June 6, 2011

Dr. Donald Berwick
Administrator
Centers for Medicare and Medicaid Services
Room 445-G Hubert Humphrey Building
200 Independence Ave. SW
Washington, DC 20201

RE: File Code CMS-1345-P

Dear Dr. Berwick,

The undersigned members of The Leadership Conference on Civil and Human Rights Health Care Task Force appreciate the opportunity to comment on the proposed rule regarding Medicare Shared Savings Program: Accountable Care Organizations (ACOs). The Leadership Conference is a coalition charged by its diverse membership of more than 200 national organizations to promote and protect the civil and human rights of all persons in the United States. As members of The Leadership Conference’s Health Care Task Force (which is co-chaired by the National Partnership for Women & Families and the National Health Law Program) we are particularly committed to reducing disparities in health and health care and ultimately achieving equity in both arenas.

Unfortunately today, our country suffers from significant disparities in health status and health care. This is in part because many vulnerable populations face barriers to high quality health care that meets their individual needs. They can face communication breakdowns, attributable to both language and cultural differences; accessibility challenges, for instance if a physician’s mammography equipment is not wheelchair accessible; and blatant discrimination, such as if a provider refuses to acknowledge a same-sex partner as a patient’s caregiver or involve the partner in a shared decision-making process when they would otherwise do so for a heterosexual spouse or partner.

As we transform the way our health care system delivers and pays for care, we must consider how we can leverage delivery and payment reform initiatives to tackle these obstacles head on. Accordingly, we have a great interest in the implementation of the Medicare Shared Savings Program. ACOs have the potential to not only improve the quality of our healthcare system overall by delivering coordinated, patient- and family-centered care, but also by greatly advancing the effort to achieve health equity. However, if implemented without the appropriate standards and quality metrics in place, ACOs could also inadvertently incentivize providers to avoid vulnerable and more costly patients, and ultimately exacerbate disparities.

The proposed rule lays a strong patient- and family-centered foundation that is critical to enabling ACOs to deliver on the former promise, and the Center for Medicare & Medicaid Services (CMS) is to be commended for its leadership. We are concerned, however, that the proposed rule largely ignores the effect ACOs may have on equity. More consideration needs to be given to how ACOs can contribute to reducing health and health care disparities as well as meet some the unique needs of minority and other vulnerable populations.
Below we offer recommendations on: (1) the elements of the proposed rule that are particularly critical to maintaining and strengthening the foundation of patient- and family-centered care, an issue important to all populations, particularly the communities we represent and (2) changes to the proposed rule that are necessary to ensure that ACOs can fully meet the needs of all their patients, including the most vulnerable, and that the Medicare Shared Savings Program will play a role in advancing the Department of Health and Human Services’ (HHS’s) commitment to reducing health and health care disparities.¹

1) Putting Patients and Families at the Center of the Medicare Shared Savings Program

The proposed rule evidences the CMS’s focus on transforming our health care system to better meet the needs of patients and families. We applaud this emphasis, and strongly encourage CMS to maintain it in the final rule. The elements of the proposed rule we discuss below, with a few key suggested modifications, are necessary components of a health care system that can deliver comprehensive, coordinated, patient- and family-centered care.

Consumer Participation in Governance

We are very pleased that the proposed rule recognized the role consumers have to play in the governance of ACOs. Consumers offer unique insight into the policies and procedures that matter to patients and families and will help to cultivate trust and build relationships among an ACO, its beneficiaries, and its community. However, for consumer representatives to have a meaningful, influential role in governance, simply one seat on an ACO’s governing body, as is proposed, is insufficient. Instead, governing bodies must include both beneficiary representatives and representatives from community-based consumer organizations (as is the policy for the Pioneer ACO Model).

Together beneficiaries and consumer advocates must possess a sufficient number of seats on the governing body to enable them to substantively influence an ACO and its operations. Beneficiary representatives and consumer advocates bring distinct perspectives to the table. Beneficiary representatives are individuals who have significant personal experience with the health care system, either as patients, caregivers, or both. Consumer advocates work for non-profit, mission-oriented organizations that represent a specific constituency of consumers or patients. Unlike other stakeholders, consumer advocates do not derive their livelihoods from the health care system and their primary emphasis is on the needs and interests of consumers and patients. We recommend that the percentage of seats identified for ACO participating providers be reduced from 75 percent to 50 percent, with the remaining half allocated to beneficiaries, consumer advocates, and other relevant stakeholders.

