Dear Secretary Sebelius:

As we commemorate World AIDS Day – we are reminded how important the Affordable Care Act (ACA) is to people with HIV across the country and to realizing the goals of the National HIV/AIDS Strategy. With this in mind, the HIV Health Care Access Working Group (HHCAWG) is sending this letter as a follow up to our October 16, 2013 correspondence.

HHCAWG remains firmly committed to supporting full and effective implementation of the ACA. We are writing to alert you to several issues that are presenting serious challenges to the enrollment process and could have negative consequences for people with HIV when coverage begins. We look forward to discussing these issues with you or your staff.

Qualified Health Plan Information

The availability of Qualified Health Plan (QHP) benefits summaries, drug formularies, and provider directories prior to registration are an important improvement to healthcare.gov. Further improvements are needed to provide people with HIV and others with chronic conditions the detailed information necessary to select the QHP that will best meet their medical needs.

Provider Networks: Access to medical providers with HIV expertise is a critical component of effective HIV care, and it is important to provide people with HIV the option of staying with their current providers. This is especially true for people currently receiving care through the Ryan White Program. It remains difficult to determine which HIV medical providers are participating in QHP networks in part because the directories do not identify when providers have HIV expertise. In addition, it can be difficult to determine the out-of-pocket fees for primary care and specialty visits. We urge the Center for Consumer Information and Insurance Oversight (CCIIO) to:

- Make the Essential Community Provider data submitted by QHPs available to navigator organizations, certified application counselors, and state HIV/AIDS programs, so they can help potential enrollees fully evaluate their coverage options.
- Specify the directory link that applies to a specific QHP. Enforce requirements for plans to maintain accurate and up-to-date provider directories. The provider directory links often provide access to the provider directories for all of the health insurer’s products making it difficult to determine which directory corresponds to a specific QHP.
- Require QHPs to identify providers with HIV expertise within their provider directories.
- Ensure the costs associated with seeing in- and out-of-network primary care and specialty providers are clearly stated as well as when the deductible applies to medical visits, including primary care visits.

Drug Formulary Information: A critical factor for people with HIV in selecting a health plan is coverage of their medications and the associated out-of-pocket costs. This is particularly important with respect to
HIV medications because substitutions can have serious negative health consequences and cost-sharing or coinsurance for these medications can be prohibitively high. In addition, many Ryan White AIDS Drug Assistance Programs (ADAPs) still do not have access to the information they need to conduct the evaluation required for them to provide premium assistance. The inability of ADAPs to access QHP formulary details is delaying enrollment for many people with HIV. **We urge CCIIO to:**

- Work with the HIV/AIDS Bureau to facilitate access to detailed QHP formulary information for ADAPs.
- Develop the functionality for enrollees to determine the estimated out-of-pocket costs for medications, including for drugs that require a coinsurance payment that is calculated based on the cost of the medication. *The current description of tiers provided by many plans is inadequate to determine the actual cost to the enrollee.*

**HIV Antiretroviral Coverage Concerns**

Where information is available, a number of disturbing trends are emerging regarding coverage of HIV antiretrovirals. We only have access to formulary data for a limited number of states and fear that the trends noted below may be widespread. The list below focuses on egregious cost-sharing designs, but we also continue to see QHPs that are not covering the HIV antiretrovirals recommended in the Department of Health and Human Services *Guidelines for the Use of Antiretroviral Agents (federal HIV treatment guidelines)*, including the single tablet regimens that are now recommended as the “preferred” course of treatment. We are concerned that QHPs may be employing these practices to discourage people with HIV from enrolling in their plan, which is illegal. Examples of the troubling plan cost-sharing designs are:

- Coventry placing all of the HIV antiretrovirals on Tier 5 requiring a 40 percent coinsurance after a deductible (of at least $1,000) and often prior authorization (Reported for Florida, Illinois, North Carolina, and South Carolina);
- BlueCross BlueShield of Georgia placing all of the HIV antiretrovirals on Tier 4 – the Specialty Tier with coinsurance up to 20 percent;
- Cigna placing all of the HIV antiretrovirals on Tier 5 with an up to 40 percent coinsurance after a deductible up to $2,750 (reported for Florida and possibly other states);
- Humana not posting its full HIV formulary online, suggesting to potential enrollees that they only cover six HIV antiretrovirals (reported for Florida, Alabama and other states) and in Florida placing all HIV drugs on a Tier 5 with a 50 percent coinsurance after a deductible;
- Aetna placing the majority of HIV drugs on Tier 3, which requires a 50 percent coinsurance, after a prescription drug deductible (reported in Florida); and
- Chinese Community Health Plan in San Francisco placing all available HIV drugs on a specialty tier with no cost sharing information available and requiring that all drugs on the specialty tier be accessed only through a specialty pharmacy.

**We urge CCIIO to investigate and resolve these issues immediately with the QHPs and to issue guidance to QHPs outlining examples of discriminatory plan designs, including placement of all of the HIV antiretrovirals that are widely prescribed on the highest cost sharing tier.** We also urge CCIIO to clarify the procedures plans must have in place to allow beneficiaries to request coverage for drugs that are not on a plan’s formulary (45 CFR § 156.122(c)) and to ensure that these procedures and policies are transparent. We also urge CCIIO to ensure that plans outline the procedures for adding new drugs to the formulary, differentiating between expedited and standard
review processes, and detailing the conditions under which each one is utilized. Finally, in evaluating coverage of HIV antiretrovirals for potentially discriminatory practices, it is important to reference the federal HIV treatment guidelines to ensure QHPs are not placing the older HIV medications on the lower cost-sharing tiers and leaving the preferred HIV antiretrovirals on the highest tiers.

Thank you for your prompt attention to these issues. We appreciate the progress that is happening every day with regards to ACA implementation and look forward to continuing to partner to ensure the ACA’s success. Please contact the HHCAWG co-chairs Andrea Weddle with the HIV Medicine Association (aweddle@hivma.org), Amy Killelea with the National Alliance of State & Territorial AIDS Directors (akillelea@nastad.org), or Robert Greenwald with the Treatment Access Expansion Project (rgreenwa@law.harvard.edu) to arrange a meeting.

Respectfully Submitted by the HHCAWG Steering Committee,


CC:

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Gary Cohen, CCIIO, Deputy Administrator and Director
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Melissa Harris, CMS Disabled & Elderly Health Programs Group, Director, Division of Benefits & Coverage
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