **Ethnicity**
  - Not Hispanic or Latino
  - Hispanic or Latino

Section 4302 Standards

- **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
  - Mexican
  - Puerto Rican
  - Cuban
  - Another Hispanic origin

Source: Implementation Guidance on Data Collection Standards for Race, Ethnicity, Sex, Primary Language, and Disability Status. October 2011. http://aspe.hhs.gov/datacncl/standards/ACA/4302/index.shtml

Note: 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.

- **Choice of more than one race:** When self-reporting or other self-identification approaches are used, respondents who wish to identify their multi-racial heritage may choose more than one race; there is no "multi-racial" category.

- **Additional granularity encouraged where supported:** OMB encourages additional granularity where it is supported by sample size and as long as the additional detail can be aggregated back to the minimum standard set of race and ethnicity categories (OMB 1997). Mexican, Puerto Rican, Cuban, and Another Hispanic Origin roll up to the Hispanic or Latino category of the OMB 1997 standards. Asian Indian, Chinese, Filipino, Korean, Vietnamese, and Other Asian roll up into the Asian category of the OMB 1997 standards. Native Hawaiian, Guamanian or Chamorro, Samoan, and Other Pacific Islander roll up to the Native Hawaiian or Other Pacific Islander category of the OMB 1997 standards.

- **OMB should authorize deviation:** Any other variation will have to be specifically authorized by the OMB through the Paperwork Reduction Act (PRA) clearance process. Paperwork Reduction Act (PRA) clearance is the term used for the process of obtaining approval from the Office of Management and Budget (OMB) for federally sponsored data collections as required by the PRA. In those cases where the data collection is not subject to the information collection clearance process, a direct request for a variance should be made to OMB.

The ACA requires that these data collection standards be used in all national, population-based health surveys to allow for the examination of health and health care disparities.

3. CURRENTLY AVAILABLE DATA ON RACE AND ETHNICITY IN THE MEDICARE PROGRAM

An important first step in developing a plan for accessing or collecting data on race and ethnicity of Medicare beneficiaries, as required by the statute, is to review the existing sources of these data as well as any evidence of the data's reliability. This section examines beneficiary-level race and ethnicity data definitions in the Medicare program from the following sources: the Enrollment Database (EDB), Medicare beneficiary surveys, Post-Acute Care (PAC) assessment instruments, and Consolidated Renal Operations in a Web-enabled Network (CROWNWeb). This section includes a description of the circumstances under which the data are collected, the specific data collected, and the method of collection, the extent to which the race and ethnicity data in these sources conform to the OMB or Section 4302 standards, and evidence about the validity of these sources. It should be noted that data on race and ethnicity is not used in any way to determine Medicare eligibility or benefits; in addition, those reporting race and ethnicity data are prohibited from discriminating against patients and or beneficiaries on the basis of race or ethnicity in the delivery of care.

A. Beneficiary race and ethnicity data in the Medicare Enrollment Database have documented validity issues and do not comply with Section 4302 standards

The EDB is the CMS database of record for all Medicare beneficiaries' enrollment information, including race. Despite several changes over time, the validity of the EDB's race data has plateaued (McBean 2004). Several studies have found that the EDB may misclassify race or ethnicity or both, particularly for groups other than Black and White. In addition, the data source that populates the EDB does not allow beneficiaries to indicate multiple races or ethnicities and the extent to which the data are self-reported or proxy reported is unknown. Changes in the EDB data over time and findings from validation study literature are described in more detail below.[3]

While CMS maintains the EDB, the race and ethnicity data populating this source is primarily generated by the Social Security Administration's (SSA) Master Beneficiary Record file and Numerical Identification file. The SS-5, an administrative form used to apply for a Social Security number, a replacement Social Security card, or to change the personal information listed on a Social Security card, is the tool used to collect SSA's data on race and ethnicity. SSA's race and ethnicity data are limited in many ways, resulting from numerous form changes and limited information on people born after 1989 (discussed below). Several studies suggest that the validity of race and ethnicity data is highest among categories that have remained consistent and lowest among categories that have changed or been added (Arday et al. 2000; Waldo 2004; Zaslavsky et al. 2012). Because CMS receives its race and ethnicity data from the SSA, these limitations have translated into wide variations in accuracy and validity across different racial and ethnic categories within CMS's data records.

From 1936 to 1980, the SS-5 provided only three options for race: White, Negro, and Other (McBean 2006). Persons who did not answer the race question were coded as Unknown. In 1977, the OMB Federal Directive 15 set the minimum classifications required for federal government

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[3] The text in this section was used and adapted from an untitled and unpublished CMS manuscript validating the data in the EDB.

reporting of race and ethnicity. OMB recommended collecting data on race and ethnicity separately and specified minimum race designations as American Indian or Alaska Native, Asian or Pacific Islander, Black, or White. It also recommended the ethnicity designations of Hispanic origin or not of Hispanic origin (Centers for Disease Control and Prevention 2015). In 1980, SSA expanded the SS-5 categories to comply with the OMB's directive. The new categories included: White; Black; Hispanic; Asian, Asian American or Pacific Islander; American Indian or Alaska Native (McBean 2006; Scott 1999). Although this updated version expanded the racial and ethnic categories available to beneficiaries, SSA did not restructure the Master Beneficiary Record to accommodate these new choices until 1982, with most responses collapsed into one of the four original categories, such as categorizing Hispanics as Other (Lauderdale and Goldberg 1996; Arday et al. 2000; McBean 2006).

Later, SSA also made changes to the required process for obtaining a Social Security number (SSN). Beginning in 1989, SSA began to automatically assign SSNs at birth, eliminating the need for most people to complete the SS-5 form. Before this change, all persons were required to complete the form to receive a SSN; after this change, only persons who needed to replace a lost or stolen card or change an applicant's name were required to complete the form. As a result, the SSA has not directly collected race or ethnicity data from the majority of individuals born after 1989. Even for those to whom the SS-5 was administered, completeness remains an issue because race and ethnicity are optional fields on the form. A large number of individuals are thus designated with "Unknown" as their race within SSA and CMS data. Figure 2 summarizes the race and ethnicity categories for Medicare beneficiaries in the EDB, by year of birth.