No representatives on the governing body should have a financial conflict of interest in the ACO on whose board they are sitting, and they should represent a wide range of beneficiary populations and provider expertise. In accordance with the proposed rule’s suggestion that diversity plans develop “multicultural health care standards and guidelines which include requirements for…providing culturally

and linguistically appropriate services, and detecting health care disparities[,]” diverse consumer
stakeholders could be invited to participate on the ACO governing body.

Community Stakeholder Participation

In addition to including beneficiaries in the governance of ACOs, the proposed rule repeatedly calls on
ACOs to establish partnerships with community stakeholders and be able to identify community resources
for high-risk patients. Given the high rates of chronic conditions among vulnerable populations, it is
particularly important that ACOs connect them with organizations that have a history and established
relationships with minority communities.

We believe this is a critically important element of the proposed rule. Today, health care providers are
often unaware of and not connected to traditionally “non-medical” community resources that play a vital
role in improving and maintaining the health and wellbeing of their patients. Providers may not know that
some of their patients have difficulty finding transportation to appointments or affordable and healthy
food in a physically accessible location, let alone where to refer them to for assistance. Nor may they
know about local smoking cessation or health education programs, or any health education program that
provides materials in alternative formats or other languages and/or American Sign Language (ASL),
especially if the providers do not live in the same community where they work. Forging collaborative
relationships between health care providers and community stakeholders and resources will better enable
our health care system to address social determinants of health and ultimately improve health outcomes.
This is particularly important in communities where there are high concentrations of vulnerable or at-risk
patients.

To ensure that this potential is realized, we urge CMS to provide additional guidance on what ACOs must
do to partner with community stakeholders, specify that the ACO should partner with a range of
community stakeholders that reflect the ACO enrollee population, and establish systems to monitor such
partnerships. In particular, we strongly caution CMS that the inclusion of a community stakeholder on the
governing body is insufficient to achieve this goal. Community stakeholder participation in governance is
critical, but it does not take the place of actual on-the-ground partnership with such groups. We also ask
that CMS add community-based organizations, including those that support community health workers
and promotores de salud, to the list of potential community resources available to help beneficiaries
follow their individualized care plans.

Patient-Centeredness Criteria

The proposed rule requires ACOs to demonstrate patient-centeredness by addressing a number of criteria
that promote patient engagement and care coordination. These criteria address the elements of care that
most resonate with beneficiaries and determine how they experience their care, including a process for
coordinating care, mechanisms for allowing beneficiary engagement and shared decision making, and
standards for beneficiary access and communication. These criteria also allow for ACOs to hold
themselves accountable on these elements, through patient and caregiver experience of care surveys,
systems to identify high-risk patients, and internal processes for measuring clinical performance.

We strongly urge you to retain the patient-centered criteria in the final rule. In addition, because an
ACO’s ability to deliver patient-centered care is so critical to improving the quality and efficiency of care
for beneficiaries as well as the ultimate success of the Medicare Shared Savings Program, we ask CMS to
specify how it will monitor and enforce the requirements that ACOs adhere to all of the criteria.
Patient Feedback

In addition to explicit roles in governance, ACOs should be required to regularly solicit input from patients and families. We strongly support the required use of patient and caregiver experience surveys and also request that CMS require ACOs to describe a plan for regular use of qualitative activities – like patient and family advisory councils, focus groups, walk-throughs, etc. – to get ongoing feedback from patients and family caregivers. These qualitative activities should require ACOs to design them to specifically include feedback from underserved populations, as appropriate to the composition of the ACO. For example, if an ACO includes patients with disabilities, the qualitative activities must be designed to specifically obtain information and feedback not only from the general ACO enrollee population but also from ACO enrollees with disabilities.

No Patient “Lock In”

The proposed rule wisely prohibits ACOs from impeding the ability of beneficiaries to seek care from providers not participating in the ACO. This protection is crucial to gaining patients’ trust and support for this new model. As we learned from negative experiences with early Medicare+Choice plans and other HMO trials, beneficiaries typically do not want to be “locked in” to a system. If ACOs are allowed to act as “gatekeepers” they will fail. Instead, ACO participants must act as “gateways” to coordinated, high quality care that is culturally appropriate and programmatically and physically accessible. If ACOs do this and they are creating regular opportunities to receive feedback from patients and families about their efforts, beneficiaries should not need to be locked in. Successful ACOs will see their patients seek care within their network, without the influence of any sort of financial incentives or penalties.

