CENTER FOR HEALTH LAW & POLICY INNOVATION
Harvard Law School

ADMINISTRATIVE, REGULATORY AND LITIGATION ADVOCACY FOR PEOPLE LIVING WITH HIV:

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Center for Health Law and Policy Innovation

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Advocacy Tools: Consumer Feedback

- CHLPI, along with a team of national and state partners has established SPEAK UP to fight against barriers to access to care and treatment
- Through SPEAK UP we identify and address discrimination
- We need your to help to hold insurers and federal and state government leaders accountable for making the promise of health reforms a reality for people living with HIV in the South
- Assess the insurance plans in your state and let us know when you see an unfair or discriminatory

To JOIN US and SPEAK UP, visit:

http://www.hivhealthreform.org/speakup/

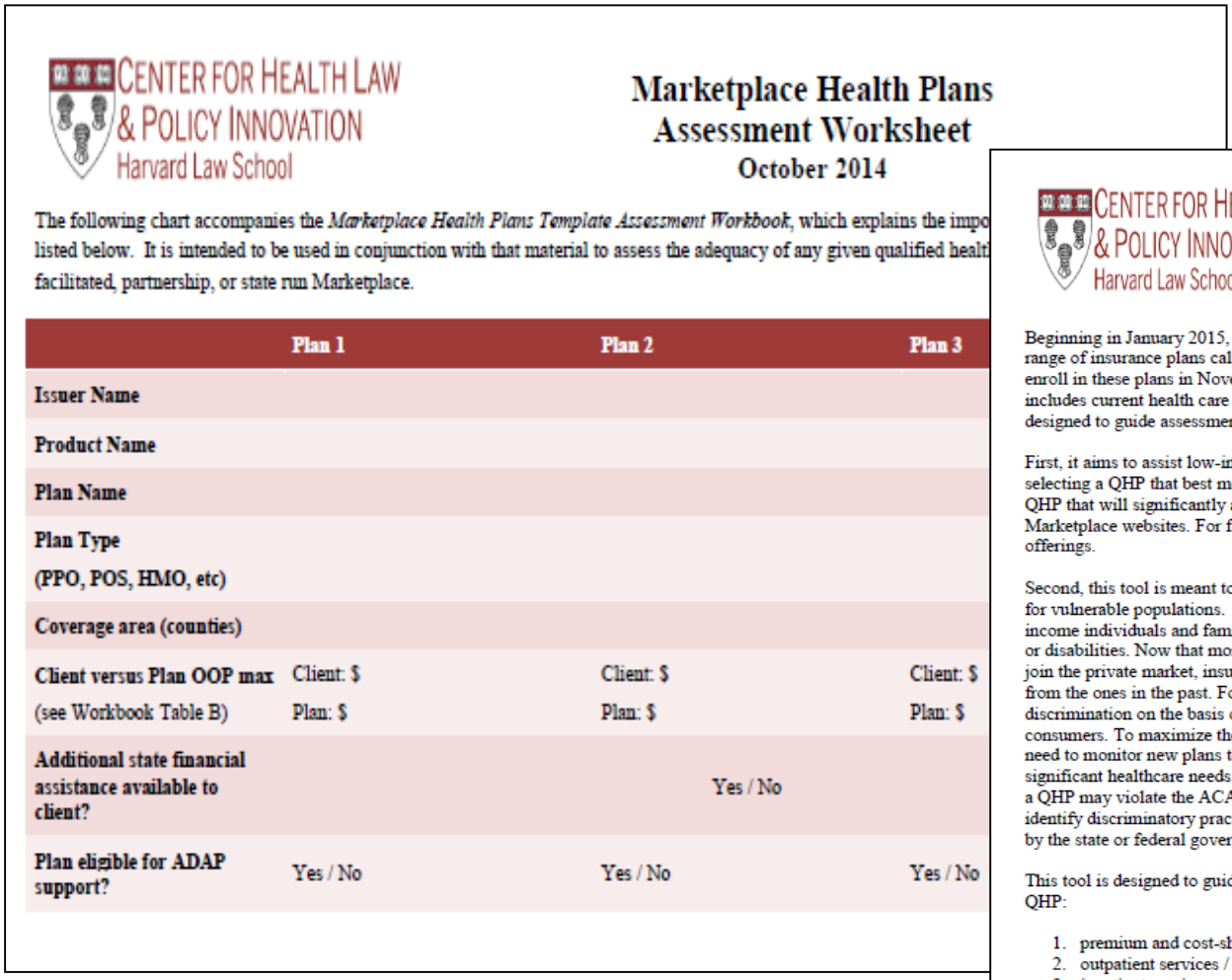
Advocacy Tools: Plan Analysis

- Analysis of available QHPs' cost sharing structures and formulary coverage is necessary to:
  - Help individuals select the plan that best meets their needs
