



American Cancer Society ☞ Children's Defense Fund-New York ☞ Coalition for Asian American Children and Families ☞ Community Service Society of New York ☞ Empire Justice Center ☞ Make the Road New York Medicare Rights Center ☞ Metro New York Health Care for All Campaign ☞ New Yorkers for Accessible Health Coverage ☞ New York Immigration Coalition ☞ Public Policy and Education Fund of New York/Citizen Action of New York ☞ Raising Women's Voices-New York ☞ Schuyler Center for Analysis and Advocacy ☞ Small Business Majority ☞ Young Invincibles

October 17, 2016

Howard A. Zucker, Commissioner
New York State Department of Health
Corning Tower
Empire State Plaza
Albany, NY 12237

RE: Addition of Part 350 to Title 10 NYCRR (All Payer Database)

Dear Commissioner Zucker:

Thank you for the opportunity to comment on the proposed rules for New York's All-Payer Database (APD). Health Care for All New York (HCFANY) is a statewide coalition of over 170 organizations dedicated to achieving quality, affordable health coverage for all New Yorkers. We strive to bring consumer voices to the policy conversation, ensuring that the concerns of real New Yorkers are heard and reflected in policy decisions.

HCFANY is pleased to see the Cuomo administration is pushing forward on its commitment to transparency through the APD. Consumers are often asked to make decisions that affect their health and finances without trustworthy information. Skeptics have argued that consumers are not interested in more health data, but HCFANY sees greater transparency in health care as a priority. Some research into the issue has suggested that consumers currently fail to use quality and cost data when making health decisions. However, consumers have never operated in a world where that information is readily available. The APD is a chance for New York to create an independent source of data that would allow consumers to better engage in their own care and become better informed about New York's health care system.

Transparency is also an important consumer issue because it has been shown to improve overall system performance, even when consumers don't directly access that data. In a review of almost 200 articles, the Agency for Healthcare Research and Quality found that public reporting is associated with improved provider performance and health outcomes, including mortality rates.¹ In New York, the Department of Health has determined that public reporting of hospital

¹ Agency for Healthcare Research and Quality, "Public Reporting as a Quality Improvement Strategy," *Evidence Report/Technology Assessment* No. 208 (July 2012), <http://www.ncbi.nlm.nih.gov/books/NBK99879/>.



acquired infection rates has likely contributed to their decline.² Consumers benefit even when the primary consumers of public quality data are providers.

Please accept the following comments on specific items in the proposed rule:

350.1 Definitions

- The definitions included in (c)(1-4), (d), and (e) should specify that the APD will collect cost information in a way that makes direct costs to consumers visible. Those definitions should also specify that the APD will collect quality data needed for the state’s health transformation projects. Many of those projects, for example, the State Health Improvement Plan, have developed quality metrics based on their anticipation that this data will be available through the APD.³

The data collected by the APD should also allow analysis of disparities in access to care and health outcomes, which requires data on socioeconomic status, race and ethnicity, disability status, languages spoken, gender identity, and sexual orientation. Lack of data is a major barrier to eliminating health disparities. The APD would provide an important public service by building the capacity to analyze disparities into the system from the start. Additionally, the enabling statute refers to an annual report that is to include disparities data – this responsibility is not yet reflected in the regulations.

350.3 APD Data Release

- (b)(1) states that “de-identified and/or aggregated APD data of a public use nature may be posted publicly to a consumer facing website.” The consumer-facing website is an important part of the mission for an APD. It should not be considered optional, as “may” indicates. The APD is a very expensive project funded by public dollars – it should provide information that is directly accessible to the public. The regulations should specify that the purpose of this consumer-facing website is to provide consumers with price and quality information that can be used to make health care decisions.
- (2)(f) states that the Department shall establish a process for waiving fees for accessing APD data. While developing this policy, the Department should consider whether the resulting research will be posted freely for public use, and whether or not the entity requesting access has a public-service mission.

350.4 APD Advisory Group

- This section should explicitly describe the process for appointing members to the advisory group. If possible, there should be an open application for any stakeholders that are interested.

² New York State Department of Health, “Hospital-Acquired Infections: New York State, 2014,” (October 2015), http://www.health.ny.gov/statistics/facilities/hospital/hospital_acquired_infections/2014/docs/hospital_acquired_infection.pdf.

³ For example, see slide 52 of the Integrated Care Workgroup materials for April 11, 2016 – the scorecard for this project is almost entirely based on information to be gathered through claims data (http://www.health.ny.gov/technology/innovation_plan_initiative/docs/2016-04-11_integrated_care_presentation.pdf).



- The regulations should also specify that consumers and consumer advocates are to be part of the advisory group. The focus groups convened by the New York Academy of Medicine were a good first step, but that engagement with consumers should expand beyond focus groups. Experts believe that engaging patients in the design and governance of transformation projects will accelerate their progress and lead to better results.⁴ Other stakeholders, such as providers and payers, are likely to focus on the technical challenges of creating the APD. Consumers will help maintain a balance between acknowledging those challenges and producing the best possible result for the public. New York has a robust and diverse consumer advocacy community that can participate meaningfully in the governance and implementation of the APD. Reserving at least 25 percent of the advisory group's positions for consumers or consumer groups would be a good target.

Additionally, the Department should expand consumer representation on the Transparency, Evaluation, and HIT Workgroup, which is responsible for developing recommendations for the state's entire HIT portfolio. That group currently has much better representation from payers and providers than for consumers.

Thank you for your attention to these comments. Please contact me with any questions at adunker@cssny.org or 212-614-5312.

Sincerely,

Amanda Dunker, MPH
Health Policy Associate
Community Service Society of NY

⁴ Christine Bechtel and Debra L. Ness, *If You Build It, Will They Come? Designing Truly Patient-Centered Health Care*, Health Affairs, May 2010, vol. 29, no. 5: 914-920, doi: 10.1377/hlthaff.2010.0305; see also Esther Han et al., *Survey Shows That Fewer Than A Third of Patient-Centered Medical Home Practices Engage Patients in Quality Improvement*, Health Affairs, February 2013, vol. 32, no. 2: 368-375, doi: 10.1377/hlthaff.2012.1183.