2) ACOs Role in Reducing Health and Health Care Disparities

Given the potential of ACOs to transform the way care is delivered to better meet the needs of patients and families, we strongly urge CMS to strengthen the rule in terms of considering the unique needs of underserved and vulnerable populations. Although reference is made to “meet[ing] the intent of the Shared Savings Program as established by the Affordable Care Act, [by] focus[ing] on achieving, as our highest-level goal, … Better care for individuals – as described by all six dimensions of quality in the Institute of Medicine report: safety, effectiveness, patient-centeredness, timeliness, efficiency, and equity” (emphasis added), reducing disparities in health care and health status is not adequately addressed throughout the proposed rule, nor are specific actions that would accomplish this goal included in requirements for ACOs. We strongly urge CMS to make the following changes to better incorporate the reduction of health and health care disparities into both the broad goals and specific requirements of the rule. Without such changes, ACOs may fail to meet the needs of vulnerable populations who most need to see improvements in care quality.

ACO Goals

The proposed rule details a number of goals which it asserts an ACO should embrace. While equity is meant to be one of the six dimensions of better care, reducing disparities is not incorporated into any of these goals for ACOs. We suggest that CMS amend the sixth goal to read as follows:

“An ACO will collect, evaluate, and use data on health care processes and outcomes sufficiently to measure what it achieves for beneficiaries and communities over time and use such data to
improve care delivery and patient outcomes, and to reduce disparities in health status and health care.”

Nondiscrimination

As a program administered by an Executive Agency, the Medicare Shared Savings Program must comply with the nondiscrimination provisions of section 1557 of the ACA. Section 1557 forbids health programs or activities that are receiving federal financial assistance, or programs administered by an executive agency, or any entity established under Title I of the ACA from discriminating upon the protected bases under Title VI of the Civil Rights Act of 1964, Title IX of the Education Amendments of 1972, the Age Discrimination Act of 1975, and section 504 of the Rehabilitation Act of 1973. In short, section 1557 of the ACA prohibits covered entities from discriminating on the basis of race, color, national origin, gender, age, or disability. Whether or not section 1557 regulations explicitly include sexual orientation or gender identity protections, ACOs should also include protections for lesbian, gay, bisexual, and transgender individuals by enumerating protections on the basis of sexual orientation and gender identity. In addition, ACOs participating in the program must not discriminate on all of these prohibited bases, because the Medicare Shared Savings Program may not aid or perpetuate discrimination by providing significant assistance to entities receiving federal financial assistance or conducting activities for a program administered by an Executive Agency as a method of undercutting the requirements of section 1557 as well as because of other potential compliance triggers.

We strongly urge CMS to prioritize working with the HHS Office for Civil Rights to ensure that the Medicare Shared Savings Program and participating ACOs are designed to provide equitable services and benefits that are accessible to all groups in compliance with section 1557. This should include specifying procedures to ensure that ACOs are in compliance with section 1557, including compliance assistance, notice available in alternative formats and languages to enrollees of their rights under this provision, including their right to reasonable accommodation and policy modifications, and periodic reviews. In addition, as the Acts’ references in section 1557 have been interpreted to require that services provided by federal grantees and the federal government meet certain standards in order to be Title VI and Rehabilitation Act compliant, ACOs must be held accountable to such standards.

For instance, ACOs must follow HHS guidance regarding Title VI’s prohibition against national origin discrimination affecting limited English proficient persons (LEP) (68 FR 47311), and should use the four-factor analysis to determine the extent of their obligation to provide LEP services. Similarly, ACOs should follow the accessibility requirements outlined for compliance with sections 504 and 508 of the Rehabilitation Act.

In addition, because the groups protected by section 1557 are known to suffer from disparities in health at the population-level, and because they may need additional services, such as language access services, actual or perceived higher costs for care may lead ACOs to avoid these groups. CMS should make clear that such avoidance would be in violation of section 1557 and is prohibited. This protection is an important and necessary complement to the provisions protecting “at-risk beneficiaries,” determined at the individual level on the basis of health status through the use of the CMS-HCC categories.

Many of our following recommendations would not only abet the reduction of health and health care disparities, but would also play a critical role in facilitating compliance with section 1557.
Demographic Data Collection and Use

According to the proposed rule, an ACO must have a process for evaluating the health needs of its assigned population, including consideration of diversity in its patient populations, and a plan to address the needs of its population. To be effective the criterion needs greater specificity and should also include documentation or enforcement requirements.