  - Understand trends in the Marketplaces, including the adoption of discriminatory cost sharing practices

- Over the past two years of open enrollment, CHLPI has provided technical assistance for community based advocates or itself done a plan analysis of the QHPs available in many Southern states, including:
  - South Carolina
  - Louisiana
  - Mississippi

- This year CHLPI is spearheading an effort to
  - Train state based communities on plan analysis; and
  - Provide support through technical assistance and seed grants to build capacity in local communities to do this work year after year

Advocacy Tools: Plan Analysis



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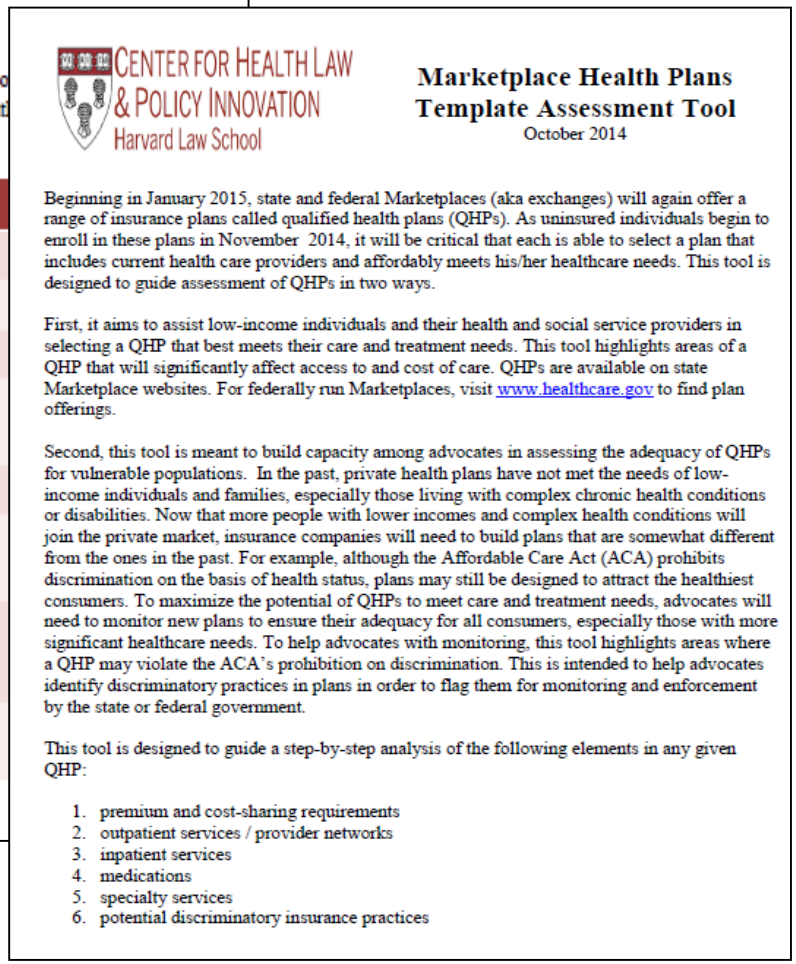
Marketplace Health Plans Assessment Worksheet
October 2014

The following chart accompanies the *Marketplace Health Plans Template Assessment Workbook*, which explains the impo
listed below. It is intended to be used in conjunction with that material to assess the adequacy of any given qualified healt
facilitated, partnership, or state run Marketplace.