Figure 2. EDB Race and Ethnicity Categories by Year of Birth

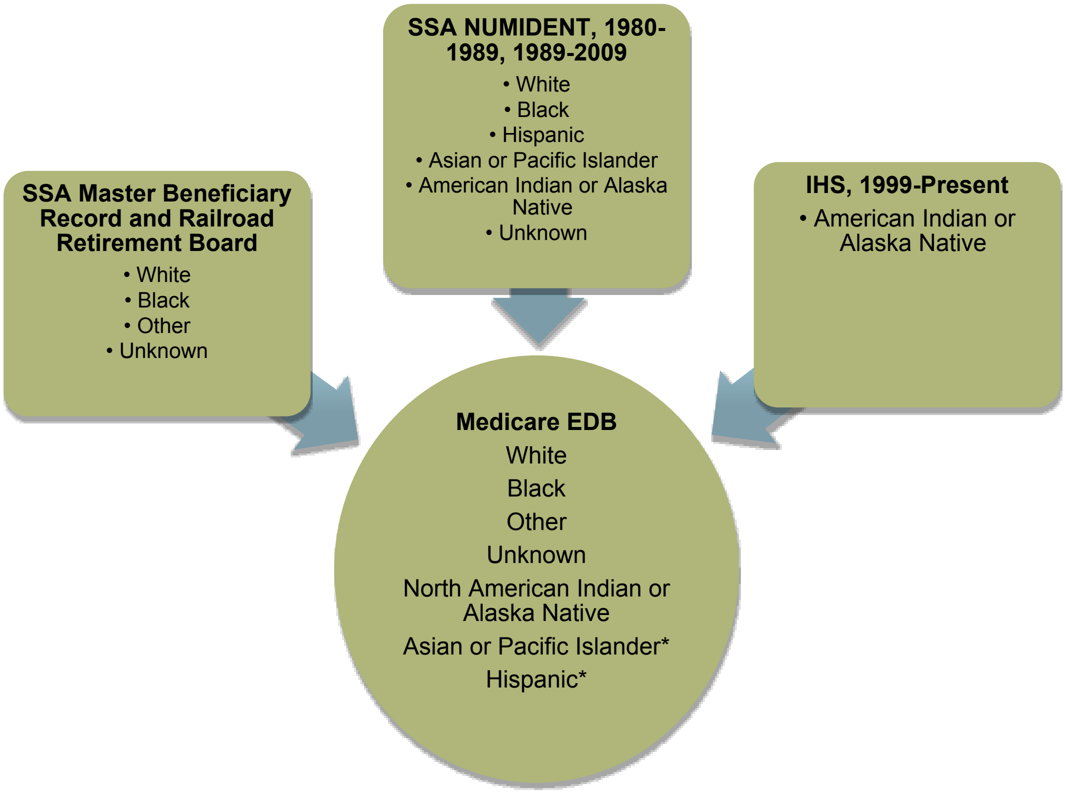
Birth year 1936-1982	Birth year 1983-1989	Birth year 1990-
• White • Negro • Other • Unknown	• White • Black • Asian, Asian American, Pacific Islander • North American Indian or Alaska Native • Hispanic	• No race or ethnicity data being added to the EDB

Source: CMS Office of Minority Health

CMS's records on Medicare beneficiaries only began adhering to SSA's changes to the five OMB categories in 1994, when CMS first integrated the expanded racial and ethnic categories into the EDB using the SSA's Numerical Identification file. At that time, the agency incorporated the expanded race and ethnicity data for approximately 35 million Medicare beneficiaries (McBean 2006). CMS conducted another substantial update of its data in 1997, when the agency mailed surveys to all beneficiaries classified as Unknown or Other, those with Hispanic surnames, or those reporting a Hispanic country of birth (Arday et al. 2000). This spanned 2.2 million people, with approximately 858,000 responding. The survey responses decreased persons classified as other race by 55 percent and those classified as Unknown by 34 percent. Individuals identifying as Asian increased by 136 percent, Hispanic ethnicity by 109 percent, and American Indian or Alaska

Native by 68 percent (McBean 2006). In 1999, the Indian Health Service also began providing CMS with information on the people it serves, increasing the number of beneficiaries classified as American Indian or Alaska Natives from 54,000 in 1999 to 152,000 in 2003 (a 181 percent increase). Since 2000, CMS has performed an annual update of race and ethnicity data using information from new SS-5 forms submitted to the SSA. The different data sources that have been used to populate the EDB over time and the race and ethnicity categories in each source are shown in Figure 3.

Figure 3. Medicare EDB Source Data: Race and Ethnicity Data Categories Over Time



Source: CMS Office of Minority Health

*Note: *Data for these categories are only available through the numerical identification system (NUMIDENT), and only for individuals requesting a replacement card, or filing for a new card.*

After demonstrating low sensitivity between beneficiaries coded as Hispanic or Asian/Pacific Islanders in the EDB and the self-reported race and ethnicity in their responses to the Consumer Assessments of Healthcare Providers and Systems (CAHPS), Eicheldinger and Bonito (2008) developed an algorithm by which to improve the accuracy of race and ethnicity data using several beneficiary-level data elements and characteristics. These included: beneficiary language preference for the Medicare Handbook, beneficiary language preference for beneficiary notices, source of beneficiary's EDB race and ethnicity codes, state of residence, and surname lists from the U.S. Census Bureau. The algorithm resulted in increased sensitivity and a large number of beneficiaries being recoded as Hispanic (2.2 million) or as Asian or Pacific Islander (0.3 million). This work developed into what is referred to as the RTI Race Code variable, which is currently available in the Master Beneficiary Summary File (MBSF), an annual file of all Medicare beneficiaries eligible for a given calendar year and is commonly used by researchers as the source for demographic information for beneficiaries eligible in the file year. The MBSF is available for years beginning in calendar year 1999. The Base A/B/D segment of the MBSF contains two race variables: RACE and RTI_RACE_CD.[4] As shown in Table 1, the two race variables in the MBSF result in different distributions of beneficiaries' race and ethnicity.

Table 1. Percentage Distribution of Medicare Enrollees by Race: MBSF Race Code versus RTI Race Code, 2008

Category	Share of beneficiaries by MBSF Race Code	Share of beneficiaries by RTI Race Code
White	83.11%	77.64%
Black	10.12%	9.77%
Hispanic	2.49%	7.80%
Asian (MBSF Race)/ Asian/Pacific Islander (RTI Race)	1.86%	2.43%
North American Native (MBSF Race)/ American Indian/Alaska Native (RTI Race)	0.43%	0.42%
Other	1.84%	1.19%

Note: The data source did not include the share of beneficiaries categorized as "Unknown" though both variables include that category.

Source: Marshall McBean, M.D., M.Sc., Principle Investigator and Director, ResDAC, The Medicare Master Beneficiary Summary File: The Old and New Information it Contains, Available at http://www.resdac.org/sites/resdac.org/files/The%20Medicare%20Master%20Beneficiary%20Summary%20File%20-%20Information%20It%20Contains%20%28Slides%29.pdf, accessed on October 12, 2015.

A timeline summarizing key changes to the EDB's race and ethnicity data collection are shown in Figure 4.

