February 1, 2016

Office of Strategic Operations and Regulatory Affairs
Division of Regulations Development
Attention: Document Identifier CMS-10440
Room C4-26-05
Centers for Medicare & Medicaid Services (CMS)
7500 Security Boulevard
Baltimore, Maryland 21244-1850

RE: CMS-10440, Data Collection to Support Eligibility Determinations for Insurance Affordability Programs and Enrollment through Health Benefits Exchanges, Medicaid and Children's Health Insurance Program Agencies

Dear Sir/Madam:

The undersigned 101 national and state organizations representing 30 states and the District of Columbia would like to thank you for your efforts to ensure that the Affordable Care Act (ACA) achieves its goal of expanding access to quality, affordable coverage for everyone in America. As part of these efforts, we applaud the significant work that the Centers for Medicare & Medicaid Services (CMS) have dedicated to developing and streamlining the applications that individuals and families can use to apply for coverage through the Health Insurance Marketplaces, Medicaid, and the Children's Health Insurance Program (CHIP). We appreciate the opportunity to offer comments on these applications as part of our joint efforts with you to ensure that the benefits of the ACA reach everyone who needs them

In general, we strongly support CMS in gathering demographic data from all applicants and non-applicants as part of the enrollment process for Marketplace, Medicaid, or CHIP coverage. These data, if properly collected, protected, and used, will help CMS achieve the goal of providing all applicants with timely and accurate information about their eligibility for coverage, advance premium tax credits, and other benefits. These data are also key to compiling a comprehensive portrait of the population that these programs serve and ensuring that services are provided in an appropriate and nondiscriminatory manner.

In particular, we believe it is vital for the applications to collect data on demographic factors associated with disparities in access to health coverage and care. These factors include race, ethnicity, disability, primary language, sex (including gender identity), and sexual orientation. Our comments on the application focus primarily on the importance of ensuring that the application collects information related to sex (including gender identity) and sexual orientation as part of ongoing efforts under the ACA to address disparities affecting the lesbian, gay, bisexual, and transgender (LGBT) population.

I. The LGBT population experiences significant disparities related to sex (including gender identity) and sexual orientation.

The LGBT population is diverse and includes individuals of all racial, ethnic, and socioeconomic backgrounds, among other differences. Regardless of their backgrounds, however, many LGBT people and their families across the U.S. today share common experiences of disparities in health status and in access to health care and coverage. A major disparity is significantly lower rates of health insurance coverage among the LGBT population compared to the general population.[1]

While we do not have adequate data from large-scale federally supported surveys to fully understand disparities in access to coverage for the LGBT population, the limited available data from smaller studies indicates that the coverage gap for LGBT people is profound: A recent study found, for instance, that 26 percent of LGBT people with incomes less than 400 percent of the Federal Poverty Level did not have insurance coverage in 2014,[2] and LGBT individuals across all income levels were less likely than the non-LGBT population to have coverage.[3]

This coverage gap has serious negative consequences for the wellbeing of LGBT individuals and exacerbates other health disparities affecting the LGBT population, which include higher rates of mental health concerns such as depression and suicide attempts, greater risk of HIV/AIDS, and higher risk of certain cancers, such as breast cancer.[4] These disparities are even greater for LGBT people who are also members of other groups disadvantaged because of their race, ethnicity, or other aspects of their identity.[5]

II. Collecting data related to sex (including gender identity) and sexual orientation is critical to better understanding and addressing these disparities.

Robust data collection on sex (including gender identity) and sexual orientation must be a critical component of efforts to address these disparities. Unfortunately, the applications outlined in CMS-10440 do not currently collect data on sex in a manner that is inclusive of transgender individuals—who are primarily distinguished from the non-transgender population by the difference between the sex they were assigned at birth and their gender identity.[a] They also do not collect any data on sexual orientation. This lack of data deprives policymakers, researchers, and advocates of crucial information about the degree to which the health reform effort is helping close the LGBT coverage gap and other related disparities.

