Thank you for the opportunity to be heard. My name is Benjamin Powell. I am a litigation attorney for Consumer Watchdog, a nonprofit public interest organization based in Los Angeles, with offices in Washington D.C.

Consumer Watchdog is a non-profit, tax-exempt consumer research, education, litigation, and advocacy organization. Established in 1985, Consumer Watchdog utilizes a combination of litigation, advocacy, and public education to effectuate its mission. The staff of Consumer Watchdog includes some of the nation’s foremost consumer advocates and experts on consumer matters. Consumer Watchdog’s legal staff advocates on behalf of consumers before regulatory agencies, the legislature, and the courts. Over the course of three decades, Consumer Watchdog attorneys have represented consumers in numerous class actions, civil lawsuits, and administrative complaints challenging unfair business practices by insurers and large corporations. A particular focus of that litigation has been to challenge the illegal and unfair business practices of health insurance companies, health care providers, health maintenance organizations, and property-casualty insurance companies, including unlawful practices that violate consumers’ privacy and health care rights. Visit us on the web at: http://www.consumerwatchdog.org/.

I understand the Department has asked for testimony from stakeholders on a number of important topics related to the impact of the proposed merger of CVS and Aetna on market consolidation, health care costs, and provider networks. Consumer Watchdog shares those
concerns, but today I would like to focus on the concerns related to item five in the Department’s Notice of this hearing, namely how the proposed merger of Aetna and CVS will impact “the cost and quality of care delivered to consumers.” In particular, today my testimony will focus on medical privacy, which has been a major concern of our clients in recent years. Specifically, the privacy of those in California who require HIV/AIDS Medications.

In its announcement about the acquisition, CVS CEO Larry J. Merlo said, “With the analytics of Aetna and CVS Health’s human touch, we will create a health care platform built around individuals.” However, both CVS and Aetna have demonstrated multiple reasons to be extremely concerned about their lack of commitment to protecting the privacy of their enrollees. Their failures in the realm of consumer privacy should give the department considerable pause before deciding to approve this acquisition and subject Californians to the mercy of this consolidated entity.

Persons with HIV are still subject to stigma, humiliation, mental anguish, embarrassment, and stress based on their HIV status. One meta-analysis of 119 studies “demonstrated that perceived interpersonal risks are associated with HIV disclosure and outlined evidence of associations with anxiety, fear and worry.” Michael Evangeli and Abigail L. Wroe, HIV Disclosure Anxiety: A Systematic Review and Theoretical Synthesis, AIDS Behavior (2017) 21:1–11, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5216111/pdf/10461_2016_Article_1453.pdf. They may also run the risk of the loss of housing, relationships, and employment when their HIV status is revealed. A 2012 national survey by the Washington Post and the Kaiser Family Foundation showed that fewer than half of respondents would feel “very comfortable” working with someone who has HIV or AIDS, or having a teacher for their children who has HIV or AIDS. Only a third would feel “very comfortable” with having a
roommate who is HIV-positive, and fewer than a quarter would feel “very comfortable” having food prepared by someone who is HIV-positive. Washington Post and Kaiser Family Foundation, 2012 Survey of Americans on HIV/AIDS, https://kaiserfamilyfoundation.files.wordpress.com/2013/01/8334-f.pdf. Such studies and analysis demonstrate that even if HIV-positive individuals do not know and cannot show who may have been made aware of their HIV status, the risk of disclosure increases stress and anxiety, and results in personal harm and injury.

Beginning with Aetna, Consumer Watchdog has brought legal actions against the company multiple times, including one case surrounding HIV/AIDS privacy concerns over a mail-order medication program. Around 2013, HIV/AIDS patients began to complain that several health insurance companies intended to make radical and dangerous changes to their policies with respect to HIV/AIDS Medications. One of the most critical changes was a requirement that HIV/AIDS patients obtain their specialty medication prescriptions via mail order, barring these plan members from the long-standing practice of visiting a specialty retail pharmacist to obtain or renew their prescriptions. This constituted a threat to the health, safety, and privacy of patients, and violated both California and federal laws.