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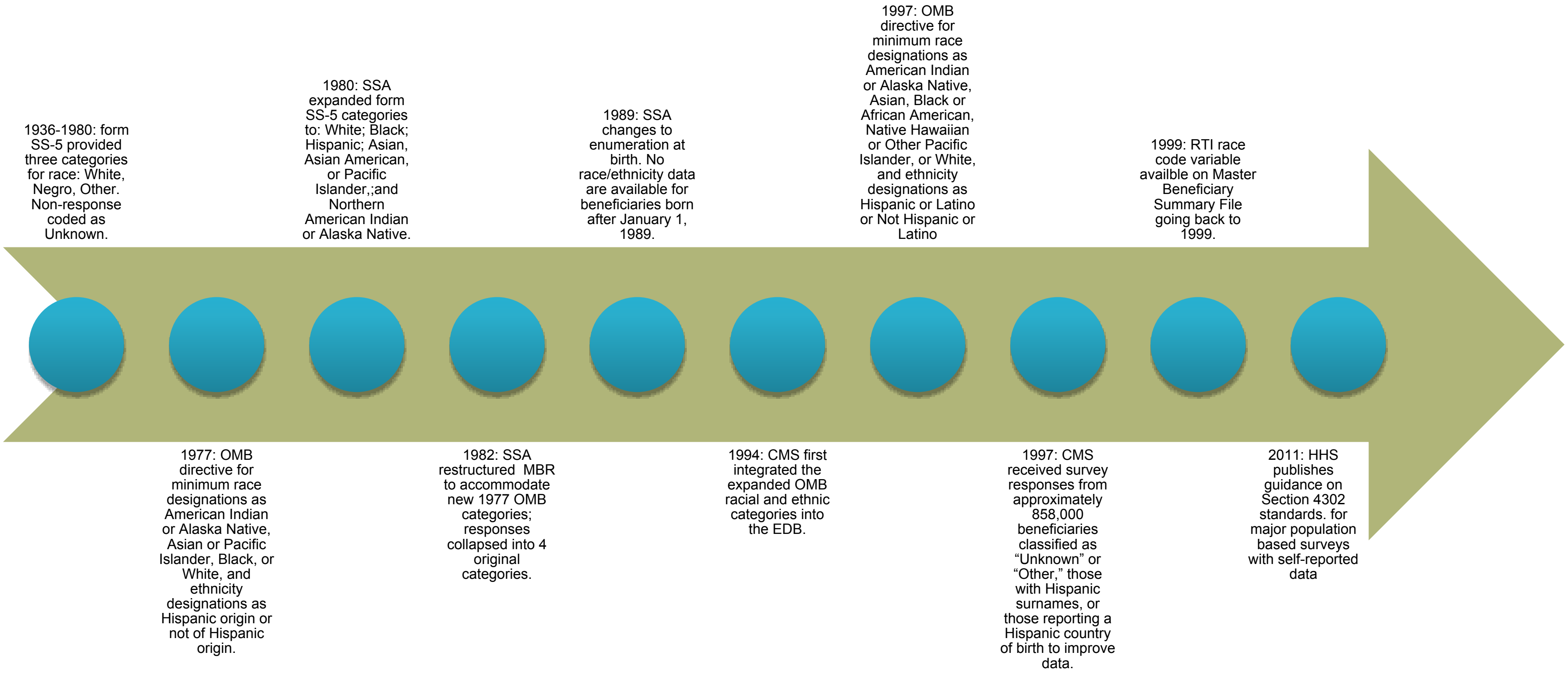
[4] The values for the RACE variable, derived from the EDB, are Unknown, White, Black, Other, Asian, Hispanic, and North American Native. The values for RTI_RACE_CD are Unknown; Non-Hispanic White; Black (or African American); Other; Asian or Pacific Islander; Hispanic; or American Indian or Alaska Native (ResDAC). This variable is created by taking the beneficiary race code historically used by the SSA, and in turn used in the EDB, and applying an algorithm that identifies more beneficiaries as Hispanic or Asian. The algorithm classifies beneficiaries as Hispanic or Asian if their SSA race code equals Asian or Hispanic, or if they have a first or last name that RTI determined was likely Hispanic or Asian in origin.

Figure 4. EDB Race and Ethnicity Data Collection Timeline, 1936-2011



1936-1980: form SS-5 provided three categories for race: White, Negro, Other. Non-response coded as Unknown.

1977: OMB directive for minimum race designations as American Indian or Alaska Native, Asian or Pacific Islander, Black, or White, and ethnicity designations as Hispanic origin or not of Hispanic origin.

1980: SSA expanded form SS-5 categories to: White; Black; Hispanic; Asian, Asian American, or Pacific Islander,;and Northern American Indian or Alaska Native.

1982: SSA restructured MBR to accommodate new 1977 OMB categories; responses collapsed into 4 original categories.

1989: SSA changes to enumeration at birth. No race/ethnicity data are available for beneficiaries born after January 1, 1989.

1994: CMS first integrated the expanded OMB racial and ethnic categories into the EDB.

1997: OMB directive for minimum race designations as American Indian or Alaska Native, Asian, Black or African American, Native Hawaiian or Other Pacific Islander, or White, and ethnicity designations as Hispanic or Latino or Not Hispanic or Latino

1997: CMS received survey responses from approximately 858,000 beneficiaries classified as “Unknown” or “Other,” those with Hispanic surnames, or those reporting a Hispanic country of birth to improve data.

1999: RTI race code variable availble on Master Beneficiary Summary File going back to 1999.

2011: HHS publishes guidance on Section 4302 standards. for major population based surveys with self-reported data

Notes: EDB (Enrollment Database), OMB (Office of Management and Budget), SSA (Social Security Administration), MBR (Master Beneficiary Record), CMS (Center for Medicare & Medicaid Services, HHS (Department of Health and Human Services).

Evidence from Studies of the EDB Suggests High Validity for Blacks and Whites, but not for Other Groups

Numerous researchers have attempted to validate the accuracy of Medicare's race and ethnicity data in the EDB. Taken together, this research suggests that the EDB performs well in identifying beneficiaries as White or Black but performs poorly in identifying other groups. Comparing a sample of the EDB to Census projections and SSA records regarding country of birth, Lauderdale and Goldberg (1996) found that the EDB significantly undercounted Hispanics, American Indians and Alaska Natives, and Asians. Conversely, the study found that coding for Whites and Blacks was relatively accurate. Conducting a similar comparison between the EDB and the Medicare Current Beneficiary Survey (MCBS), an ongoing, representative sample of Medicare beneficiaries including self-reported race, both Arday et al. (2000) and Waldo (2004) found that while data has improved over time, only Whites and Blacks are correctly classified, with poor agreement between the datasets for other minority groups. In a more recent analysis, Zaslavsky et al. (2012) compared the EDB to data from the Medicare CAHPS survey, finding that Medicare enrollment data under-identifies Hispanics, Asians, Pacific Islanders, and American Indians and Alaska Natives. In summary, evidence shows that that the EDB performs well in identifying beneficiaries as White or Black but performs poorly in identifying other groups (Arday et al. 2000; Waldo 2004; Zaslavsky et al. 2012).

In addition to validity concerns, the EDB does not conform to OMB standards as shown in Figure 5. Specifically, Native Hawaiian or Other Pacific Islander is combined with Asian. The EDB data do not distinguish between race and ethnicity, per the OMB 1997, as CMS's data do not allow beneficiaries to report both a race and an ethnicity. Instead, each Medicare beneficiary is assigned a race *or* an ethnicity, which greatly limits CMS's ability to accurately categorize racial and ethnic minorities. Furthermore, it limits CMS's ability to understand the health and access needs of its beneficiaries (Census 2012b; Frey 2014). Importantly, and contrary to the OMB and Section 4302 standards, the EDB and derivative files do not capture data for multiracial or multiethnic identities, allowing instead for only one race or ethnicity. This limitation will be increasingly consequential, as the 2010 Census documented that people reporting multiracial identities grew by a larger percentage than those reporting a single race—a 32 percent increase between 2000 and 2010 (Census 2012a). As a result, the errors associated with the EDB's inability to capture these groups will only increase.

Figure 5. Medicare EDB Compared to OMB 1997 and Section 4302 Standards

Medicare EDB

- **Race**
  - White
  - Black
  - American Indian or Alaska Native*
  - Asian or Pacific Islander*
  - Hispanic*
  - Other
  - Unknown

OMB 1997 Standards**

- **Race**
  - White
  - Black
  - American Indian or Alaska Native
  - Asian
  - Native Hawaiian or Other Pacific Islander
- **Ethnicity**
  - Not Hispanic or Latino
  - Hispanic or Latino

Section 4302 Standards

- **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
  - Mexican
  - Puerto Rican
  - Cuban
  - Another Hispanic origin

Source: CMS Office of Minority Health

*Note: *Data for these categories are only available through NUMIDENT, and only for individuals requesting a replacement card, or filing for a new card. **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.*

B. More granular race and ethnicity data are collected on surveys, but only for a subset of beneficiaries

This subsection briefly reviews the background, scope, and modality of three different surveys of Medicare beneficiaries: (1) the Medicare Current Beneficiary Survey (MCBS), (2) the Health Outcomes Survey (HOS), and (3) the Consumer Assessment of Healthcare Providers and Systems (CAHPS), and summarizes the race and ethnicity data collected on those surveys.

- The MCBS is a continuous, multipurpose survey of a nationally representative sample of Medicare beneficiaries, conducted annually by CMS since 1991. Although the sample size has changed from year to year, recent surveys have included approximately 15,000 Medicare beneficiaries in a given year (CMS Office of Enterprise Management 2014). A trained interviewer conducts the survey either at the participant's home or a facility, if the beneficiary resides in the facility.