Making efforts to address LGBT disparities via the routine, standardized collection of sex (including gender identity) and sexual orientation data has become a significant priority for the U.S. Department of Health and Human Services (HHS), particularly under the ACA. For instance, over the last several years HHS has:

- Drawn on its authority under ACA Section 4302 to develop a strategy for initiating the collection of sexual orientation and gender identity data through its flagship health survey, the National Health Interview Survey;[6]
- Developed a sexual orientation and gender identity data collection module for the largest federally supported health survey, the Behavioral Risk Factor Surveillance System (BRFSS); as of 2015, at least 24 states and territories were using this module on

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[a] A transgender individual is someone whose gender identity—the individual's innate, core sense of gender—is different from the sex that the individual was assigned at birth, meaning the sex that is on the individual's original birth certificate. A transgender man is a man who was assigned female at birth, and a transgender woman is a woman who was assigned male at birth. Some transgender individuals identify outside the male/female gender binary.

their BRFSS questionnaires, in addition to approximately a dozen other states and territories that ask about sexual orientation and/or gender identity using questions that differ from this module;[7]

- Increasingly added sexual orientation and/or gender identity demographic questions to surveys and programmatic data collection instruments at the Substance Abuse and Mental Health Services Administration, the Health Resources and Services Administration, and other divisions across the Department[8]

In order to effectively address LGBT health disparities, including those affecting multiply disadvantaged groups such as LGBT communities of color, the applications outlined in CMS-10440 should clarify the existing sex question to be inclusive of transgender individuals. They should also begin collecting demographic data on sexual orientation on a voluntary basis, similar to the current collection of race and ethnicity data on these applications.

III. Models exist for asking questions on sex (including gender identity) and sexual orientation that are appropriate for the application context.

Models already exist for how data on sex (including gender identity) and sexual orientation can be collected on both the electronic and paper applications outlined in CMS-10440. Specifically, we recommend updating the current sex question to clarify what is being asked and to incorporate gender identity, which is an important component of sex. This approach will reduce the risk of identity verification failure for transgender applicants, ensure that the applications appropriately assess eligibility for benefits for all individuals who can become pregnant (which includes transgender men, who are individuals with a male gender identity who were assigned female at birth), and aid insurance carriers in addressing concerns of fraud related to claims for services that appear to conflict with an individual's recorded sex. We also recommend adding a question about sexual orientation immediately after the questions about ethnicity and race. Like other commenters, we support the collection of race, ethnicity, and other demographic data from ***all*** applicants and non-applicants, not just from the primary point of contact for the application.

A. Sex (including gender identity)

The sex question asked on all versions of the application presently has two answer options: "male" and "female." We recommend updating this question to the two-step question for sex (including gender identity). On both the online and paper applications, this question would replace the current sex question that is asked for each applicant immediately after the applicant's Social Security number. This question has two parts because many transgender individuals identify simply as men or women, meaning that their transgender status is only apparent through the difference between their gender identity and the sex that they were assigned at birth. This question should be asked as follows, with the sex assigned at birth question asked immediately after the gender question:

What is your gender?

- *Female*
- *Male*
- *Transgender: Male to Female*

- *Transgender: Female to Male*

What is the sex listed on your original birth certificate?

- *Female*
- *Male*

These two data points—gender and sex assigned at birth—have the following utility:

Identity verification

The existing sex question is troubling to many transgender applicants, who report being unsure of how to answer, particularly when their gender identity does not match their official identity documents. While some transgender people have changed their sex on record with the Social Security Administration (SSA) and in other state and federal records, there are many transgender people whose SSA files and other records are still listed under the sex they were assigned at birth and therefore do not match their current gender identity. When filling out the application, these individuals must either misrepresent themselves or risk having their application delayed because they fail identity verification. In particular, while HealthCare.gov does not check sex as part of the identity verification process, a state may have a process of establishing eligibility for Medicaid that does involve a check of sex data and therefore exposes transgender individuals to identity verification failure.

The two-step question will facilitate a better application experience for transgender individuals and will help ensure that their applications are appropriately processed. With this question design, identity verification would follow these steps:

1. Compare the "gender" data to official records as relevant.
2. If identity verification fails due to a gender mismatch, compare the "sex assigned at birth" data to the records in question.

