Health Record Banking Alliance

11 October 2018

Ms. Seema Verma, Admistrator
Center for Medicare and Medicaid Services - U.S. Department of Health & Human Services
200 Independence Avenue, S.W., Mailstop 314G
Washington, D.C. 20201

Re: Lifetime longitudinal digital patient records (sent via email to Seema.Verma@cms.hhs.gov)

Dear Ms. Verma,

Recently you spoke about imagining one's data – clinical data, claims data, genomic data, and wearables data – all in one place. The non-profit Health Record Banking Alliance (HRBA) has been working for over a decade towards this very goal. We applaud and strongly agree with your emphasis on the importance of a healthcare record that "*begins from the time of [birth] and collects all of our data throughout our lifetime."* Indeed, such a personal health record (PHR) can engage and empower the patient and his or her family in their care. Another important PHR benefit is that it can serve as the patient's comprehensive, unified, longitudinal record.

Our work towards unified patient PHRs over many years has resulted in a number of conclusions about how this can be accomplished and what can be done to accelerate the process. We are convinced that comprehensive PHRs can most readily be created and maintained if the patient requests the data (thus triggering the HIPAA requirement for its provision) and completely controls all access to the record (which ensures trust, an essential element of such a system). Further, we believe that comprehensive PHRs are most efficiently and effectively aggregated into community repositories, as most care for individuals in a community is provided locally. Finally, we realize that such community repositories, known as health record banks (HRBs), must absolutely prevent large-scale breaches in order to be trusted. A recently published security architecture for patient records, the personal grid, does just that by storing each record in a separate file, separately encrypted, thereby eliminating large-scale record access by anyone (including the operator of the system) [Yasnoff WA: A Secure and Efficiently Searchable Health Information Architecture. *J Biomed Inform,* 61:237-46, 2016].

We also believe that you could rapidly accelerate the development of HRBs through two key policy changes:

1. Establish, in collaboration with the Office of the National Coordinator for Health IT, a single national standard for electronic health information exchange, and require its use, as mandated by Congress in the HITECH Act of 2009.
2. Require that all providers deposit the new electronic patient record information created at each patient encounter in a place of the patient's choosing as a precondition of payment. Clearly, the value of each patient encounter cannot fully be realized unless the medical records from that encounter are readily available for future care through such a mechanism, which is entirely consistent with the mandate for patients to have "*access to their electronic health information in a single, longitudinal format that is easy to understand, secure, and may be updated automatically"* in the 21st Century Cures Act.

We would welcome the opportunity to discuss these issues with you or other appropriate CMS delegates, and would be pleased to share our accumulated knowledge and expertise related to the goal of comprehensive electronic patient records when and where needed. Thank you in advance for your collaboration and assistance.

Sincerely,

/s/ Richard Gibson, MD, PhD – President (richard.gibson@healthbanking.org and 503.313.7837)