- The HOS is a self-reported health outcomes survey used in managed care settings. Its primary goals are to monitor activities of managed care organizations and to improve the quality of health care. The HOS is a mailed survey with telephone follow-up to beneficiaries. The survey provides instructions for the beneficiary to answer the survey questions or for a family member to proxy-report if necessary. The sample sizes and response rates vary from year to year. For the survey fielded in 2014, a sample of 575,422 beneficiaries yielded 261,638 completed surveys (Medicare Health Outcomes Survey).

- The CAHPS survey of Medicare beneficiaries enrolled in Medicare health plans was first conducted in 1998; a fee-for-service (FFS) version began in 2001. Both surveys are conducted by mail, telephone, or a combination, to gather information from Medicare beneficiaries on experiences with their health providers and health plans. The beneficiary is expected to complete the survey on his/her own, but the survey includes questions asking if anyone helped the beneficiary and how that person helped. The FFS survey targets a sample of approximately 275,000 beneficiaries annually. The sample size for the MA & PDP CAHPS Survey was 837,817 in 2014. For many of the setting-specific CAHPS surveys, CMS has de-identified data, but the In-Center Hemodialysis CAHPS has identifiable data available.

As summarized in Table 2, the race and ethnicity data collected on the MCBS and the HOS align with Section 4302 categories, while the CAHPS surveys align with the OMB 1997 categories. All three surveys ask separate questions about Hispanic or Latino origin or descent and all are beneficiary-level data, self- or proxy- reported, and allow for multiple responses. While these surveys yield race and ethnicity data that are aligned with the Section 4302 standards, they are only available for a small subset of surveyed beneficiaries. For example, the MCBS samples about 15,000 beneficiaries annually, and represents a fraction of the 53.8 million Medicare beneficiaries in 2014 (Trustees' Report 2015). Even the relatively larger sample of 275,000 beneficiaries in FFS CAHPS, represents only about 0.5 percent of beneficiaries annually.

Table 2. Summary of Medicare Beneficiary Surveys' Race and Ethnicity Data

Data Source	Race question/categories *	Separate Hispanic/Latino(a)/Spanish origin question(s)/categories	Year data collection began
Medicare Current Beneficiary Survey (MCBS)	Q: Looking at this card, what is your race? 1. American Indian or Alaska Native 2. Asian 3. Black or African American 4. Native Hawaiian or Other Pacific Islander 5. White 6. Some other race Q: (If Asian) Looking at this card, are you Asian Indian, Chinese, Filipino, Japanese, Korean, Vietnamese, or some other Asian group?** 1. Asian Indian 2. Chinese	Q: Are you of Hispanic, (Latino/Latina), or Spanish origin? 1. Yes 2. No Q: Looking at this card, are you Mexican, Mexican American, or (Chicano/Chicana), Puerto Rican, Cuban, or of another Hispanic, (Latino/Latina) or Spanish origin? 1. Mexican/Mexican American/Chicano(a) 2. Puerto Rican 3. Cuban 4. Other Hispanic, Latino(a), or Spanish origin	1991

Data Source	Race question/categories *	Separate Hispanic/Latino(a)/Spanish origin question(s)/categories	Year data collection began
	3. Filipino 4. Japanese 5. Korean 6. Vietnamese 7. Other Asian Group Q: (If Native Hawaiian or Other Pacific Islander) Looking at this card, are you Native Hawaiian, Guamanian or Chamorro, Samoan, or some other Pacific Islander group?** 1. Native Hawaiian 2. Guamanian or Chamorro 3. Samoan 4. Other Pacific Islander		
Medicare Advantage and Prescription Drug Plan Consumer Assessment of Healthcare Providers & Systems (CAHPS) Survey	Q: What is your race? Please mark one or more. 1. White 2. Black or African American 3. Asian 4. Native Hawaiian or other Pacific Islander 5. American Indian or Alaska Native	Q: Are you of Hispanic or Latino origin or descent? 1. Yes, Hispanic or Latino 2. No, not Hispanic or Latino	1998 health plan/2007 drug plan
Fee-for-service Medicare Consumer Assessment of Healthcare Providers & Systems (CAHPS) Survey	Q: What is your race? Please mark one or more. 1. White 2. Black or African American 3. Asian 4. Native Hawaiian or Other Pacific Islander 5. American Indian or Alaska Native	Q: Are you of Hispanic or Latino origin or descent? 1. Yes, Hispanic or Latino 2. No, not Hispanic or Latino	2001
Medicare In-Center Hemodialysis CAHPS***	Q: What is your race? (One or more categories may be selected.) 1. White 2. Black or African American	Q: Are you of Spanish, Hispanic, or Latino origin or descent? 1. No, not Spanish/Hispanic/ Latino 2. Yes, Puerto Rican	2014

Data Source	Race question/categories *	Separate Hispanic/Latino(a)/Spanish origin question(s)/categories	Year data collection began
	3. American Indian or Alaska Native 4. Asian Indian 5. Chinese 6. Filipino 7. Japanese 8. Korean 9. Vietnamese 10. Other Asian 11. Native Hawaiian 12. Guamanian or Chamorro 13. Samoan 14. Other Pacific Islander	3. Yes, Mexican, Mexican American, Chicano 4. Yes, Cuban 5. Yes, other Spanish/Hispanic/ Latino	
Health Outcome Survey (HOS)	Q: What is your race? (One or more categories may be selected)**** 1. White 2. Black or African American 3. American Indian or Alaska Native 4. Asian Indian 5. Chinese 6. Filipino 7. Japanese 8. Korean 9. Vietnamese 10. Other Asian 11. Native Hawaiian 12. Guamanian or Chamorro 13. Samoan 14. Other Pacific Islander	Q: Are you Hispanic, Latino/a or Spanish Origin? (One or more categories may be selected) 1. No, not of Hispanic, Latino/a or Spanish origin 2. Yes, Mexican, Mexican American, Chicano/a 3. Yes, Puerto Rican 4. Yes, Cuban 5. Yes, Another Hispanic, Latino/a or Spanish origin	1998

**Respondents can choose all that apply.*

***CMS updated the race/ethnicity items on the MCBS in 2013. However, since these items are only asked of the supplemental sample, it will take until 2016 to have information on the full sample.*

****For many of the setting-specific CAHPS surveys, CMS has de-identified data, but the In-Center Hemodialysis CAHPS has identifiable data available.*

*****Since April 2013, the HOS has collected measures of race, ethnicity, sex, primary language, and disability status in accordance with the standards established by the Affordable Care Act §4302. These newly expanded demographic measures, combined with the self-reported health status measures captured by the HOS, provide a rich source of data that may be useful for research on Asian American and Pacific Islander populations. In the 2014 Cohort 17 Baseline survey, there were 8,445 Asian and 1,048 NHOPI respondents. See http://www.hosonline.org/globalassets/hos-online/newsletters/summer-2015.pdf*

Sources: 2013 Medicare Beneficiary Survey Questionnaire. Retrieved from: https://www.cms.gov/Research-Statistics-Data-and-Systems/Research/MCBS/Questionnaires.html; 2016 Medicare Advantage Prescription Drug Survey. Retrieved from: http://www.ma-pdpcahps.org/Documents/2016_Medicare_Advantage_Prescription_Drug_(MA_PD)_English_Mail_Survey.pdf;