	Plan 1	Plan 2	Plan 3
Issuer Name			
Product Name			
Plan Name			
Plan Type (PPO, POS, HMO, etc)			
Coverage area (counties)			
Client versus Plan OOP max (see Workbook Table B)	Client: $ Plan: $	Client: $ Plan: $	Client: $ Plan: $
Additional state financial assistance available to client?		Yes / No	
Plan eligible for ADAP support?	Yes / No	Yes / No	Yes / No



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Marketplace Health Plans Template Assessment Tool
October 2014

Beginning in January 2015, state and federal Marketplaces (aka exchanges) will again offer a range of insurance plans called qualified health plans (QHPs). As uninsured individuals begin to enroll in these plans in November 2014, it will be critical that each is able to select a plan that includes current health care providers and affordably meets his/her healthcare needs. This tool is designed to guide assessment of QHPs in two ways.

First, it aims to assist low-income individuals and their health and social service providers in selecting a QHP that best meets their care and treatment needs. This tool highlights areas of a QHP that will significantly affect access to and cost of care. QHPs are available on state Marketplace websites. For federally run Marketplaces, visit www.healthcare.gov to find plan offerings.

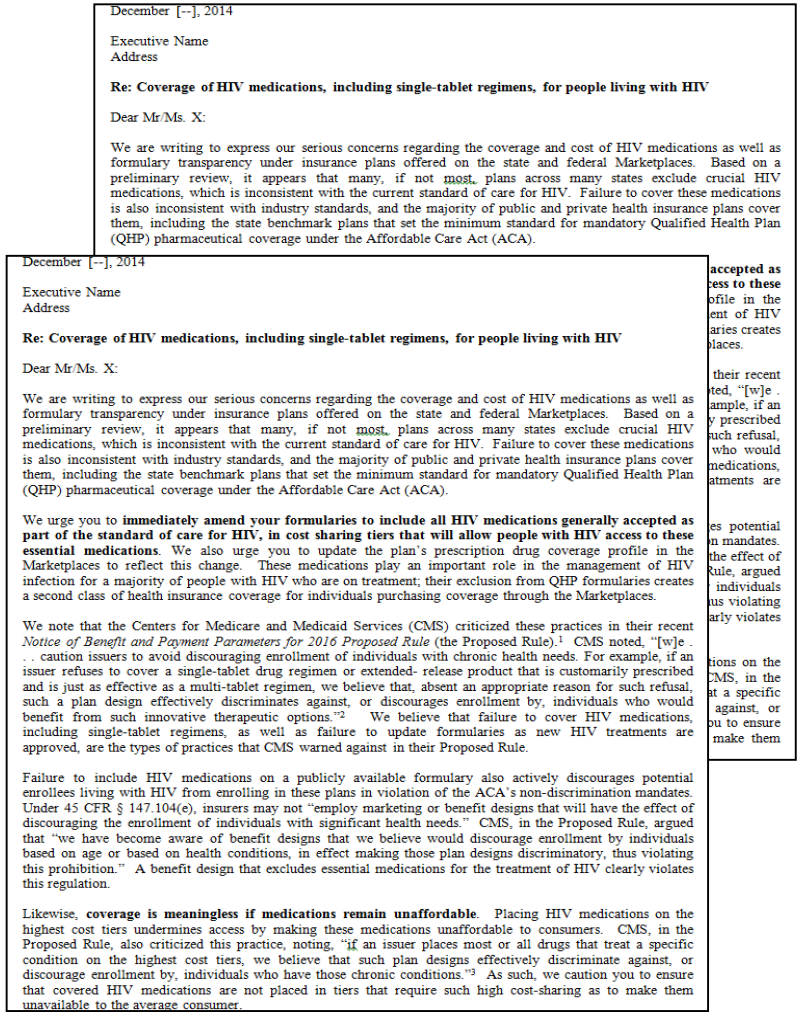
Second, this tool is meant to build capacity among advocates in assessing the adequacy of QHPs for vulnerable populations. In the past, private health plans have not met the needs of low-income individuals and families, especially those living with complex chronic health conditions or disabilities. Now that more people with lower incomes and complex health conditions will join the private market, insurance companies will need to build plans that are somewhat different from the ones in the past. For example, although the Affordable Care Act (ACA) prohibits discrimination on the basis of health status, plans may still be designed to attract the healthiest consumers. To maximize the potential of QHPs to meet care and treatment needs, advocates will need to monitor new plans to ensure their adequacy for all consumers, especially those with more significant healthcare needs. To help advocates with monitoring, this tool highlights areas where a QHP may violate the ACA's prohibition on discrimination. This is intended to help advocates identify discriminatory practices in plans in order to flag them for monitoring and enforcement by the state or federal government.