Consumer Watchdog, along with our colleagues at Whatley Kallas, LLP, brought lawsuits against United Healthcare Insurance Company and Anthem Blue Cross of California, the nation’s largest health insurers at the time, challenging their new mail order policies. Those two companies commendably agreed to resolve those cases by (1) permitting members to opt out of the mail-order program, and (2) providing compensation to any members who had already been compelled to use the mail-order program. The cases garnered much national media
attention and highlighted the threat to patient privacy and health that is synonymous with mail-order delivery of HIV/AIDS medications.

Against this backdrop, and despite the national attention, in November of 2014, Aetna sent letters to its members announcing that it would be implementing a mail-order requirement for certain HIV/AIDS Medications, raising all of the exact same concerns as in the previous cases. Aetna additionally made all visits to retail brick and mortar pharmacies “out of network,” subjecting plan members to potentially ruinous expenses. Aetna’s new mail-order program proposed to replace the expertise of pharmacists with access to an 800 number operated by Aetna and staffed by customer service representatives rather than trained pharmacists.

In 2014, Consumer Watchdog sued Aetna over its mandatory mail-order program for HIV medications.1 In 2015, we brought a related action against Aetna’s subsidiary, Coventry, in Florida.2

Consumer Watchdog argued that Aetna’s treatment of HIV/AIDS patients was discriminatory under the Affordable Care Act, the Americans with Disabilities Act, and civil rights law:

- Due to the complex nature of HIV/AIDS drug regimens, patients rely on their community pharmacists who, working directly with patients, monitor potentially life-threatening adverse drug interactions and side effects.

- Mail-order delivery of these medications, often requiring large refrigerated containers, is not a viable option for many patients and can raise major privacy implications, particularly for those individuals who have not revealed their medical condition to employers, co-workers, friends, and family members.

- Because there is no cure for HIV/AIDS, the virus continually mutates around the

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1 For more information and to access the Complaint filed in that matter, visit: http://www.consumerwatchdog.org/case/aetna-and-coventry-discriminate-against-hiv-aids-patients-violation-affordable-care-act

medications prescribed to treat it, requiring constant monitoring and immediate provision of new medication regimens to address changes in the disease. Periods of medication changes are particularly sensitive times for HIV/AIDS patients.

- Community pharmacists, who often have greater contact with HIV/AIDS patients than physicians and know their complete drug regimen, also provide essential advice and counseling that help HIV/AIDS patients and families navigate the challenges of living with a chronic and often debilitating condition.

- Aetna’s mail-order pharmacy program replaced these life-saving interactions with an 800 number that placed the burden of securing life-sustaining medications on chronically ill patients.

- HIV/AIDS patients were forced to call-in each month to renew their prescriptions—and work their way through automated robocalls, messages and multiple call center staff—increasing stress and fatigue for patients who are literally fighting to stay alive, exacerbating their condition.

- The use of mail-order providers also creates the very real risk of delayed, lost or stolen shipments, resulting in dire consequences for many patients who must strictly adhere to their medication regimes or face serious illness or death.

- If HIV/AIDS patients did not obtain their specialty medications by mail, they were required to pay full-price for their medications—easily thousands of dollars or more each month—to purchase their medications at their community pharmacy.

The lawsuits against Aetna and Coventry garnered extensive national media coverage.3

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After a hard-fought legal battle, we settled that case with a great outcome. Aetna agreed to remove HIV/AIDS medications from the exorbitantly-priced “specialty drug tier” and discontinued the mandatory mail-order prescription program that it put into effect for individual plan members, which plaintiffs alleged jeopardized the health and safety of their plan members who have HIV/AIDS.\(^4\)

Now, we’ve come to find out that even in settling that case, Aetna disregarded the privacy rights of its members in favor of, presumably, cutting costs. As part of that settlement, Aetna agreed to send a notice to all affected enrollees advising them of their right to obtain their HIV/AIDS Medications from a community pharmacy of their choice, where their privacy would be protected. In July 2017, Aetna or its vendor mailed the notice letter to approximately 12,000 individual Aetna enrollees nationwide using an envelope with an oversized glassine window. The envelope window displayed a portion of the text of the notice letter itself, disclosing the fact that the notice letter was being sent to those members of Aetna health plans who had been prescribed “HIV Medications.”