Fee-for-service Medicare Consumer Assessment of Healthcare Providers & Systems Survey. Retrieved from: https://www.cms.gov/Research-Statistics-Data-and-Systems/Research/CAHPS/Downloads/FFS-CAHPS-Survey-English.PDF; In-Center Hemodialysis CAHPS Survey, English Questionnaire, Standard Version. Retrieved from https://ichcahps.org/SurveyandProtocols/SurveyMaterials.aspx#catid2. 2015 Medicare Health Outcomes Survey Instrument 3.0. Retrieved from: http://www.hosonline.org/globalassets/hos-online/survey-instruments/hos_2015_survey.pdf

C. Race and ethnicity data are collected on post-acute care (PAC) assessment instruments, but data are available only for users of PAC and validity has not been tested

Race and ethnicity data are currently collected on the different assessment instruments administered in four of the Medicare PAC settings (see Table 3).[5] These assessment instruments are the Minimum Data Set (MDS), used in skilled nursing facilities (SNFs); the Outcome and Assessment Information Set (OASIS), used for home health services; the Inpatient Rehabilitation Facility Patient Assessment Instrument (IRF-PAI); and the Long-Term Care Hospital (LTCH) Continuity Assessment Record & Evaluation (CARE) Data Set. The primary purpose of the PAC assessment instruments is to capture the person's clinical condition(s) and functional status, as Medicare uses this information to adjust its payments and assess quality of care.

Each assessment instrument collects beneficiary-level demographic information, including race and ethnicity. The current question about race on each instrument asks for beneficiary self-report and is standardized across the MDS, OASIS, IRF-PAI, and CARE as shown in Table 3. Respondents may select one or more of the following response categories that conform to the OMB 1997 standards: American Indian or Alaska Native; Asian; Black or African American; Hispanic or Latino; Native Hawaiian or Other Pacific Islander; and/or White. The PAC assessment instruments provide respondents with clear descriptions of each category. The instruments do not ask separate race and ethnicity questions, though a respondent may select all that apply.

On all PAC assessment instruments, the race and ethnicity questions are asked when the beneficiary is first admitted to the PAC setting and may be repeated in subsequent assessments.[6] If an individual is incapable of responding, the setting coordinator (e.g., administrator, nurse, therapist, etc.) will retrieve that information from medical and other records or ask a spouse or a close relative to report. Given that some Medicare beneficiaries who use PAC services are unable to respond to the assessor, it is likely that some of these responses are completed without their input. Further, the source of the data—self-report or proxy—is not recorded on the assessment. As the primary purpose of the assessment instruments is to collect clinical information, field training in administering the assessment tools generally focuses on sections unrelated to race and ethnicity. It is unclear whether the race data collected in the PAC assessment instruments have been validated

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[5] The Hospice Item Set (HIS), implemented on July 1, 2104, is collected and submitted on all patient admissions and discharges. The HIS is a standardized tool for abstracting data from the clinical record. As such, it is not a patient assessment tool and is not administered directly to the patient and/or family and/or caregivers. There is a field for race data that can be populated with clinical record data or observer identification if there is nothing in the record (see https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/Hospice-Quality-Reporting/Downloads/HIS-Training-Slides.pdf). For additional information about the HIS and the difference between an item set and an assessment instrument see https://www.cms.gov/medicare/quality-initiatives-patient-assessment-instruments/hospice-quality-reporting/downloads/his-fact-sheet.pdf

[6] For example, the LTCH CARE Data Set asks the same race and ethnicity question at admission, patient expiration, planned discharge, and unplanned discharge.

against other sources of data and for completeness. In addition, only a portion (14 percent in 2010) of the Medicare population receives PAC care in any given year. Therefore, this is not a comprehensive source of race and ethnicity data for beneficiaries (CMS 2012).

Table 3. Summary of PAC Assessment Instruments' Race and Ethnicity Data

Data Source	Race question/categories *	Separate Hispanic/Latino(a)/Spanish origin question(s)/categories	Year data collection began
Minimum Data Set (MDS)	Q: Race/Ethnicity (Check all that apply) 1. American Indian or Alaska Native 2. Asian 3. Black or African American 4. Hispanic or Latino 5. Native Hawaiian or Other Pacific Islander 6. White	No separate Hispanic/Latino(a)/Spanish origin question/categories	1998
Outcome and Assessment Information Set (OASIS)	Same as MDS	No separate Hispanic/Latino(a)/Spanish origin question/categories	1999
Inpatient Rehabilitation Facility Patient Assessment Instrument (IRF-PAI)	Same as MDS	No separate Hispanic/Latino(a)/Spanish origin question/categories	2002
Long-Term Care Hospital Continuity Assessment Record & Evaluation (CARE) Data Set	Same as MDS	No separate Hispanic/Latino(a)/Spanish origin question/categories	2014

**Respondents can choose all that apply.*

Sources: Minimum Data Set Version 3.0 Resident Assessment and Care Screening. Retrieved from: https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/NursingHomeQualityInits/Downloads/Draft-of-the-MDS-30-Nursing-Home-Comprehensive-NC-Version-1140.pdf; Outcome and Assessment Information Set-C1/ ICD-10 Version Guidance Manual. Retrieved from: https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/HomeHealthQualityInits/HHQIOASISUserManual.html; Inpatient Rehabilitation Facility Patient Assessment Instrument Version 1.4. Retrieved from: https://www.cms.gov/Medicare/Medicare-Fee-for-Service-Payment/InpatientRehabFacPPS/Downloads/IRF-PAI-Version-1-4.pdf; Long-Term Care Hospital Continuity Assessment Record & Evaluation (CARE) Data Set Version 2.01. Retrieved from https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/LTCH-Quality-Reporting/Downloads/2013-LTCH-QR-Program-Manual-v20-Final.zip (Appendix C).

D. Race and ethnicity data are available for the small percentage of Medicare end stage renal disease beneficiaries, but the extent to which the data are self-reported is unclear

An additional source of race and ethnicity information exists for beneficiaries with end stage renal disease (ESRD) who have had a dialysis treatment. Renal providers collect this information on CMS Form 2728 (OMB #0938-0046), which is used to establish Medicare eligibility for individuals who are new to Medicare, reclassify current Medicare beneficiaries as ESRD patients, and collect demographic and diagnostic information on all new ESRD patients, regardless of their Medicare entitlement.

Data from Form 2728, also known as the Medical Evidence report, is housed in CROWNWeb, a CMS-mandated, Web-based data collection system launched in June 2012 that provides dialysis facilities with a means of electronically reporting patient treatment summaries, activity reports, CMS forms such as the 2728, and monthly clinical data to CMS in real time. While Form 2728 has been revised over the past 20 years to include different race and ethnicity question formats, the most current version (CMS-2728-U3 dated August 2015 and effective October 1, 2015) asks for a self-report to indicate all of the following applicable racial categories: White, Black or African American, American Indian/Alaska Native, Asian, Native Hawaiian or Other Pacific Islander (see Table 4), The ethnicity field includes two response categories: Not Hispanic or Latino, and Hispanic or Latino. Further, country of origin is requested for those selecting Hispanic or Latino ethnicity, or the Native Hawaiian or Other Pacific Islander racial category. The CROWNWeb Form 2728 training module notes that the race and ethnicity fields are required elements for the form to be considered complete, but the country of origin detail is optional.[7] However, the module also notes that the race and ethnicity fields are prepopulated from a patient's record and does not specify the source data, whether the source data is self-reported, or whether the source(s) utilize categories that conform to what is on the 2728 form.

Though a potential source of more granular race and ethnicity data, the Form 2728 information on the CROWNWeb is available for a small segment (less than one percent) of the Medicare population and it remains unclear whether the data in the CROWNWeb system are reflective of a patient's self-report or are drawn from another patient record source of unknown race or ethnicity response categories.