This tool is designed to guide a step-by-step analysis of the following elements in any given QHP:

1. premium and cost-sharing requirements
2. outpatient services / provider networks
3. inpatient services
4. medications
5. specialty services
6. potential discriminatory insurance practices

Advocacy Tools: Outreach to Insurers

- It is important not to skip reaching out to insurers
- CHLPI used its plan analysis to identify plans that failed to cover STRs
- CHLPI sent a letter to all major insurers in over ten states regarding this practice
- Several insurers, including Kaiser in California, modified their formularies in response to these letters



December [--], 2014

Executive Name
Address

Re: Coverage of HIV medications, including single-tablet regimens, for people living with HIV

Dear Mr/Ms. X:

We are writing to express our serious concerns regarding the coverage and cost of HIV medications as well as formulary transparency under insurance plans offered on the state and federal Marketplaces. Based on a preliminary review, it appears that many, if not most, plans across many states exclude crucial HIV medications, which is inconsistent with the current standard of care for HIV. Failure to cover these medications is also inconsistent with industry standards, and the majority of public and private health insurance plans cover them, including the state benchmark plans that set the minimum standard for mandatory Qualified Health Plan (QHP) pharmaceutical coverage under the Affordable Care Act (ACA).

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We urge you to **immediately amend your formularies to include all HIV medications generally accepted as part of the standard of care for HIV, in cost sharing tiers that will allow people with HIV access to these essential medications**. We also urge you to update the plan's prescription drug coverage profile in the Marketplaces to reflect this change. These medications play an important role in the management of HIV infection for a majority of people with HIV who are on treatment; their exclusion from QHP formularies creates a second class of health insurance coverage for individuals purchasing coverage through the Marketplaces.

We note that the Centers for Medicare and Medicaid Services (CMS) criticized these practices in their recent *Notice of Benefit and Payment Parameters for 2016 Proposed Rule* (the Proposed Rule).[1] CMS noted, "[w]e . . . caution issuers to avoid discouraging enrollment of individuals with chronic health needs. For example, if an issuer refuses to cover a single-tablet drug regimen or extended- release product that is customarily prescribed and is just as effective as a multi-tablet regimen, we believe that, absent an appropriate reason for such refusal, such a plan design effectively discriminates against, or discourages enrollment by, individuals who would benefit from such innovative therapeutic options."[2] We believe that failure to cover HIV medications, including single-tablet regimens, as well as failure to update formularies as new HIV treatments are approved, are the types of practices that CMS warned against in their Proposed Rule.

Failure to include HIV medications on a publicly available formulary also actively discourages potential enrollees living with HIV from enrolling in these plans in violation of the ACA's non-discrimination mandates. Under 45 CFR § 147.104(e), insurers may not "employ marketing or benefit designs that will have the effect of discouraging the enrollment of individuals with significant health needs." CMS, in the Proposed Rule, argued that "we have become aware of benefit designs that we believe would discourage enrollment by individuals based on age or based on health conditions, in effect making those plan designs discriminatory, thus violating this prohibition." A benefit design that excludes essential medications for the treatment of HIV clearly violates this regulation.

