Five Ways Medicare’s Patient Data-Sharing Will Rock Health Care

written by Theresa Hush | March 22, 2018

Medicare came closer to fulfilling its promise of patient data-sharing last week with the announcement of bundled initiatives to connect health care consumers with their health care data.

First, the Trump administration announced the launch of myHealthEData, a government-wide initiative designed to permit patients to control their healthcare data and determine how it can be used. Several federal agencies will be involved: CMS, Veterans Affairs, ONC and the National Institutes of Health, all under the direction of the White House Office for American Innovation. The effort is designed to break down barriers that limit or block patients’ access to their data, to ensure that they can securely direct their data to desired applications, and to require providers to permit access.

The next step is Medicare’s Blue Button 2.0, an access program to make Medicare Parts A, B and D claims data available to beneficiaries in a secure and universal format. CMS has recruited more than 100 organizations to develop applications that would enable Medicare beneficiaries to view and share their claims data. Currently, Medicare beneficiaries may be able to obtain a non-interactive PDF of some claims data. CMS urged private health plans to initiate similar programs, implying that it may leverage Medicare Advantage plans to do so.

Along with increased access to claims data, CMS announced that it will require providers to update systems to provide patients with secure electronic data for sharing via applications. The requirements will include those with 2015 Edition certified technology (CEHRT), beginning in 2019. CMS stated that it would require data sharing upon discharge and would mandate certain types of data.

The American Medical Association (AMA) applauded the CMS effort. The American Hospital Association (AHA), while supporting the myHealthEData initiative and patient data-sharing, did not support changes in the certification requirements for 2019 because of concerns over variability in applications and issues with standards.

Health Data “from the Patient’s Perspective” Is a Misnomer

It will take time for patient data-sharing to come to fruition. But this will happen. The drive toward patient engagement—often a euphemism for patient payment—will continue. This is why it’s essential for patients to have full access to their data and to understand their costs, a topic we have addressed along with other reforms like price transparency.

But there is a problematic element to some of the thinking around this issue. The myHealthEData initiative’s stated objective is to approach data-sharing “from the patient’s perspective.” Yet, the data is not created by the patient; rather, it is created by the provider. That introduces a data perspective that is definitely not the patient’s—with some significant consequences that will require resolution. Here are just a few:

1. Erroneous claims data will surface in patient records.

Because claims data originates in codes provided for insurance and processing, errors may be introduced into patient history. The objective of getting reimbursement has governed selection of diagnosis codes, use of modifiers and pre-requisites for procedures. Once “rule out” diagnoses were prohibited for laboratory orders, physicians or their staffs often listed the possible chronic disease for the diagnosis, anyway, making it part of the patient’s record.

Electronic records don’t necessarily improve the quality of the data; they just make it easier to obtain. Given the return to “thin” coverage and restricted coverage for pre-existing conditions, the inclusion of codes for possible diseases raises rates and makes it hard for patients to secure their own insurance, should they lose group coverage. Patients will soon understand the significance of such errors.

Once patients can access their records and view conditions recorded as diagnoses that they don’t have, they will want a way to correct the record and disseminate those corrections. They will fight erroneous data; providers and insurers should be prepared to address these demands.

As patients review their own records, they will undoubtedly also discover diagnoses and procedures that are truthful, but which they object to being in the record or provided to others. Elimination of this data would certainly be a serious problem, since an accurate record of the patient is the goal of data sharing with other providers. All the more reason for providers to anticipate this issue and proactively address ways to deal with it .

2. Recording of provider actions and procedures is error-prone.

Templates that speed physician use of an EMR can create a “click the box” mentality, whereby clinicians quickly tick off elements that did *not* occur, such as noting there was *no* physical exam when physician and patient had just a conversation, or marking *no* full reconciliation of medicines when they had an abbreviated discussion of prescriptions. Time is short. Patient and physician process a lot of information during a visit, increasing potential for incorrect data entry or automatic ticking of boxes.

The risk of error is compounded by the need for physicians and staff also to address quality measures during a patient’s visit. Additional coded data of varying degrees of accuracy come from many sources, be it the patient, the check-in nurse or the physician. Incorrect responses could even be hard wired into the EMR system. Yes, all of these happen.

Just as for claims data, we will need a validation mechanism for patients to review and provide corrections or register disputes of recorded data. These records document services between provider and patient. They are not merely a record of what the provider did or advised; they are legal documentation of what happened.

3. EMR records will also show evidence of what was *not* done.

Patients expect their providers to meet a certain standard of health care. While “measure results” may or may not be included in patient records as a discrete category, it probably should be. Patients should be aware of what quality measures they and/or their physicians are expected to meet, so they can be part of the process of achieving appropriate measures.

But that heightened awareness will also bring to light any lack of attention to conditions or poor processes governing care. As a result, patients may demand more accountability for quality as well as cost. Providers must prepare to address astute patients’ desires for documentation of measures, quality results and comparisons with other patients.

4. Data will reveal provider biases.

Most patient complaints arise from a belief that physicians don’t take their complaints seriously or treat them with respect. Studies of physician-patient conversations reveal that physicians universally tend to cut off patients and not fully hear their concerns. Like all people, physicians also have attitudes that shape their practices and influence how they deal with certain patient groups. Research has substantiated that both women and patients of color face challenges in being taken seriously. Patients who harbor concerns about their care will search their data to identify these biases and may hold organizations accountable for discrimination.

Health care systems should proactively address biases in care by seeking patient feedback and working through issues with providers. Sharing data will reveal the problem’s scope and necessitate coaching and cultural sensitivity training as part of ongoing efforts.

5. EMR data will create demand for medical literacy and Shared Decision-Making.

Patients who do capture their data, store it and want to take charge of their health are in the vanguard of a consumer force that health care organizations must take seriously. While a minority of patients may initially take full advantage of shared data, those who do will know that they are pioneering a consumer health movement. They will be motivated by what they see (or don’t) in their own data to demand reform in health care and a seat at the medical decision-making table. Having their data is only the first step in consumer-driven health care reforms.

Providers need to ready methods for responding to consumers’ needs for engagement with information, programs and processes such as Shared Decision-Making.

Patient Feedback and Involvement Will Make Data-Sharing Work

Providing electronic data to patients is an important and essential step toward helping patients fully participate in health care decisions. But stakeholders cannot afford to be pollyannaish about the effects. As with quality data on physicians, the real value of health care data owned by patients is to begin the conversation of what is possible to improve their health status. That includes a close examination of current data for validity and gaps.

Providers should recognize the opportunity to win trust among new and existing patients. By providing data along with avenues for patients to validate, correct and provide input or concerns, providers enlist their patients in the first part of a mutually trustful relationship. That trust will create the foundation for real Value-Based Health Care.

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