Table 4. CROWNWeb's Race and Ethnicity Data

Data Source	Race question/categories *	Separate Hispanic/Latino(a)/Spanish origin question(s)/categories	Year data collection began
CROWNWeb	Q: Race (Check all that apply) 1. White 2. Black or African American 3. American Indian/Alaska Native (Print Name of Enrolled/Principal Tribe __________________) 4. Asian 5. Native Hawaiian or Other Pacific Islander*	Q: Ethnicity 1. Hispanic or Latino 2. Not Hispanic or Latino	2012

**If categories are selected, respondents are directed to a separate question that asks Country/Area of Origin or Ancestry.*

Source: 2014 End Stage Renal Disease Medical Evidence Report Medicare Entitlement And/Or Patient Registration Form. Retrieved from: http://www.usrds.org/2015/appx/4/2014_CMS_ESRD_Forms.pdf

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[7] Available through http://mycrownweb.org/pcw_course/completing-cms-2728-form/, accessed October 14, 2015.

E. Summary of Existing Medicare data sources

As summarized in Table 5, Medicare has limited race and ethnicity data on all beneficiaries from the EDB and more granular race and ethnicity data on a small sample of beneficiaries from beneficiary surveys. PAC assessment instruments also collect race and ethnicity data, though the data have not been validated, and are only available for beneficiaries that use PAC. No source of currently available data for all Medicare beneficiaries is compliant with the Section 4302 standards for race and ethnicity data. Specifically, the EDB contains demographic information on all individuals enrolled in Medicare, and its race and ethnicity data are not compliant with OMB Directive 15 standards and have demonstrated validity limitations. Moreover, beneficiaries born after 1989 will have missing race and ethnicity information as they become eligible for Medicare, and thus the variable will become less complete over time. While more robust data on race and ethnicity are available through other CMS sources, these sources only capture information on a small share of the beneficiary population and some also do not comply with the OMB or align with Section 4302 standards.

Table 5. Summary of Key Features of Currently Collected Race and Ethnicity Data from Medicare Beneficiaries, by Source

Beneficiary Survey	Uses OMB 1997 Data Categories	Aligns with Section 4302 Data Categories*	Captures Data on All or Some Current Beneficiaries	Captures Data on All or Some Beneficiaries Born after 1989	Captures All Future Beneficiaries	Self-Reported
EDB	No	No	Some	No	No	Self or proxy
MDS	Yes	No	Some	Some	No	Self or proxy
OASIS	Yes	No	Some	Some	No	Self or proxy
IRF-PAI	Yes	No	Some	Some	No	Self or proxy
LTCH CARE	Yes	No	Some	Some	No	Self or proxy
MCBS	Yes	Yes	Some	Some	No	Self or proxy
MA & PDP CAHPS	Yes	No	Some	Some	No	Self or proxy
FFS CAHPS	Yes	No	Some	Some	No	Self or proxy
In-Center Hemodialysis CAHPS	Yes	Yes	Some	Some	No	Self or proxy
HOS	Yes	Yes	Some	Some	No	Self or proxy

Beneficiary Survey	Uses OMB 1997 Data Categories	Aligns with Section 4302 Data Categories*	Captures Data on All or Some Current Beneficiaries	Captures Data on All or Some Beneficiaries Born after 1989	Captures All Future Beneficiaries	Self-Reported
CROWNWeb	Yes	No	Some	Some	No	Self or proxy

**Administrative data collections are not subject to the Section 4302 data standards. The comparison is provided here as a framework for consideration for future improvements to race and ethnicity data collections.*

F. Other avenues for data collection

While this section has reviewed the history and current state of key sources of beneficiary-level race and ethnicity data in the Medicare program, it is important to note that CMS requests and receives information from Medicare beneficiaries in other ways—at the time of enrollment in Parts A, B, C, and D and through MyMedicare.gov.[8] However, the Medicare program does not currently collect information on race and ethnicity in these instances. As discussed in Section 4, these contacts with beneficiaries could be leveraged to collect race and ethnicity data from beneficiaries in the future.

CMS also collects race and ethnicity data on Medicaid enrollees, but the quality of the data vary because it is collected by the states, which determine the form of the question and the mode of collection (Sebelius 2011). As evidence of the variable quality of the state-collected race and ethnicity data, CMS uses the race data from the EDB, rather than the race and ethnicity data collected by the state, for internal analysis of dual-eligible beneficiaries. Although there is an effort to push states to improve this data collection, it does not appear to be a viable source of data currently.

In addition to currently available data, we note here that the Medicare and Medicaid Electronic Health Records (EHR) Incentive Programs provide incentive payments to eligible professionals, eligible hospitals, and critical access hospitals, and Medicare Advantage organizations that demonstrate meaningful use of certified EHR technology.[9] As the EHR Incentive Programs evolve, there is a greater focus on the advanced use of EHR technology, promotion of interoperability, health information exchange between providers, and improved patient outcomes. Demographic information (sex, race, ethnicity, date of birth, preferred language) is included as part of structured data fields captured, transmitted, and shared. Preferred language is defined as "the language by which the patient prefers to communicate." Race and ethnicity coding must follow the OMB standard five race categories: American Indian or Alaska Native, Asian, Black or

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[8] MyMedicare.gov does not collect data on race and ethnicity from beneficiaries. It currently collects health insurance information (IEQ), personal health and family medical history such as medical conditions, allergies, immunizations, etc. The IEQ is set to be phased out in mid-2016. (Correspondence with CMS Division of Call Center Systems, November 9, 2015.)

[9] The Medicare and Medicaid Electronic Health Records (EHR) Incentive Programs began in 2011 and, for eligible professionals, incentive payments will continue until 2016 for Medicare and 2021 for Medicaid. The programs require successfully demonstrating meaningful use of certified EHR technology for an applicable EHR reporting period for each payment year of the program. Meaningful use describes the use of certified electronic health record technology that, among other requirements, furthers the goals of information exchange among health care professionals and hospitals.

African American, Native Hawaiian or Other Pacific Islander, and White; and two ethnicity categories: Hispanic or Latino and Not Hispanic or Latino. Demographic information is required, if known, in all summary of care documents (called consolidated clinical document architecture (C–CDA) transmitted by providers during transitions of care or referrals to another provider for effective care coordination under the Health Information Exchange (HIE) Objective. Demographic information must also be part of a patient's accessible online health information after being seen by the provider or after a hospital discharge under the Patient Electronic Access Objective (measure 2).

Additionally, the Base EHR definition (or certification criteria) included in the EHR Incentive Program Stage 3 final rule provides for the capture of demographic data within certified EHR technology (CEHRT) [10], including the capture of more granular data on race and ethnicity and of data that extends beyond a more limited understanding of clinical care data—such as the collection of social, psychological, and behavioral health information[11]. The ability to capture this information in CEHRT supports provider efforts to provide improved, patient-centered care and reduce health disparities. Providers participating in Stage 3 of the EHR Incentive Program will be required to use CEHRT that can capture more granular data on race and ethnicity starting in 2018, when that program requires the use of the 2015 Edition Certified technology.

As of August 2015, 476,000 health care providers received payment for participating in the EHR Incentive Programs. In 2013, CMS revealed that more than half of all eligible providers received payments for participating in the programs.

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[10] The 2015 Edition CEHRT unlike the 2014 Edition CEHRT requires granular race data to be able to be captured and to be shared where available.

[11] Note: The social, psychological, behavioral health criteria is not part of the BASE EHR definition nor a requirement for stage 3. This criteria is optional certification criteria available to support the broader care continuum.