Pregnancy

Some transgender men—men who were assigned female at birth—retain the ability to become pregnant and give birth to a child. Because pregnancy affects household size and eligibility for Medicaid benefits, it is important that transgender men are not screened out of questions on the electronic application regarding pregnancy. In order to ensure that transgender men can correctly identify themselves as men without being forced into a skip pattern that causes them to bypass the pregnancy questions, the skip pattern around the questions related to pregnancy on the electronic application should be driven by the data on sex assigned at birth.

Claims processing

The two-step question design will also aid insurance carriers in appropriately complying with new requirements related to nondiscrimination in coverage of preventive screenings that are typically associated with only one sex, such as prostate exams, mammograms, and cervical Pap tests.[9]

Specifically, the “sex assigned at birth” data would be reported to insurance companies, Medicaid, and CHIP for purposes purely related to claims processing. These data will facilitate the provision of and reimbursement for services that do not appear to conform to the individual’s gender on file with the carrier. For example, an individual listed as male could still be covered for a cervical Pap test, without delay or denial, because the insurance company would have data on record indicating that the individual’s sex assigned at birth was female.

The “gender” data collected on the application would be used as follows:

- Individuals answering *male* or *transgender male* to the gender question would be enrolled in coverage as male.
- Individuals answering *female* or *transgender female* to the gender question would be enrolled in coverage as female.

This information would be used for all official correspondence with the enrollee, their medical providers, and benefit managers.

B. Sexual orientation

We recommend adding a question about sexual orientation in conjunction with the existing questions on race and ethnicity. Like these other demographic questions, sexual orientation should be optional information gathered solely to help ensure that everyone has the same access to coverage. On both the online and paper applications, this question should immediately follow the optional questions on race and ethnicity that are part of the first page of information filled out for each applicant:

Do you consider yourself to be:

- *Straight or heterosexual*
- *Gay or lesbian*
- *Bisexual*
- *Other*

Collecting sexual orientation and sex (including gender identity) data in the manner recommended above has many purposes. Among other uses, it will broadly promote better understanding of consumers from diverse backgrounds; help monitor compliance with LGBT-inclusive nondiscrimination requirements; and facilitate the functioning of operations related to outreach and consumer assistance.

IV. Adding these questions to the applications is realistic and feasible.

Updating the applications to improve the mandatory sex question and add an optional sexual orientation demographic question is a realistic and feasible approach to ensuring that the Marketplaces, Medicaid, and CHIP are able to optimally serve all applicants, including LGBT individuals.

The Affordable Care Act allows demographic data to be collected on coverage applications so long as responses are not required to any questions not strictly related to establishing eligibility for coverage.[10] CMS guidance on this matter reiterates that states may not require responses to questions not directly related to eligibility, but neither the ACA nor CMS guidance prohibits states from asking any such questions as long as responses are not required.[11]

We are aware that, for a family application, a single individual is charged with filling out the application for all family members. Because this raises concerns around the reporting of potentially sensitive data such as sexual orientation, we strongly believe that the sexual orientation question—like the race and ethnicity questions—should be optional.

Recent research does indicate, however, that asking sexual orientation and sex (including gender identity) questions in the coverage application context is acceptable to a substantial majority of LGBT individuals. Overall, 86 percent of a nationally representative sample of LGBT adults with incomes under 400 percent FPL would agree to answer these questions on a Marketplace application, and this willingness does not vary significantly at lower income levels—in fact, 87 percent of respondents with incomes under 139 percent FPL said they would answer these questions, compared to 93 percent with incomes between 139 and 200 percent FPL and 85 percent with incomes between 201 and 300 percent FPL.[12]

As is the case with race and ethnicity data, the minimal burden of responding to a demographic question related to sexual orientation and to a sex question that includes gender identity is balanced by the overriding importance of these data to ensuring that the Marketplaces, Medicaid, and CHIP are able to provide appropriate services to all applicants, particularly those who are members of populations that experience health disparities. **As part of the process of updating the federal applications, we therefore strongly urge CMS to also explicitly clarify that State-Based Marketplaces (SBMs) may update their applications to improve the sex question as described above and to add an optional sexual orientation question in the section of the application that includes the optional race and ethnicity demographic questions.**

We also urge CMS to confirm that the questions outlined above are a floor, not a ceiling. For instance, CMS should clarify that, if an SBM currently wishes to add additional categories to the "gender" question to better reflect the needs of non-binary and gender-nonconforming individuals (e.g., individuals who identify outside the male/female gender binary), they are allowed to do so, and we encourage HealthCare.gov to take this step for the federal applications in the future. In general, we very strongly urge HealthCare.gov to work with SBMs, insurance carriers, and other Marketplace stakeholders to evolve their systems to better recognize and reflect the realities of non-binary and gender-nonconforming individuals, particularly given the issues affecting this population that are addressed in the proposed rule on ACA Section 1557.

