Discriminatory practices by Qualified Health Plans (QHPs) in the health insurance marketplaces, exorbitant drug pricing by the pharmaceutical industry, and a lack of clear guidance from the federal government regarding the legality of co-payment assistance programs for QHP beneficiaries are proving to be major barriers to affordable treatment for HIV and hepatitis C, according to a new policy guide produced by the Fair Pricing Coalition (FPC).

“The QHPs mandated by the Affordable Care Act are good news for many people living with HIV and/or hepatitis C, as it means they can’t be denied health insurance, because of pre-existing conditions,” explained FPC Co-Chair Lynda Dee. “This ensures the provision of essential health benefits, including important primary care services, access to specialists, and prescription drug benefits.

“However, many plans are proving financially disastrous for people living HIV, hepatitis C, and other chronic diseases,” Dee added. “This situation is made worse by high drug prices being set and increased annually by manufacturers, along with an inexcusable lack of direction from the U.S. Department of Health and Human Services regarding co-pay assistance programs for people receiving care under ACA-mandated plans.”

According to FPC’s policy guide, *Health Insurance Marketplace Plans and People Living with HIV and/or Viral Hepatitis: The Success of the Affordable Care Act Requires Fair Drug Pricing and Access*, numerous drug pricing and access issues are becoming increasingly apparent:

- Some health insurance companies are not including certain standard-of-care HIV medications in their formularies, essentially circumventing the non-discrimination backbone of ACA.
- Many QHPs are placing prescription medications for HIV and hepatitis C in “specialty drug” tiers (Tier 4 or 5), which impose extremely high out-of-pocket costs.
- High prices of drugs used to treat HIV and hepatitis C are a key driver of QHPs placing standard-of-care medications in the highest tiers, resulting in prohibitive out-of-pocket costs.
- QHPs are failing to be transparent regarding their drug formularies and the associated cost sharing, thereby prohibiting people living with HIV and/or hepatitis C from making educated plan choices.
- Some manufacturers and not-for-profit payers have indicated that they are unwilling to extend their co-payment assistance programs to QHP beneficiaries because of conflicting government guidance.

“These are major barriers to life-saving treatment, when in fact we need to be making access to affordable treatment as easy as possible,” said Tim Horn, an FPC member. “Nationally, only 25
percent of people living with HIV are receiving HIV treatment and keeping the virus in their blood in check. This is essential in terms of protecting their own health and preventing ongoing transmission of the virus. We need to get more people on treatment, not fewer, which won’t be possible if they cannot afford their costly medications.”

Among the possible short- and long-term solutions offered by the FPC:

1. Require access to all U.S. Department of Health and Human Services (HHS)- preferred and HHS-alternative antiretrovirals for HIV and all FDA-approved treatments for hepatitis C.
2. Monitor tiering of HIV and hepatitis C drugs for discriminatory practices, such as placing all recommended treatment options on the highest cost-sharing or specialty tiers.
4. Confirm Secretary of Health Kathleen Sebelius’ indication that manufacturers and non-profit payers may help defray out-of-pocket costs for medications under ACA through co-payment assistance programs.
5. Lower the out-of-pocket spending caps for individuals and families with incomes up to 250 percent of the federal poverty level.
6. Insist that insurance companies include HIV and hepatitis C expertise on their pharmacy and therapeutics committees or that they consult disease experts regarding formulary and tiering decisions.

“The problems outlined in the policy report are not insurmountable,” said Dee. “The FPC believes that the Affordable Care Act, while not perfect, has tremendous potential to redress disparities for U.S. residents whose access to healthcare has previously been at the whim of conflicting political and economic forces. This applies not only to HIV/AIDS and viral hepatitis, but also to many other chronic, debilitating, and costly health challenges beyond the capacity of individuals to manage on their own.”

The FPC supports urgent attention to these matters for all U.S. residents at this moment of new hope for achieving universal, affordable, quality health care.

The FPC policy guide can be accessed here:


The Fair Pricing Coalition (FPC), founded by the late Martin Delaney of Project Inform, is a national coalition of activists who work on HIV and viral hepatitis drug pricing issues and to help control drug costs for patients who are privately insured, underinsured and uninsured. The FPC also works to ensure access for recipients of state ADAPs, Medicare, and Medicaid as well as for other underinsured and uninsured individuals.