4. OPTIONS FOR IMPROVING RACE AND ETHNCITY DATA COLLECTION IN MEDICARE

As discussed in the previous section, the Medicare program currently collects race and ethnicity data from several sources; however, these sources have current and future limitations that impact the extent to which they can be used for quality and resource use measurement or payment adjustment. Specifically, Medicare does not have any source of accurate race and ethnicity data that is compliant with either the OMB 1997 or Section 4302 standards for race and ethnicity data for all Medicare beneficiaries. Further, these data are not currently collected and reported to CMS for most beneficiaries born after 1989.

Beyond the IMPACT Act requirements, there are broader dividends to collecting adequate race and ethnicity data. Robust race and ethnicity data would enable the Medicare program to develop policies that better address racial and ethnic disparities in health and health care delivery; however, the lack of adequate administrative data proves a large impediment. Existing data inadequacies are particularly acute for Medicare beneficiaries who existing research has shown face health and health care disparities, as currently available information disproportionately misclassifies members of certain racial and ethnic populations or communities (Arday et al. 2000; Waldo 2004; Zaslavsky et al. 2012). Improving CMS's race and ethnicity data could facilitate access to improved measures of disparity and lead to a better understanding of the extent to which policies affect high risk, high needs populations.

This section presents several approaches that could be considered for the collection of better data on race and ethnicity for purposes of specifying Medicare quality and resource use measures and potentially for other purposes, such as research on disparities in care. Although not every approach addresses every gap of the current data sources as measured against the Section 4302 standards, the following six approaches would assist in closing some of the gaps in the existing data by collecting accurate race and ethnicity data that: (1) cover more beneficiaries (e.g., current, those born after 1989, future); (2) comply with the OMB 1997 Directive 15 Standards (or Section 4302 for major population-based surveys) for race and ethnicity categories, including allowing for separate and multiple responses for race and ethnicity; and/or (3) are self-reported whenever possible. CMS may be able to adopt one or more of these approaches through its administrative authority. However, if CMS is unable to do so, or if additional funding is required, further legislation may be necessary. CMS intends to consider the following six approaches for accessing race and ethnicity data individually, in combination with one another, and compared to making no changes, that is, continuing to use existing EDB data with its known limitations.

Option 1. Leverage new PAC assessment instrument

Race and ethnicity data collected on current PAC patient assessment instruments have several limitations: While they conform to the OMB 1997 standards, there are no separate questions for race and ethnicity; responses may not be self-reported; and data on the extent to which they are proxy-reported are not currently collected. To improve the race and ethnicity data collected in the PAC setting, CMS could include questions on the new or modified multi-setting PAC assessment instrument that could be developed to collect standardized patient assessment data in the four specified PAC settings, per the IMPACT Act.

The development of this instrument would present an opportunity to improve on the race and ethnicity data currently collected on the individual PAC assessment instruments. The appropriateness of the Section 4302 categories for this administrative data collection could be assessed, and those categories potentially added. The inclusion of the expanded race and ethnicity categories developed under Section 4302 could be added and the completeness and quality of the data received in response could be evaluated to identify further improvements. An additional question to collect information about whether race and ethnicity are self- or proxy-reported could also be added. The data on race and ethnicity would be captured along with other data on the assessment instruments. A process to merge the data onto the EDB would also need to be developed and the necessary resources identified. Over time, as more beneficiaries use PAC services, their information would be added or over-written with the most recent assessment's data.

Collecting race and ethnicity data in this new way in PAC settings would address some of the limitations of the existing PAC data as well as the limitations of the existing beneficiary data on the EDB. The primary limitation of this PAC-focused approach is that it would yield race and ethnicity data for beneficiaries only when they use of one of the four PAC settings and only after the instrument is implemented. Relying solely on this approach to new data collection would mean that new race and ethnicity data would not be collected until a beneficiary has PAC utilization and would never be collected for beneficiaries who do not ever use PAC, which may be inadequate. The law establishes broader Medicare focus in studying and addressing racial and ethnic disparities across care settings, which is particularly important given that care delivery in a given setting typically intersects with other settings. PAC is often, though not always, delivered following an inpatient stay. In some cases, care in an acute care hospital may substitute for PAC. The Medicare program may ultimately find greater utility in data collection that is not tied to utilization of any specific setting because it would yield data on beneficiaries who do not use a specified setting or those who do not have any utilization.

Option 2. Collect race and ethnicity data from beneficiaries upon enrollment in Parts A and B

CMS could explore the possibility of collecting data from Medicare beneficiaries upon enrollment in Parts A or B of the Medicare program, which could also serve as a potential vehicle for collecting additional demographic data needed to determine quality, resource use, or payment, as well as for measuring and addressing disparities. This information is not currently collected on enrollment forms and would require either a modification to the enrollment forms, or a supplemental mail or electronic survey that is fielded when a beneficiary enrolls in these parts of the Medicare program. There is precedent for this type of supplemental data collection in that, as noted earlier, CMS had surveyed all beneficiaries classified as Unknown or Other, those with Hispanic surnames, or those reporting a Hispanic country of birth (Arday et al. 2000). This new data collection option, though a larger undertaking than this previous experience, could be modeled on that effort, with consideration given to using different survey modes (e.g., online) beyond the mail survey that was undertaken in 1997.

The primary advantage of this survey option, is that it would yield self-reported data that are consistent with the 4302 standards and would provide data on new beneficiaries. It would require reformatting existing Parts A and B enrollment materials or the creation of a supplementary data collection tool to capture this information. As with other options, CMS could explore populating the EDB with these new data collected via survey to facilitate access to the new race and ethnicity variables. A primary limitation is that the data would only be as comprehensive as the response rate these activities could achieve because reporting would be voluntary. The agency could develop an evidence-based survey strategy that draws on research focused on maximizing beneficiaries' voluntary response rates. Another limitation is that it would collect data only for new beneficiaries; to address this limitation, this approach could be supplemented with data from a survey of existing beneficiaries. Finally, this process could have substantial costs associated with it, especially if it requires sending out additional mailings or making additional phone calls beyond those currently conducted. Even using existing forms could prove costly, since those forms would need to be updated.

Option 3. Collect race and ethnicity data upon enrollment in Medicare Advantage or Prescription Drug Plans

CMS could explore collecting race and ethnicity data when Medicare beneficiaries elect to enroll in a Medicare Advantage (MA) or stand-alone prescription drug plan (PDP). It could be collected by MA plans (and PDPs) and shared with the Medicare program, as suggested by McBean (2004), and could also serve as a potential vehicle for the collection of additional demographic data needed to determine quality, resource use, and payment as well as for measuring and addressing disparities. This information is not currently collected on enrollment forms and would require either an amendment to the enrollment forms, or a supplemental mail or electronic survey that is fielded when a beneficiary enrolls in these parts of the Medicare program. The exploration of this option would include determining if CMS has the authority to collect this data as part of MA and PDP enrollment, and possibly what steps would be necessary to obtain this authority. This option could yield data that are consistent with the section 4302 standards and provide data on new and some existing beneficiaries. As with other options, CMS could explore populating the EDB with these new data collected via survey to facilitate access to the new race and ethnicity variables. One limitation is that the data would only be as comprehensive as the response rate these activities could achieve because reporting would be voluntary. CMS could develop an evidence-based survey strategy that draws on research into maximizing beneficiaries' voluntary response rates. Another limitation is that either CMS or Medicare Advantage Organizations and PDPs would need to bear the additional cost of implementation.

An additional limitation is that, currently, just over 28 percent of Medicare beneficiaries are enrolled in a MA plan, though that share is expected to grow over the next decade (Boards of Trustees of the Federal Hospital Insurance and Federal Supplementary Medical Insurance Trust Funds 2015). In contrast, in 2014, about 69 percent of all Medicare beneficiaries were enrolled in Part D plans (MedPAC 2015). Thus, collecting information solely through MA would not yield data on beneficiaries who elect traditional (fee-for-service) Medicare.