V. Robust nondiscrimination and privacy protections are critical corollaries to improved data collection on sexual orientation and sex (including gender identity).

We strongly support the continued inclusion on the paper applications of a statement clarifying that the ACA provides protections from discrimination on the basis of race, color, national origin, sex, age, sexual orientation, gender identity, and disability. We are concerned to note, however, that the electronic version of the application does not include this information. We therefore recommend that the following language from the written form be added to Section II, "Privacy," on the electronic application as outlined in "Attachment A: List of Items in the Electronic Application to Support Eligibility Determinations for Enrollment through the Health Insurance Marketplace and for Medicaid and the Children's Health Insurance Program" (added text in italics):

> … We won't ask any questions about your medical history. Household members who don't want coverage won't be asked questions about citizenship or immigration status.
>
> *Federal law prohibits discrimination on the basis of race, color, national origin, sex, age, sexual orientation, gender identity, and disability. You can file a complaint of discrimination by visiting **www.hhs.gov/ocr/office/file**.*

VI. Conclusion

Collecting more and better data on underserved populations is a critical component of ensuring that the benefits of the ACA reach everyone who needs them. The applications outlined in CMS-10440 are central to the health reform effort, and we appreciate your attention to ensuring that these forms allow applicants to share information that will expedite the processing of their applications without delay or error and that will help the Marketplaces, Medicaid, and CHIP optimally serve diverse populations.

Thank you for your consideration of this important issue, and we look forward to working with you to ensure that all Marketplaces, Medicaid programs, and CHIP programs are clearly open and welcoming places where everyone—including LGBT people and their families—can have access to quality, affordable coverage. If you have any questions or need further information, please contact Kellan Baker, Senior Fellow at the Center for American Progress, at kbaker@americanprogress.org or (805) 390-2309.

Sincerely Yours,

Adolescent Counseling Services (CA)
AIDS Alabama
AIDS Foundation of Chicago
AIDS Project Los Angeles
APLA Health & Wellness (CA)
California Lesbian, Gay, Bisexual, and Transgender Health and Human Services Network
California Pan-Ethnic Health Network
Callen-Lorde Community Health Center (NY)
CAMP Rehoboth Community Center (DE)
Campus Pride
Center for American Progress
Coalition for Asian American Children and Families (NY)
Colorado Consumer Health Initiative
Colorado Organization for Latina Opportunity and Reproductive Rights (COLOR)
Community Catalyst

Community Healthcare Net (NY)
Consumers for Affordable Health Care (ME)
Empire Justice Center (NY)
Empire State Pride Agenda (NY)
Equality California
Equality Delaware Foundation
Equality Delaware Inc.
Equality Federation
Equality Florida
Equality North Carolina
Equality Pennsylvania
Equality Virginia
Fair Wisconsin
Fairness Campaign (KY)
Families USA
Family Equality Council
FORGE, Inc. (WI)
Foundation for a Healthy Kentucky
FreeState Legal/Equality Maryland
Georgia Equality
Georgians for a Healthy Future
GLMA: Health Professionals Advancing LGBT Equality
Health Action New Mexico
Hispanic Health Network (CT)
HIV Prevention Justice Alliance (IL)
Imperial Valley LGBT Resource Center (CA)
Kentucky Health Justice Network
Kentucky Voices for Health
Latino Commission on AIDS
Legacy Community Health (TX)
Lesbian Health Initiative of Houston, Inc.
Lesbian, Bisexual, Gay and Transgender Caucus of the American Academy of Physician Assistants, Inc.
Lesbian, Gay, Bisexual & Transgender Community Center, New York City
LGBT Task Force of Health Care for All NY
Maryland Citizens' Health Initiative Education Fund
Maryland Women's Coalition for Health Care Reform
Metro New York Health Care for All
Minnesota AIDS Project
Montana Women Vote
National Alliance of State & Territorial AIDS Directors
National Black Justice Coalition
National Center for Lesbian Rights
National Center for Transgender Equality
National Latina Institute for Reproductive Health
National Latino AIDS Action Network
National LGBT Cancer Network
New Hampshire Voices for Health

