

April 18, 2018

Oversight Council
Center for Health Information and Analysis
501 Boylston Street, Ste 5100
Boston, MA 02116

RE: CHIA Budget Annual Public Hearing (FY'19)

Dear Oversight Council:

My name is Cloud Cray, and I'm the founder of Patient Price, a company based here in Boston, dedicated to the reduction of healthcare costs through pricing transparency and health insurance literacy.

I am writing to express my concern over a specific portion of the proposed FY19 budget. The Oversight Council has proposed a \$750,000 retained revenue account to help fund the development, operation, and maintenance of the APCD - as this account is only to be funded by the sale of Case Mix and APCD data to third-parties such as my own, this effectively serves as a revenue target. While this number is down from last year's \$1,000,000, it still reflects an unreasonable goal for the center. Year-to-date, as FY18 approaches close, the center has only collected approximately \$422,000 between the Case Mix database and the APCD combined. Of that amount, \$75,000, or 18% of that revenue, came from my company alone.

Although this may be small in comparison to the operating budget of the center as a whole, and pales in comparison to contributions by payer and provider organizations, for us this was an incredible expense. We applied for access to the APCD around this time last year, then opted to receive the next release of the data once it was available, which we purchased last month. There are few companies our size who have been approved to access this data, and fewer still who have paid the full price to do so, and I would like to share a little of my experience.

We were approved to receive our data extract, but we received some disappointing news with that approval. We were clear in our application that we would be offering our tool for free to consumers, and thus we would not be reselling any data we received from CHIA. And yet, we were designated as "resellers", the highest-priced tier for purchasing data. I would also add that the definition of "resellers" has been amended twice since we first reached out. We also showed clear evidence that purchasing the data would be a significant financial burden to our company, but were denied any sort of waiver. In addition to that, we were given the caveat that we would not be allowed to actually use the data in production - rather, the center would need to approve of anything before we launched it, meaning we could very well be purchasing this data and never actually be able to use it. The center was unwilling to enter an alternate arrangement, such as "pay upon approval" - we would have to purchase the entire thing up front at the full price.

Despite these terms, we persisted. In the fall, we were told that the data would be ready by late November or early December, so we began to prepare accordingly. However, as you know, the data release was considerably delayed, and during that time, we incurred significant operational expenses.

But after sufficient fund raising, and after the data was ready for release, we cut the check for \$75,000 and received the data a few weeks later - last month.

Yet after all of that, we did not receive the full extent of the data requested. And despite our application explicitly stating the details we required twice, and despite confirmation from their staff that the information we need is available and should have been included in our extract, the center is attempting to charge us an additional \$18,000 to include this detail, insisting that would be a "discounted rate". Price concerns aside, this also continues to set back our already-delayed progress.

While the technical staff assured us that this would be a "quick" request to fulfill, the finance team has refused to even answer the phone to discuss the matter, insisting this be treated as an entirely new release of data, and that they intend to charge us as such. While the state regulation requires CHIA to charge "user fees sufficient to defray the center's cost of providing such access to non-governmental entities," this strikes me as excessive.

I'm not sure if my experience is an anomaly, or if this behavior is by design, but when a government agency is the sole gatekeeper of something like the APCD, and they are given certain targets of revenue, the temptation may be there to price things inappropriately, and not offer the support necessary for companies like mine once the check clears. I'm not certain that this is the appropriate venue to ask for help resolving this matter, but if this is a symptom of CHIA lacking resources to provide support, or a function of some annual revenue target, then I do need to bring it to attention today.

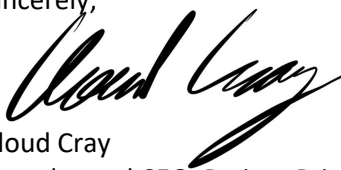
I understand that the center has high costs, has been dealt significant budget cuts in the last two years, and receives pressure from all sides. But setting an amount of revenue they are expected (or enticed) to generate, while simultaneously entertaining plans to release certain data publicly, sends mixed messages on the center's priorities as the sole steward of this data. This structure incentivizes the center to maximize the money they can extract from the healthcare ecosystem, rather than invest their expertise and data into organizations with missions aligned with theirs.

When I first reached out to CHIA, I was excited to work with an organization that shared my dedication to cost-reduction and pricing transparency. And yet despite that common mission, and despite providing 18% of the revenue they've generated from selling this data, CHIA is either unable or unwilling to give us the support we need to succeed.

I would like this counsel to consider how this budget, and ultimately any decision regarding the finances of CHIA, affects the culture of the organization and the Massachusetts health IT ecosystem as a whole. When I started this company, Massachusetts was the obvious choice - the progressive attitude towards pricing transparency and cost reduction, together with the willingness to adopt new technologies and to foster innovation in the health IT space, I knew that Boston was the place to be. However, at this rate, I certainly won't purchase next year's data. In fact, if these delays persist, my company may not be around anyway.

Thank you for your time.

Sincerely,

A handwritten signature in black ink, appearing to read "Cloud Cray". The signature is fluid and cursive, with a long, sweeping underline that extends to the right.

Cloud Cray
Founder and CEO, Patient Price Inc