Likewise, **coverage is meaningless if medications remain unaffordable**. Placing HIV medications on the highest cost tiers undermines access by making these medications unaffordable to consumers. CMS, in the Proposed Rule, also criticized this practice, noting, "if an issuer places most or all drugs that treat a specific condition on the highest cost tiers, we believe that such plan designs effectively discriminate against, or discourage enrollment by, individuals who have those chronic conditions."[3] As such, we caution you to ensure that covered HIV medications are not placed in tiers that require such high cost-sharing as to make them unavailable to the average consumer.

Advocacy Tools: Regulatory Advocacy

- State insurance regulators have frontline oversight of the insurance market
  - Now oversee both the ACA Marketplaces & the traditional health insurance
  - Some states are actively engaged in their ACA responsibilities
  - Most states have not overhauled their insurance

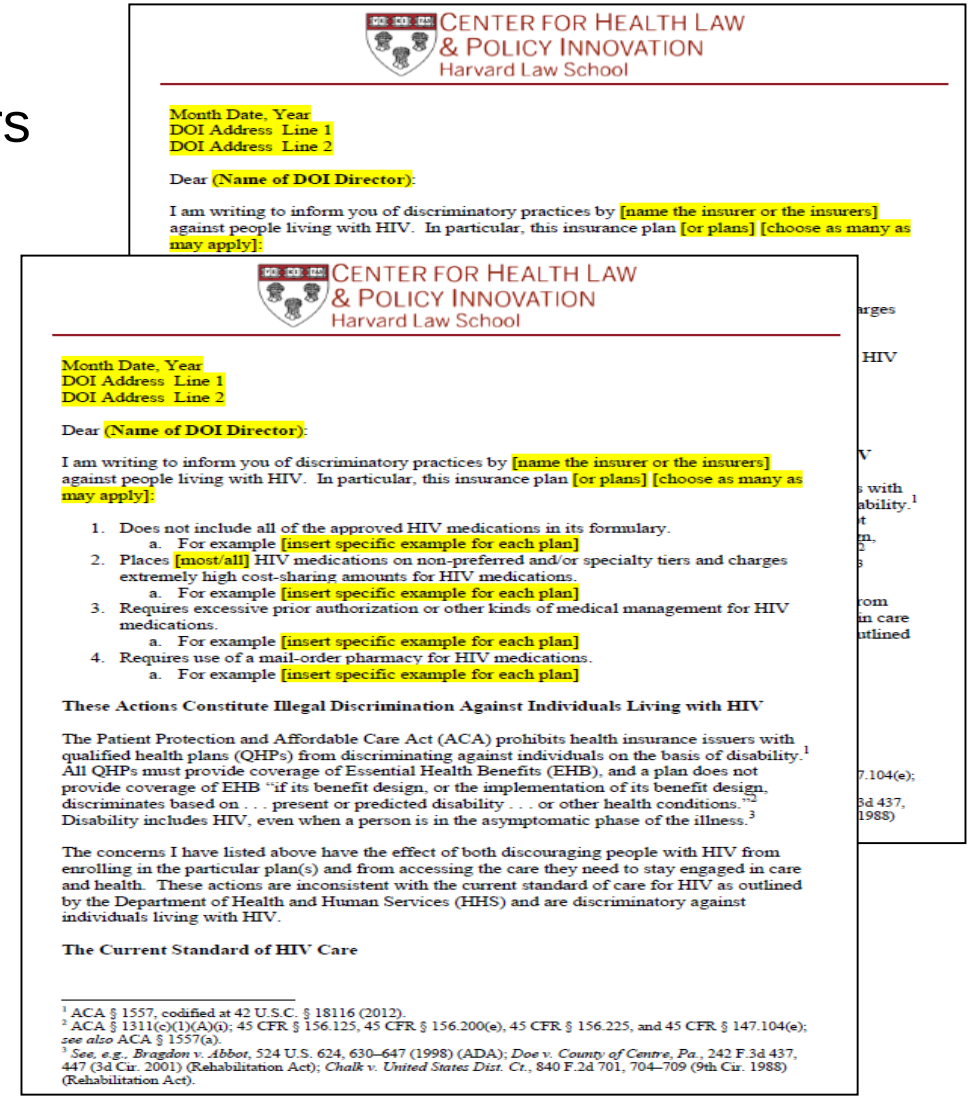
- State Department of Insurances (DOIs) must face consumer pressure
  - Few insurance regulators receive complaints from the HIV community documenting discriminatory practices
  - The lack of complaints allows them to ignore the discriminatory actions of their local insurers

