March 1, 2017

Danielle Tarino
Substance Abuse and Mental Health Services Administration
U.S. Department of Health and Human Services
Attn: SAMHSA-4162-20
5600 Fishers Lane, Room 13N02B
Rockville, MD 20857

Re: Delay of Final Rule on the Confidentiality of Substance Use Disorder Patient Records

Dear Ms. Tarino,

AcademyHealth was recently made aware of Secretary Price’s desire to obtain additional public input regarding the rule governing substance use disorder (SUD) patient record disclosures.

By way of background, AcademyHealth is a nonpartisan, professional home to more than 4,000 health services researchers, policy analysts, and practitioners working to learn how our health system works, how to support patients and providers in choosing the right care, and how to improve health through care delivery. As such, we are deeply invested in the production and use of high-quality data – data that is secure, comprehensive, timely, and relevant – to ensure we have the greatest possible understanding of the factors affecting Americans and their health and health care.

Therefore, roughly three years ago, when our members began noticing data about patients with SUDs disappearing from Medicare and Medicaid files – both of which are used regularly in our field – we took on their concerns as our own. After all, these data offer by far the most comprehensive and detailed snapshot of health claims in the United States. Given the tremendous implications of these records’ removal for behavioral health services research (and for health services research more broadly), AcademyHealth responded to the Notice of Proposed Rulemaking (NPRM) on the Confidentiality of Substance Use Disorder Patient Records. Our comments can be found online here.

In our comments, we voiced our appreciation for SAMHSA recognizing the need to balance between research and privacy within the proposed rule as well as the critical need for researchers to have access to the data. As described in a post on The Incidental Economist blog in January, the withholding of these SUD records from those data sets have far-reaching repercussions, not the least of which is the compromised integrity of Medicare and Medicaid Research Identifiable Files, among others:

“The data scrubbing made it impossible to use Medicare and Medicaid records to study efforts to combat addiction and the consequences of substance use. Beyond that, the non-
random withholding of data would predictably skew research into any condition that was more common among people with substance use disorders…”

As our country grapples with how to tackle the growing opioid epidemic and to quell struggles with addiction and more, we need reliable, comprehensive data to study the approaches to advancing patients’ safety. Improving the lives of individuals who struggle with medical illnesses depends on solid research into quality care and outcomes, and patients with substance use disorders should have the same opportunities as other patients to benefit from such research.

We were greatly appreciative last year of the U.S. Department of Health and Human Services’ move to modernize the rule governing SUD disclosures to researchers, and we implore HHS to enact this rule. We owe it to American taxpayers to make the most of their dollars and to do our part to ensure they receive the best care possible, at the greatest value, with the best outcomes.

We hope you will move not delay the enactment of this rule any longer and will enact it on the newly proposed effective date of March 21, 2017.

If there is any assistance we can provide to the Department, or any questions we could answer, we would welcome the opportunity to work with you. Thank you for the opportunity to submit these comments.

Sincerely,

Lisa Simpson, MB, BCh, MPH, FAAP
President and CEO, AcademyHealth