In so doing, Aetna disclosed approximately 12,000 individuals’ HIV status to any person coming into contact with the letter, including co-workers, neighbors, family members, roommates, apartment managers, and postal workers, egregiously violating their privacy rights.

Attorneys for Consumer Watchdog represent a John Doe HIV patient in an action against Aetna for this latest violation of patient privacy. The new lawsuit alleges Aetna breached the

\(^4\) For more information, visit: http://www.consumerwatchdog.org/courtroom/aetnacoventry-members-may-obtain-hivaids-meds-retail-pharmacies-protect-privacy
settlement agreement in the prior legal action by disclosing patients’ HIV status in a mailing sent by Aetna.5

Rather than accepting responsibility, Aetna has blamed others, including lawyers for Consumer Watchdog, for its own privacy breaches.6

While we would like to believe that if CVS is permitted to acquire Aetna, it would help Aetna solve its problems, we simply cannot expect CVS to acquire Aetna and clean up the mess, as CVS has demonstrated on multiple occasions that it does not put a priority on its own enrollees’ privacy rights. For example, Consumer Watchdog is involved in one lawsuit currently in California federal court against CVS for implementing its own mail-order requirement for HIV/AIDS Medications, very similar to the programs that were implemented by United and Anthem Blue Cross. CVS refuses to end the program, despite the aforementioned litigation and despite our continued insistence that the program has serious and unavoidable privacy consequences for its members taking HIV/AIDS Medications.

Additionally, in a case strikingly similar to Aetna’s egregious privacy breach, in the state of Ohio, CVS took almost exactly the same steps Aetna did, sending a letter to approximately 6,000 enrollees taking HIV Medications in an envelope with two glassine windows, showing the “CVS/caremark” logo, the words “Ohio Department of Health,” and the designation “PM 6402 HIV” directly above the enrollee’s name.

The reference to the recipient’s HIV status was plainly visible through the glassine window. With the envelope referring in big red letters to “new prescription benefits,” the privacy rights of these enrollees were once again blatantly violated.

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5 For more information and to access the Complaint filed in that matter, visit http://www.consumerwatchdog.org/courtroom/hiv-patient-advocates-announce-lawsuit-against-aetna-over-disclosures
Consumer Watchdog, along with co-counsel, represent three John Doe plaintiffs in a lawsuit against CVS in Ohio.\(^7\) The disclosure of patients’ HIV status violates Ohio Rev. Code section 3701.243. The John Doe plaintiffs—who have brought the class action anonymously to protect their privacy—seek an injunction against CVS, barring it from using a glassine envelope in the future for any communications where the HIV status of any individuals is referenced in any way.

In sum, both Aetna and CVS have a demonstrated lack of concern about the privacy of their enrollees, especially with regard to their customers who take HIV/AIDS Medications. There is simply no reason to expect that allowing CVS to acquire Aetna will result in any improvement whatsoever in these blatant violations of patient privacy. These companies have already exhibited that at current sizes, privacy considerations are simply not a priority. Allowing these organizations to consolidate into one, larger entity would surely worsen these problems, as more enrollees to manage will result in decreased attention to the problems plaguing this very at-risk and vulnerable segment of their customers. We urge the Commissioner and the Department to require these two companies to first demonstrate that they have a greater respect for privacy rights before the merger is consummated. To that end, as a condition of approving the merger, the Commissioner should require CVS to embed an independent privacy overseer in the company, reporting annually to the Commissioner and to the public on the actions taken by CVS and its newly-acquired subsidiary, Aetna, to ensure patient privacy within the merged company. This will provide the third-party accountability necessary to ensure that the health and privacy rights of affected consumers are protected.

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