- Appropriate topics for complaints to state regulators in private health insurance plans include:
  - Changing coverage after the open enrollment period ends
  - Refusing to cover the care and treatment people living with HIV need
  - Requiring unreasonably high cost-sharing for HIV treatment

ADVOCACY TOOLS: REGULATORY ADVOCACY

- The DOI Template supports the development of grievance letters from advocates/providers to state DOI regulators
  - A simplified version of the letter is also available for consumers
  - Both available at CHLPI.org

- The DOI Template can also be modified to send to insurers
  - Success in Louisiana when this letter was modified to send to insurers
  - Consider copying relevant insurers on the letter to regulators



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Month Date, Year
DOI Address Line 1
DOI Address Line 2

Dear (Name of DOI Director):

I am writing to inform you of discriminatory practices by [name the insurer or the insurers] against people living with HIV. In particular, this insurance plan [or plans] [choose as many as may apply]:

1. Does not include all of the approved HIV medications in its formulary.
   a. For example [insert specific example for each plan]
2. Places [most/all] HIV medications on non-preferred and/or specialty tiers and charges extremely high cost-sharing amounts for HIV medications.
   a. For example [insert specific example for each plan]
3. Requires excessive prior authorization or other kinds of medical management for HIV medications.
   a. For example [insert specific example for each plan]
4. Requires use of a mail-order pharmacy for HIV medications.
   a. For example [insert specific example for each plan]

These Actions Constitute Illegal Discrimination Against Individuals Living with HIV

The Patient Protection and Affordable Care Act (ACA) prohibits health insurance issuers with qualified health plans (QHPs) from discriminating against individuals on the basis of disability.[1] All QHPs must provide coverage of Essential Health Benefits (EHB), and a plan does not provide coverage of EHB "if its benefit design, or the implementation of its benefit design, discriminates based on . . . present or predicted disability . . . or other health conditions."[2] Disability includes HIV, even when a person is in the asymptomatic phase of the illness.[3]

The concerns I have listed above have the effect of both discouraging people with HIV from enrolling in the particular plan(s) and from accessing the care they need to stay engaged in care and health. These actions are inconsistent with the current standard of care for HIV as outlined by the Department of Health and Human Services (HHS) and are discriminatory against individuals living with HIV.

The Current Standard of HIV Care

[1] ACA § 1557, codified at 42 U.S.C. § 18116 (2012).
[2] ACA § 1311(c)(1)(A)(i); 45 CFR § 156.125, 45 CFR § 156.200(e), 45 CFR § 156.225, and 45 CFR § 147.104(e); *see also* ACA § 1557(a).
[3] *See, e.g., Bragdon v. Abbot*, 524 U.S. 624, 630–647 (1998) (ADA); *Doe v. County of Centre, Pa.*, 242 F.3d 437, 447 (3d Cir. 2001) (Rehabilitation Act); *Chalk v. United States Dist. Ct.*, 840 F.2d 701, 704–709 (9th Cir. 1988) (Rehabilitation Act).

ADVOCACY TOOLS: LITIGATION

- Litigation can be necessary, despite being costly and time consuming
  - State and federal regulators have said that litigation can provide helpful political cover
  - For example, the federal government issued an interim final rule requiring issuers of Marketplace plans to accept premium and cost-sharing payments made by the Ryan White program only after CHLPI filed a lawsuit against Louisiana insurers refusing to accept third party payments

- Litigation can and should happen at the same time as consumer feedback, plan analysis, outreach to insurers, and regulatory advocacy
  - Recently released regulations implementing Section 1557 of the ACA provide consumers with a private right of action
  - CHLPI has recently launched a litigation initiative to help combat insurance discrimination

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