Option 4. Leverage existing CMS data collection through the MyMedicare Portal

The goal of this option is to leverage the online Medicare Patient Portal (MyMedicare.gov) through which Medicare beneficiaries can update and correct information in their patient profiles. Medicare beneficiaries who included an email address in their enrollment application could be encouraged annually to visit the Portal and review their demographic information. While the information technology architecture exists for this option, the Portal would have to be programmed and the interface formatted to incorporate the race and ethnicity questions.

This option leverages existing CMS data collection portals that could yield data adherent to Section 4302 standards and could, potentially, collect data on new and some existing beneficiaries. As with other options, CMS could explore populating the EDB with these new data collected via survey to facilitate access to the new race and ethnicity variables, and the data would inherently only be as comprehensive as the response rates these activities could achieve because reporting will be voluntary. The agency could develop an evidence-based survey strategy that draws on research into maximizing beneficiaries' voluntary response rates.

Option 5. Leverage existing CMS data collection through the Federal Marketplace portal

This option leverages race and ethnicity data collected through the application for federal Marketplace coverage when Federal Marketplace (healthcare.gov) policyholders become Medicare beneficiaries. When applying for coverage through the Marketplace, applicants have the option of providing race and ethnicity data. The categories conform to the more granular Section 4302 standards, applicants can indicate all categories that apply, and race and ethnicity are collected separately.

Advantages of this option are that it would utilize existing CMS data collection portals that yield data adherent to the Section 4302 standards and could potentially collect data on new and some existing beneficiaries. As with other options, CMS would explore populating the EDB with these new data collected via survey to facilitate access to the new race and ethnicity variables. As with options 2, 3, and 4, the data would only be as comprehensive as the response rates these activities achieve because reporting is voluntary. It should be noted that more than one-third of applicants do not provide these data (ASPE 2015), and the voluntary nature of this data collection may yield low completion rates. Additionally, Marketplace enrollees who join the Medicare program each year only represent a small subset of Medicare beneficiaries. Overall, it is likely that the amount of data captured through this approach will be small.

Option 6. Leverage race data collected by providers under EHR certification

This option capitalizes on the Office of the National Coordinator for Health Information Technology (IT) Health IT Certification Program. This program, established to develop and oversee national programs for the certification of health information technology by the Health Information Technology for Economic and Clinical Health Act, helps to ensure that health IT in multiple settings—such as physician offices, hospitals, and PAC settings—conforms to the standards and certification criteria adopted by the Secretary of Health and Human Services. Standards for demographic data set forth in the 2015 Edition health IT certification criteria require that a user of the record have the ability to record, change, and access patient demographic data including race, ethnicity, preferred language, sex, sexual orientation, gender identity, and date of birth. The requirements specify that "a user can record a patient's race(s) and ethnicity(ies) according to concepts in the 'Race & Ethnicity–CDC' code system Version 1.0" but that "the software must be able to 'roll-up' each one of the patient's race(s) and ethnicity(ies) and record the race(s) and ethnicity(ies) according to the OMB Standards for Maintaining, Collecting, and

Presenting Federal Data on Race and Ethnicity, Statistical Policy Directive No. 15, as revised, October 30, 1997 (ONC 2015).” The ‘Race & Ethnicity-CDC’ code system Version 1.0 includes more than 900 granular concepts for representing patient race and ethnicity. Patients must be able to decline to answer and may specify more than one race and ethnicity according to the ‘Race & Ethnicity-CDC’ code system Version 1.0 standard.

While this option could yield standardized race and ethnicity data elements collected in multiple provider settings on certified EHRs, it has limitations that may prevent it from being viable in the short run. Only clinical providers with certified EHRs are guaranteed to conform to these data standards; therefore, only beneficiaries who see these providers would have their data collected electronically using these standards, limiting the number of beneficiaries for whom information is available. In addition, patient-level data are not currently reported to government entities. A new system would need to be developed to facilitate patient-level reporting to CMS. Beyond the technical barriers and potentially substantial cost, the primary obstacle to this option may be privacy concerns. Because multiple stakeholders—including providers, patients, and federal agencies—are sensitive to compromising patient privacy by sharing identifiable patient-level data collected through EHRs, collecting race and ethnicity and other demographic data via the EHR may be controversial. Also, as finalized under the Stage 3 EHR Incentive Program, and as proposed in the Merit-Based Medicare Incentive Payment System (MIPS), providers would not be required to use EHRs that are certified to be able to capture the more granular race and ethnicity concepts in the ‘Race & Ethnicity-CDC’ code system Version 1.0 standard until 2018.

A summary of the six options discussed in this section is shown in Table 6.

Table 6. Summary of Options

Option	Captures Data on All or Some Current Beneficiaries	Captures Data on All or Some Beneficiaries Born after 1989	Captures All or Some Future Beneficiaries	Potential opportunity to provide further detail to race and ethnicity data collected	Self-Report	New Data Collection
1. Leverage new PAC assessment instrument	Some (limited to PAC users)	Some (limited to PAC users)	Some (limited to PAC users)	Assess appropriateness of Section 4302 categories for potential use	Yes	Yes
2. Collect data upon enrollment in Medicare Parts A and B	No	All	All	Assess appropriateness of Section 4302 categories for potential use	Yes	Yes
3. Collect data upon enrollment in MA or PDPs	Some (limited to MA enrollees)	Some (limited to MA enrollees)	Some (limited to MA enrollees)	Assess appropriateness of Section 4302 categories for potential use	Yes	Yes
4. Leverage existing CMS data collection through the MyMedicare portal	Some (limited to MyMedicare.gov users)	Some (limited to MyMedicare.gov users)	Some (limited to MyMedicare.gov users)	Assess appropriateness of Section 4302 categories for potential use	Yes	Yes
5. Leverage existing CMS data collection through the Federal Marketplace portal	No	Some (limited to Federal marketplace users)	Some (limited to Federal marketplace users)	Assess appropriateness of Section 4302 categories for potential use	Yes	Yes
6. Leverage race data collected by ONC-certified EHRs	Some (limited to beneficiaries who utilize providers with certified EHRs)	Some (limited to beneficiaries who utilize providers with certified EHRs)	Some (limited to beneficiaries who utilize providers with certified EHRs)	Current Standard is OMB 1997 categories	Yes	Yes

5. STRATEGIC PLAN NEXT STEPS

The IMPACT Act requires a strategic plan for collecting or otherwise accessing data on race and ethnicity for the purposes of specifying quality measures, and resource use or other measures under sections 1899B (c) and (d) of the Act and, as the Secretary determines appropriate, other similar provisions of the Medicare program, including payment adjustments. Beneficiary data used for these purposes should be valid and complete. Currently available Medicare data are inadequate on a number of dimensions that, as presented in the previous section, could be addressed to varying degrees by several options for accessing and collecting race and ethnicity data. Because options require tradeoffs between data quality, time, cost, and other resources, a key next step in this strategic plan is to develop an evidence base for comparing the options on these dimensions. That evidence base would assess (1) legal implications of program data collection, (2) requirements for future statistical analyses that will use the data, and (3) resources required to collect and analyze any new data. To achieve successful completion of this assessment, CMS will designate a point of contact that will work across the agency. This point of contact will ensure that evidence collected on each option, and any additional options CMS may consider, will enable the agency to weigh the quality of the data that will be collected against the feasibility (e.g., time, IT systems, or cost) of collecting it. Executing this plan will enable CMS to meet the requirements of the IMPACT Act, advance the Agency's goals to achieve better care, smarter spending, and healthier people and align with the CMS Quality Strategy.

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