



August 7, 2014

U.S. Senate Committee on Finance  
Attn. Chairman Ron Wyden  
Hon. Charles Grassley  
219 Dirksen Senate Office Building  
Washington, D.C. 20510

**RE: Request for Information on Health-Care Data**

Dear Chairman Wyden and Senator Grassley:

On behalf of the American Academy of Family Physicians (AAFP), representing 115,900 family physicians and medical students nationwide, I write in response to your letter dated June 12, in which you seek stakeholder feedback on questions surrounding access to health-care data. The AAFP thanks you for your leadership in seeking this information, and respectfully submits the following answers to your questions:

**1. What data sources should be made more broadly available?**

The AAFP believes that expanding access to numerous sources of health-care data will accelerate improvements in health-care quality and value, for example:

Patient Data Generated Outside the Physician Practice

In order to provide high-quality primary care, family physicians should know the sum total of relevant healthcare events and clinical data associated with a patient when they present to the physician office. Patients receive services outside of the family physician's practice—for example tests, diagnoses, and treatments in other physician offices, as well as admission or discharge from an inpatient facility. Care in the physician office may be less effective if the physician does not know, for example, that a week prior to the visit, the patient was hospitalized, or that another physician changed the patient's medication. Therefore the physician practice should have real-time access at the point of care to all relevant patient-specific data generated in settings outside of that practice.

Data to Support Clinical Decision-making

The ability to harness relevant data in order to practice evidence-based medicine is a critical need for family physicians. Applying protocols and guidelines in specific cases (e.g. when a

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mammogram is appropriate for a pregnant woman; when a referral for surgery is appropriate for a patient with back pain) requires timely access to public health data and research, which changes as bodies of evidence evolve. Such protocols often are in formats that are difficult to access in real time during a busy family physician's work day (for example, pulling journal articles, or .pdf files on a computer). Given the time constraints that family physicians work within, such data should be integrated into the workflow, i.e. into clinical decision support tools within the electronic medical record (EMR) or other health IT.

### Provider Data

In primary care, referring a patient to the appropriate subspecialist or inpatient facility is a critical function. To ensure the most medically appropriate referral, family physicians ought to have as much relevant data as possible about providers (physicians, hospitals, etc.) in their community, including but not limited to (1) the provider's quality and outcomes scores, (2) cost data, (3) accessibility of the provider (e.g. which insurance is accepted), and (4) information about the patient and case mix of the provider. In general the AAFP supports the concept of data "democratization," meaning that the public generally benefits from disclosure of health data, and that in general the solution to problems and controversies created by information disclosure (e.g. the CMS April 9, 2014 Part B data release) is more disclosure, rather than less.

### CMS Data Sets

The AAFP praised CMS's April 9, 2014 release of 2012 Part B data, and recognizes the work that you did to help bring this about. The AAFP believes that patients, the provider community, public-health researchers, and the U.S. taxpayer will continue to benefit from additional sets of data released to the public and encourages the Committee to continue to work with CMS to do this. For example, the Part B data release, while valuable, did not tie procedures to diagnoses. Therefore, certain questions remain unanswered—for example, did a physician perform a colonoscopy as a preventive measure, or to diagnose and treat gastrointestinal bleeding? Release of the corresponding ICD-9 codes along with the provider and CPT data would be a welcome additional step. Additionally, CMS ought to release similar data sets based on claims under Medicare Parts A, C, and D. As to Part C, the public would benefit from data that Medicare Advantage plans use to determine risk adjustment.

## **2. How, in what form, and for what purposes should this data be conveyed?**

### Standardization of Data

It is clear that the amount of health data will continue to grow geometrically. Ultimately, this data will be most useful if it is standardized, i.e. encoded in a standard vocabulary (in the way that ICD-9 and CPT are standard codes for diagnoses and procedures, respectively). The task of fully standardizing health data, however, is a monumental one—and therefore represents a very long process that will be achieved only incrementally.

Until a national consensus on data standardization emerges, at a minimum, electronic health record (EHR) vendors should be required to use open application programming interfaces (open APIs). Open APIs facilitate the move toward interoperable health records, by allowing developers to assist providers and patients to access and interpret health data that otherwise would be inaccessible. The Committee's leadership in this area is critical—we cannot wait for data to be fully standardized before achieving interoperability. Health data ultimately belongs to

the patient, not to EHR vendors, and an EHR vendor should not be permitted to “hoard” patient data in order to gain a business advantage.