A vital component of evaluating the health needs of a patient population is data collection. Specifically, CMS should direct ACOs to collect data on patients’ race, ethnicity, language, gender, disability, sexual orientation, and gender identity. (See addendum for a memo from members of the Health Care Task Force with recommendations for implementing the data collection requirements under section 4302 of the ACA, including standards and best practices for collecting these data categories.)

This data should then be put to use by ACOs as they analyze the needs of their population, assess health and health care disparities, and develop interventions. The data will also be a critical tool for ensuring compliance with section 1557. In particular, ACOs should be required to stratify and report their quality metrics, including patient and caregiver experience survey results, by the categories listed above. To the maximum extent possible based on available data, data should be collected and stratified by racial and ethnic subgroups (e.g. the general category “Asian and Pacific Islander” could be stratified further into Chinese, Vietnamese, Korean, etc.). Without stratification, it will be unclear whether the ACO model will be effective not only at providing care but also improving equity and reducing healthcare disparities. Furthermore, while we recognize it will add a layer of complexity to the calculations, CMS should eventually establish a process for incorporating stratified quality metrics into the shared savings determination.

Culturally and Linguistically Appropriate Care and Services

After collecting and using data to evaluate the diversity of its population, ACOs should be expected to take a number of specified steps to address the needs of diverse populations. The proposed rule should ensure that ACOs recognize that addressing the needs of a diverse population includes many factors, such as race, gender, gender identity or expression, sexual orientation, disability, income status, English proficiency, age, and others.

To begin with, ACOs must demonstrate that they have systems in place to identify and update the languages spoken by LEP individuals and processes to provide language services for these individuals at all points of contact with the ACO. To do this effectively, the ACO should be able to obtain additional funding to pay for language services. It would also be beneficial to have ACOs report to CMS and publicly post information about the languages, including ASL, spoken by their providers and their staff so that patients and caregivers can access the providers who are best able to meet their needs. In addition, ACOs should be expected to have a process in place (or clear path to develop such a process) to exchange language information when patients transition to another provider or setting of care, both within and outside the ACO.

All written materials – including but not limited to information regarding patients’ rights and responsibilities within an ACO, notices and vital documents, information and forms related to beneficiary opt-out of claims data sharing, individualized care plans, patient and caregiver experience surveys, and marketing materials – should be developed in a culturally and linguistically appropriate manner, be at a literacy level no higher than fifth grade, and be provided in alternative formats such as large font print,
Braille, audio-recording, and CD. These materials should be translated into the top two languages other than English of the ACO patient population as well as any additional languages spoken by at least 5 percent or 500 individuals of the ACO patient population. For ACO beneficiaries who speak or read languages for which materials are not translated, the ACO must provide oral communication of this information utilizing either competent bilingual staff or interpreters. Staff must also be trained in the use of TTY and telephone and video relay systems used by Deaf and hard-of-hearing individuals.

Furthermore, an ACO’s website must include information for members who speak languages other than English. The website may include translated information or taglines that give an LEP individual a telephone number to call to access information in non-English languages either through the use of competent bilingual staff or interpreters. All technology should meet section 508 requirements for access to all intended users. In addition, consideration should be given to other points of internet entry in light of the persistent digital divide and recognition that many vulnerable populations access the internet in locations other than their homes or through mobile devices. For instance, research has shown that non-Hispanic Blacks and English-dominant Latinos are significantly more likely than Non-Hispanic Whites to exclusively use cell phones for wireless information. ACO website access could therefore be improved by coordinating applications for mobile devices or other alternative technologies.

ACOs should also have systems in place to identify patients from different cultural backgrounds (including race, ethnicity, language, gender, disability, sexual orientation, and gender identity) and consistently provide culturally appropriate care and information to these individuals at all points of contact with the ACO. Below we discuss in greater detail what this should entail regarding individuals with disabilities. For individuals from the LGBT community, there are three important elements of culturally appropriate care we would like to address here.