New York Lawyers for the Public Interest
NM Religious Coalition for Reproductive Choice
North Carolina Justice Center
Northwest Health Law Advocates (WA)
OASIS-Latino LGBT Wellness Center (NY)
One Colorado
Oregon Foundation for Reproductive Health
Our Family Coalition (CA)
Out2Enroll
OutFront Minnesota
Planned Parenthood Federation of America
PFLAG National
Phoenix Pride LGBT Center
Pride Action Tank (IL)
Pride Center of Staten Island (NY)
Progressive Leadership Alliance of Nevada
PROMO (MO)
Rainbow Health Initiative (MN)
Raising Women's Voices
Resource Center (TX)
RiverStone Consulting (NY)
Saint Louis Effort for AIDS (MO)
Seedco (NY)
Service Employees International Union
Southwest Louisiana Area Health Education Center
Southwest Women's Law Center (NM)
St. Francis College School of Nursing (NY)
Stonewall Columbus (OH)
The Gender Wellness Center/AO Fox Hospital/The Bassett Health Care Network (NY)
The Health Initiative (GA)
The Sargent Shriver National Center on Poverty Law
Transcend Legal (NY)
Transgender Law Center (CA)
UHCAN Ohio
UR Medicine (NY)
Utah Health Policy Project
Whitman-Walker Health (DC)
Women's Way (PA)
Young Invincibles

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[1] Gates GJ. (2014). In U.S., LGBT more likely to be uninsured than non-LGBT. *Gallup Well-Being*. Available from http://www.gallup.com/poll/175445/lgbt-likely-non-lgbt-uninsured.aspx

[2] Baker KE, Durso LE, Cray AS. (2014). *Moving the Needle: The Impact of the Affordable Care Act on LGBT Communities*. Available from https://www.americanprogress.org/issues/lgbt/report/2014/11/17/101575/moving-the-needle/

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[3] Gates, *supra* note 1

[4] U.S. Department of Health and Human Services. (2010). "Lesbian, Gay, Bisexual, and Transgender Health." Available from http://www.healthypeople.gov/2020/topicsobjectives2020/overview.aspx?topicid=25

[5] Institute of Medicine. (2011). *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding*. Available from http://www.iom.edu/Reports/2011/The-Health-of-Lesbian-Gay-Bisexual-and-Transgender-People.aspx

[6] U.S. Office of Minority Health. (2011). Improving Data Collection for the LGBT Community. Available from http://minorityhealth.hhs.gov/templates/content.aspx?lvl=2&lvlid=209&id=9004

[7] Unpublished research from the Center for American Progress. (2015).

[8] See, e.g., http://www.samhsa.gov/prevention/specific-populations and http://www.hrsa.gov/LGBT/annualreport.pdf

[9] Centers for Medicare and Medicaid Services, Center for Consumer Information and Insurance Oversight. (2015). FAQs about Affordable Care Act Implementation (Part XXVI). Available from: https://www.cms.gov/cciio/resources/fact-sheets-and-faqs/downloads/aca_implementation_faqs26.pdf

[10] 45 C.F.R. 155.405, 45 C.F.R. 155.260

[11] Centers for Medicare and Medicaid Services, Center for Consumer Information and Insurance Oversight. (June 18, 2013). Guidance on State Alternative Applications for Health Coverage. Available from https://www.cms.gov/CCIIO/Resources/Regulations-and-Guidance/Downloads/state-alt-app-guidance-6-18-2013.pdf. This guidance states, "States must only ask questions that are necessary for determining eligibility for coverage in a Qualified Health Plan (QHP) and all insurance affordability programs, or for the administration of these programs. Questions that are not essential to these purposes or programs cannot be required."

[12] Unpublished research from the Center for American Progress. (2014).