### Real-Time vs. Claims-Based Data

For health data to be useful to family physicians, it must be available in real time, i.e. without delay. If a patient who was discharged from the hospital presents to a physician practice the following week, the physician must be able to review the updated patient record. CMS is currently working to make claims-based data fully available, but ultimately this form of data will not lead to fully interoperable EHRs due to the time lag (for example, a hospital may take weeks or even months to send a Medicare claim to the MAC, and there is additional processing time between the MAC and CMS). Therefore physician practices will receive updated health information about patient events in other settings only after a significant delay. Nonetheless, CMS should continue to make more claims-based data available, and should also work with state Medicaid programs to make Medicaid data available. The Committee’s leadership in this area is critical, and could be helpful in urging private insurers to grant access to commercial claims data.

On a separate track, we must continue to make progress on real-time interoperability. The AAFP has been active in efforts to develop standards for both packaging of data (e.g. Continuity of Care Record (CCR), and Continuity of Care Document (CCD)), as well as the transport of data (e.g. Direct Project). These efforts must continue alongside CMS’s efforts to make claims data available.

### **3. What reforms would help reduce the unnecessary fragmentation of health care data? What reforms would improve accessibility and usability of health care data for consumers, payers, and providers?**

In addition to the efforts outlined above, the AAFP urges the Committee to continue to drive progress in the following areas:

- Extend interoperability requirements under Meaningful Use to all parties with custody of health data. There remain parties that have custody of health data (e.g. public-health departments, clinical labs), which are not required to achieve interoperability. It should be obvious that fully interoperable EHR in the United States will not be realized if pockets of health information are not required to be accessible to other providers.
- Require Health IT vendors to produce open APIs that are well-documented and made available to their users. As mentioned earlier, this is a major barrier to achieving interoperability of health information.
- Continue to move to value-based payment models. Fee-for-service medicine does not align with the move toward interoperable health data; for example, a provider in fee-for-service receives payment to repeat a patient’s chest x-ray, but does not receive payment to make the effort to track down a recent x-ray at another location, or invest in infrastructure to enable exchange of such x-ray data. Thus the Committee’s ongoing leadership in driving payment and delivery reform will serve as a catalyst to achieving interoperable health IT. Enacting the Committee’s legislation to permanently repeal and replace the SGR formula would be a major step in moving to such value-based models of payment.

- Provide physician practices with additional resources to incentivize them to produce shareable patient data. Just as family practices need access to patient data from other settings, so too do other settings need patient data from the primary-care practice. An emergency physician ought to be able to look up an arriving patient's medical record and know immediately whether the patient suffers from chronic conditions, and which medications have been prescribed for the patient. Accordingly, physician practices continue to need resources and training on how to transform their practices to meet meaningful-use requirements. Such resources and training should include facilitation of sharing data, as well as ensuring data security.
- Align data reporting (such as quality measure reporting) requirements and standards across all federal programs and commercial payers.

**4. What barriers stand in the way of stakeholders using existing data sources more effectively and what reforms should be made to overcome these barriers?**

EHR Vendors should not Control Access to Health Data

Until interoperability is realized, family physicians and other providers will continue to depend on health IT vendors for access to patient data. Under most health IT contracts, the medical records belong to the vendor—not the providers, and importantly, not to patients. These vendors also generally control which other vendor products can access the data, further limiting physicians' choice on which products to use. Some EHR vendors “hoard” data because restricting its availability is a business advantage; it can help them retain customers, retain patients, and generally retain their market advantage. As mentioned above, the principal reform that the Committee should support is promoting open APIs, which would extend control over data to the providers.

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Thank you for the opportunity to comment on the Committee's interest in access to health data. If the AAFP can be of further assistance, please do not hesitate to have your staff contact Andrew Adair ([aadair@aafp.org](mailto:aadair@aafp.org)), Government Relations Representative.

Sincerely,



Jeffrey J. Cain, MD, FAAFP  
Board Chair