First, as the proposed rule places strong emphasis on patient-centered care and ensuring that patients and their families have an informed role in decision-making, it is vital for LGBT people that ACOs use a broad definition of family, inclusive of same-sex partners, as well as non-biological and non-adoptive children of same-sex partners. We encourage CMS to adopt language similar to the broad definitions of family provided in the Department of Labor’s regulations implementing the Family and Medical Leave Act (FMLA), see 29 C.F.R. § 825.122, with the addition of including people who are related by “blood or affinity,” a category used in existing Office of Personnel Management regulations, see 5 C.F.R. § 630.201(b) (2010).

We recommend the following definition of family members modeled after the FMLA and OPM regulations:

“Family member means: a husband or wife as defined or recognized under State law for purposes of marriage in the State where the employee resides, including common law marriage in States where it is recognized; a biological, adoptive, step or foster father or mother, or any other individual who stood in loco parentis to the child; a biological, adopted, or foster child, a stepchild, a legal ward, or a child of a person standing in loco parentis; or any other person related by blood or affinity.”

Second, while we strongly support the efforts by CMS to encourage continuity of care by promoting care coordination between health care providers and ensuring that information is shared in a way that is beneficial to the patient’s needs, it is important that these coordinating activities have an emphasis on patient privacy. Data on sexual orientation and/or gender identity should only be shared with health care
team members directly involved with the care of the patient and should only be discussed when medically necessary.

Third, health care providers should be encouraged to use the appropriate name and pronoun for transgender patients both in and outside the presence of the patient.

**Rights of Individuals with Disabilities**

The proposed rule does not explicitly address the issue of Medicare beneficiaries eligible by virtue of Social Security disability but how this population is treated by an ACO is important. Nonelderly Medicare beneficiaries with disabilities differ from the elderly in several ways – they are more likely to have a cognitive or mental impairment, report fair or poor health status, and encounter access problems and cost-related barriers to care. If ACOs do not take the needs of individuals with disabilities into account and provide the services and supports they need to live as independently and productively as possible within their communities, they are likely to face ongoing challenges.

In their application to participate in the Medicare Shared Savings Program, ACOs must demonstrate their ability to coordinate care for individuals with disabilities. Significant coordination needs may include rehabilitation, long-term home- and community-based services and supports, and services not required by Medicare beneficiaries over age 65 (e.g., maternity care).

Furthermore, CMS should require ACOs to specifically identify beneficiaries with disabilities and undertake individual assessments that will help identify individuals that may fall within a “high risk” population for which ACOs will be required to develop individualized care plans and identify community supports. Partnerships with community-based and advocacy resources are particularly essential to people with disabilities, as providers typically do not have experience with meeting such needs as home modifications like bathroom grab bars or ramps, and ways to ensure that an individual’s rent is paid and pets are taken care of during temporary hospitalizations, yet these needs are essential bridges to ensuring that older persons and people with disabilities can live independently and holistically in the community.

Close attention should be paid to the experiences and outcomes of individuals with disabilities who receive care from ACOs. Stratifying the reporting of quality measures according to disability status is a key way to ensure high quality care for this population and we encourage CMS to do so. Additionally, CMS should direct the Medicare Beneficiary Ombudsman to pay particular attention to this population. We also urge CMS to conduct an annual evaluation to determine the extent to which the care of individuals with disabilities is provided in an appropriate, culturally sensitive, and competent manner by the ACO. This evaluation should be explained in greater detail, including physical, communication and programmatic access to providers and information (including accessible offices and equipment, modified exam time, etc.). The evaluation should include disability-specific quality and patient experience measures. To the extent a beneficiary in an ACO is receiving substandard or inappropriate care, both the beneficiary and the ACO should be notified immediately and a correction plan should be developed and implemented.

Without a coordinated focus on meeting the needs of people with disabilities, the goals of ACO’s to reduce spending and duplication of services will not be met, as people with disabilities will continue to seek out services at hospitals or other providers, and bear increased risks of injury, losing their homes, and unnecessary, unwanted, and costly institutionalization. CMS must create a mechanism for monitoring and enforcement to ensure that the provider offices have accessible equipment and programmatic access
capacity. Infrastructure must be established to understand and enforce accessibility rules which, in the long term, will result in the desired cost savings.

**Dually Eligible Beneficiaries**

Dually eligible beneficiaries – individuals who hold health coverage through both Medicare and Medicaid – represent many of the individuals who most need the high-quality, well-coordinated care that may be furnished through an integrated system. This population also includes a higher proportion of people of color, women and people with disabilities, and many of the communities whose interests Task Force members represent.

