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ACA Implementation for People with HIV:
Overcoming Challenges to Accessing Medications

U.S. Conference on AIDS
September 10, 2015

Carl Schmid
Deputy Executive Director
I Am (Still) Essential Campaign

• Broad coalition of disease groups representing the patient perspective
• Focus mainly on Essential Health Benefits & Rx coverage
• Administration initially proposed that every insurance plan had to only cover one drug per class
  – Strong Patient Community Reaction
FOR IMMEDIATE RELEASE
January 31, 2012

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MORE THAN 2,500 PATIENTS AND ADVOCATES CALL ON HHS TO ENSURE ESSENTIAL HEALTH BENEFITS PROVIDE COMPREHENSIVE, QUALITY AND AFFORDABLE HEALTH CARE

Patient Protections Must Remain the Highest Priority Say ‘I Am Essential’ Campaign & Other Petition Signers in Response to HHS Essential Health Benefits Bulletin

Washington, DC (January 31, 2012) — National advocacy organizations for chronically ill and disabled patients will file a petition today at 3pm with Department of Health and Human Services (HHS) Secretary Kathleen Sebelius voicing concern about HHS’ approach to Essential Health Benefits in the department’s December 16 bulletin. The petition will also serve as public comments on the bulletin, which are due to HHS today.

So far, more than 2,500 patients and advocates from 49 states, the District of Columbia and Puerto Rico
151 PATIENT GROUPS SEND LETTER TO HHS SECRETARY ON ESSENTIAL HEALTH BENEFITS PROPOSAL

The AIDS Institute, Arthritis Foundation, Easter Seals, National Alliance of Mental Illness, Parkinson’s Action Network, and others urge Secretary Sebelius to protect individual needs of patients

Washington, DC, December 18, 2012—One hundred and fifty-one patient groups delivered a joint letter to Secretary Kathleen Sebelius today, requesting improvements to the proposed Essential Health Benefits (EHB) rule issued by the Department of Health and Human Services (HHS) last month. The letter comes during the thirty-day comment period the department has offered before it finalizes rules for EHB coverage.

In its November 26 issuance, the HHS outlined the types of benefits, including those pertaining to prescription drugs, that insurance plans must cover beginning in 2014. Under the department’s proposed regulation, health plans must either cover one-drug per class or the same number of drugs as the state’s benchmark plan, whichever is greater.

The patient groups state in their letter to Secretary Sebelius that while the new rule marks an improvement from the “one-drug per class” proposal the department had previously advanced, it does not go far enough in safeguarding patient access to required medications. Because the rule only requires plans to meet a target number of drugs per class without regard to what actual drugs are covered, “plans can choose not to include certain necessary drugs for any reason, and still meet the requirements of EHB coverage,” the letter says.
Implementation Issues

• Limited benefits
  • Medications not covered on formularies
  • No process to include new Rx
  • Utilization management

• High cost-sharing
  • Use of co-insurance
  • HIV/AIDS Rx subject to co-insurance in about 55% of plans, with an average co-insurance of 35% (Avalere)
  • Placing all drugs in a class on highest tier (discrimination?)

• Lack of transparency and uniformity
  • Formularies difficult to access
  • Need for plan-finder tools
HHS Rule for Plans in the Future

- Improved Plan Transparency
- Improved Exceptions Process
- Prohibit Mail-order only Plans (2017)
- Define Discrimination
  
  “May be discrimination if a plan places all or almost all Rx to treat a certain illness on highest tier”
I AM (Still) ESSENTIAL

For Immediate Release
December 19, 2014

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279 Patient Groups Applaud Proposed Changes to Essential Health Benefits
Coalition Endorses Additional Patient Protections and Urges Further Action against Discrimination

Washington, DC (December 19, 2014) – Today, the “I Am (Still) Essential” coalition of patient groups sent a letter signed by 279 organizations to Health and Human Services (HHS) Secretary Sylvia Mathews Burwell applauding the recently released Notice of Benefit and Payment Parameters for 2016 which, once finalized, define Essential Health Benefits (EHB) for Qualified Health Plans (QHPs) in the future under the Affordable Care Act (ACA). The letter detailed how the many positive changes in the proposed rule will improve the plans available to patients. The letter also suggests additional changes that will increase positive patient outcomes and urges the rule to be finalized without diminishing any of the proposed improvements.
For Immediate Release
May 15, 2015

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219 PATIENT GROUPS URGE HHS TO SCRUTINIZE 2016 PLANS FOR HIGH COST-SHARING & DISCRIMINATION
CMS to Begin Plan Review on May 18th

Washington, DC – Today, the “I Am (Still) Essential” coalition of patient groups called on the Obama Administration to ensure that the many patient protections included in the Notice of Benefit and Payment Parameters for 2016 and the Letter to Issuers are adhered to and strictly enforced as part of the 2016 upcoming Qualified Health Plan (QHP) review.

The 219 patient and community organizations signed a letter to HHS Secretary Sylvia Mathews Burwell which stated, “We strongly urge you to ensure that CMS fulfills its duties and adequately reviews the 2016 plans…and reject QHPs that do not meet the ACA’s anti-discrimination standards.”
Importance of the Patient Voice

• “I Am (Still) Essential” has provided a unified voice for the patient community

• Ingredients to Success:
  • Focus on common, unifying issues
  • Use simple messaging
  • A way for patient groups from around the country to be educated and engaged
  • Numbers count
  • Use of media
  • Meetings with Administration
  • No great administrative and bureaucratic infrastructure
Next Steps

• 2016 Plan Review
  – Urge CCIIO to review plans for discrimination
  – React to Plans after Nov. 1

• Maximum Out of Pocket Costs for Individuals in Family Plans

• ACA Discrimination Proposed Rule

• 2017 Letter to Issuers

• Ongoing Implementation Issues

• Website and Social Media
Thank you!

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