Although ACOs will vary in their proportions of dual eligibles, this vulnerable population may require special protections, no matter how modest their numbers. We urge CMS to take a number of preliminary steps to assure such protections within the Medicare Shared Savings Program. First, CMS should encourage ACOs to include long-term care services and support providers as participants to maximize coordination of services for dual eligibles. Second, CMS should identify dual eligible beneficiaries as a “high risk” (functionally impaired) populations for which ACOs are required to develop individualized care plans and identify community supports. Third, CMS should identify performance measures specific to dual eligibles, such as standards for hospital admission rates for nursing facility residents.

In the proposed rule, CMS requested comment on strategies to provide preference to ACOs that serve a large dual eligible population. We believe that ACOs that serve large numbers of these patients could warrant an incentive payment if they also build the structure necessary to effectively serve dual eligible beneficiaries and take extra steps to coordinate care and benefits for these individuals. Regardless of which particular incentives CMS chooses, it is vitally important that ACOs are not rewarded for having a large percentage of dual eligibles within their beneficiary population without additional modifications to the program that will ensure ACOs are equipped to and held responsible for meeting the populations’ unique needs.

**Medically Underserved Populations**

The proposed rule restricts Federally Qualified Health Centers (FQHCs) and Rural Health Centers (RHCs) from forming ACOs and from registered FQHC Medicare patients from being aligned with an ACO. While we recognize that this determination was made according to CMS’s interpretation of the statutory language of the ACA, we remain concerned about the impact of this decision on beneficiaries who live in rural areas.

Nearly one quarter of Medicare beneficiaries live in rural areas. In 12 states alone roughly one half of the Medicare population resides in rural areas. Many of these beneficiaries live with multiple chronic conditions and could significantly benefit from improved access to primary care services and better care coordination. Of the nearly 19 million medically underserved patients served by federally qualified health centers nearly 1.4 million are Medicare beneficiaries. This means that nearly one and half million

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Medicare beneficiaries – some of the poorest beneficiaries with the greatest health risks – will not have access to the kind of care coordination an ACO can provide.

We strongly urge CMS to take all steps available to ensure that ACOs that include FQHCs and RHCs are available in rural areas, including facilitating outreach between the ACOs and FQHCs and RHCs and working with FQHCs and RHCs to develop the capacity to become ACOs. In the meantime, CMS should also establish a system for monitoring rural beneficiary access to ACOs.

Conclusion

We know that providers around the country are anxious to begin forming ACOs. We also know that they want to deliver the best quality care to all of their patients. We believe our recommendations will enable them to do both at once.

We greatly appreciate this opportunity to comment on the proposed rule for the Medicare Shared Savings Program and ACOs and looking forward to working with you as you continue to implement important provisions of the ACA.

Sincerely,

American Association of People with Disabilities (AAPD)
Asian American Justice Center
Asian & Pacific Islander American Health Forum (APIAHF)
Disability Rights Education and Defense Fund
Human Rights Campaign
Japanese American Citizens League
NAACP
National Black Justice Coalition
National Center for Transgender Equality
National Coalition for LGBT Health
National Council of Jewish Women
National Council of La Raza (NCLR)
National Gay and Lesbian Task Force
National Health Law Program
National Partnership for Women & Families
The Leadership Conference on Civil and Human Rights
Transgender Law Center
Overview:

Recommendations Related to Data Collection Requirements in Section 4302

Section 4302 of the Patient Protection and Affordable Care Act (ACA), adding new section 3101 to the Public Health Service Act, requires Department of Health and Human Services (HHS) to ensure that certain data is collected throughout all HHS programs, activities and surveys. In particular, it requires that data be collected on race, ethnicity, primary language, sex, and disability status. It also permits the Secretary to extend this requirement to any other demographic data regarding health disparities. To implement this section, HHS must determine the scope of this provision (specifically to what and whom the new data collection requirements apply), what standards should be used to collect this data, and what, if any, other demographic categories should be required for collection.

This overview provides information and recommendations related to implementing this provision from organizations representing communities and populations who will be most affected by the effective implementation of this new requirement. The accompanying memorandum includes background information and more details related to these

a. Overarching Recommendations

- Ensure community input and engagement in the design, planning, implementation and dissemination of data.

- Utilize community-based outreach strategies to ensure robust participation of respondents from targeted communities, including limited English proficient populations.

- Train staff in collecting demographic data, including explaining why this data is being collected.

- Adopt clear privacy and nondiscrimination protections.

- Safeguard that patient/enrollee reporting of demographic data be voluntary.

- Support analyses based on multiple demographic variables.
b. **Scope**

- Apply the new data collection requirements to federally-supported health care providers (at the point of care), publicly administered or financially assisted health programs (at enrollment), and federally supported national surveys and research.

- Include all data collection requirements, including categories added at the Secretary’s discretion, in any federal reporting requirements imposed for purposes of measuring quality.

c. **Specific Recommendations**

i. **Race and Ethnicity**

- Implement the Institute of Medicine’s (IOM’s) recommendations on the standardization of race and ethnicity data.

- Avoid prioritization schemes or other preference categories for multiracial respondents.

- Utilize multiple sampling strategies to improve the collection and reporting of smaller populations.

ii. **Primary Language**

- Implement the IOM’s recommendations on the standardization of spoken language need.

- Encourage the collection of written language need.

- Ensure compliance with Title VI and Sec. 1557 non-discrimination requirements by providing translated health surveys and increasing HHS’ language assistance capacity.

iii. **Disability Status**

- Standardize questions about functional limitations using American Community Survey (ACS) questions as a starting point.

- Ensure that standardized disability questions identify people with functional limitations associated with certain cognitive, emotional, or learning impairments.

- Collect activity limitation information at enrollment and point of care (in the electronic health record) and information about accommodations a patient needs to access services and to improve the quality of care.
• Explore with CMS the possibility of retrieving information on locations where people with disabilities receive care who are Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) beneficiaries.

• Require identification of the number of providers with accessible facilities and equipment, including medical diagnostic and treatment equipment, as a condition of federal approval of state Medicaid plans and Medicaid waivers.

• Condition the receipt of federal funds for the Affordable Choices of Health Benefits Plans, the Medicare Shared Savings Program, and the Community-based Collaborative Care Networks mandated by the ACA on both assurance of accessibility for people with disabilities and on the regular reporting of data to meet requirements of Section 4302.

• Collect health care practitioner training data available through the University Centers for Excellence in Developmental Disabilities (UCEDDs) as a starting point.

• Identify performance standards and monitoring measures related to disability competency as a condition of receiving Federal financial assistance for health care and related services.

• Mount a targeted research project to assess the availability, content, and quality of disability competency training being offered through professional healthcare education and training programs.

• Include development of mechanisms for collecting and reporting information about healthcare provider cultural competency in serving people with disabilities under section 5307 of the ACA.

• Add a query about disability cultural competency training to the existing queries about staff training to state-mandated healthcare provider facility site reviews required for Medicaid funding.

• Require Federally Qualify Health Centers (FQHCs) to collect data on disability and functional status.

iv. **Sex**

• Collect biological sex data at varying points throughout the health care process, in sufficient quantities for useful analysis.

• Ensure sex data is collected alongside other data categories because of interactions between sex and other identities that might affect health care.
v. **Sexual Orientation and Gender Identity**

- Establish standard specifications for collecting sexual orientation and gender identity data, including same-sex relationship status, utilizing existing best practices.

- Include sexual orientation and gender identity metrics, including same-sex relationship status, on all federally supported HHS surveys.

- In all data collection instruments utilized by HHS programs and activities, provide standardized opportunities for participants to disclose their gender identity, sexual orientation, and relationship status, including a same-sex relationship.

vi. **Standardization of Non-Mandatory Data Collection Regarding Immigrants**

- Standardize questions about citizenship or immigration status to ensure that questions are formulated in a way that removes any threat respondents may perceive.

- Ensure privacy protections are in place and ensure data provided is confidential and will not be shared with immigration officials.

- Provide clear direction on circumstances in which asking questions regarding citizenship or immigration status is inappropriate.

For more information on these recommendations or the accompanying memo (available online: [http://healthlaw.org/images/stories/issues/healthdisparities/2011_4_28_LCCR_Data_Collection.pdf](http://healthlaw.org/images/stories/issues/healthdisparities/2011_4_28_LCCR_Data_Collection.pdf)), please contact The Leadership Conference on Civil and Human Rights’ Health Care Task Force. The Co-Chairs of the Task Force are Portia Wu, National Partnership for Women & Families, [pwu@nationalpartnership.org](mailto:pwu@nationalpartnership.org), and Mara Youdelman, National Health Law Program, [youdelman@healthlaw.org](mailto:youdelman@healthlaw.org).