

## Comments on CMS-2025- 0050-0031

I am a chronic rare disease patient, former caregiver, Medicare and Medicaid patient, and patient advocate who has had to access and share her medical records since well before widespread electronic sharing of medical records.

I learned of this important request for information late in the game. I have more on which I could comment but provide what I have been able to put together before the deadline.

PC-1. What health management or care navigation apps would help you understand and manage your (or your loved ones) health needs, as well as the actions you should take?

- a. What are the top things you would like to be able to do for your or your loved ones' health that can be enabled by digital health products?

Have complete digital medical records, including images from imaging, in one place and be able to easily share and organize what I choose to share of those and when with specific providers. Also have the choice of with whom, including providers, I do not wish to share all or some of those records. Have the ability to wholly or partially cut providers from further being able to access or see my health records after they are no longer involved in my care and/or sharing of some records or the provider's involvement in my health care presents or appears to present a threat to it. Have easy ability to request correction of errors or submit addenda to medical records and have changes or addenda appear in the record next to or with the original record in question. For privacy and to ensure that the data is not lost, to have a way of backing it up that is not cloud based in case something happens to the device on which it is stored.

The above is the top thing by far above all others.

Emphasis should be placed on achieving the above for patients first to have a solid base on which to build other things – and before AI can safely be applied to patient health data.

It seems that results from AI are much based on the information that is fed to it. Bad information -- erroneous or incomplete -- can lead to bad results. At present from what I have seen of AI at work, I also get the impression that it may have been unleashed upon us before it was ready for prime time. In word processing where AI seems to now be employed – such as in phone texting – it

takes me longer to compose what I write before I send it because I have to try to correct all the mistakes AI makes and nonsense it creates when it changes what I type.

Another top thing in this category:

Track health and keep a private digital record of health and environment outside of medical visits that can be compared and used to try to understand fluctuations or changes in health and do what might be done to address those. Share such with providers with whom and when I choose to do so. Examples:

- record and patterns of blood pressure, heart rate and possibly other measurable vitals taken outside of medical visits
- medication tracking and drug app that describes and gives prescribing information for pharmaceuticals and similar information for over the counter supplements and drugs and can analyze and pick up bad combinations and the like.
- lab test app that explains tests and what results mean.
- symptom diary and symptom checker
- food diary and nutrition app
- ability to look up or measure air quality and weather and have record of humidity, exposure to wildfire smoke or other pollutants, and environmental factors that can affect health by date/time and over time
- exercise app that gives simple exercises that can be done at home to address specific problems.

**b. If you had a personal assistant to support your health needs, what are the top things you would ask them to help with? In your response, please consider tasks that could be supported or facilitated by software solutions in the future.**

The top thing that I would ask a personal assistant to help with is resolving problems with access to or denial of care or quality and continuity of care for whatever reason such may present.

- Have the personal assistant put the complaint or a proposed complaint together or suggest to whom and how to present a complaint for greatest chances of success.
- Prepare an appeal or assist in identifying grounds for appeal and help prepare an appeal if it a matter of denial from the payer.
- Provide a list of patient rights and laws and enforcement measures that may apply and who might help.
- Suggest other providers or places to get needed care and solutions (such as potential sources for help with travel and expenses, help with whatever has to

be done to get approval for coverage of the care if it is out of state, etc.) if extraordinary measures – often likely given that I have a combination of rare or uncommon medical issues -- are necessary to get to the alternative.

- Help with correction of errors or omissions in my medical record.

**PC-2. Do you have easy access to your own and all your loved ones' health information in one location (for example, in a single patient portal or another software system)?**

**a. If so, what are some examples of benefits it has provided?**

**b. If not, in what contexts or for what workflows would it be most valuable to use one portal or system to access all such health information?**

**c. Were there particular data types, such as x-rays or specific test results, that were unavailable? What are the obstacles to accessing your own or your loved ones' complete health information electronically and using it for managing health conditions or finding the best care (for example, limitations in functionality, user friendliness, or access to basic technology infrastructure)?**

The following response, with some of my experiences included, addresses what I have to say on all the above and explains why I indicated patients should be able to choose who, even amongst providers, can see their medical record. See especially the abstract in *Italics* of a panel discussion I presented a few years ago on this a bit below.

**First of all:**

No, I do not have easy digital access to all my health information in one place.

For a patient to have all the records in one place would be most useful in sharing the records to establish care with a new provider and to share information with providers easily in general as well as to have more control over sharing the record.

To have one's complete health information in digital form in one place seems to be the exception rather than the rule among the many patients I know.

I have access to separate patient portals for different health centers for the care I have received there in recent years. The health information in each portal is not all my health information for the care I have received during the years.

The limited information that is in the portals is available by logging in online. To transfer it to my devices, I would have to download or take screen shots of it record by record.

It is my understanding that all of the doctors listed as my providers on the portals have access to what is in my portal as soon as I have referral to an appointment with them before I have even seen them. That is even the case for doctors who are no longer involved in my care including doctors whom I fired from my care because I considered them harmful to my care or disrespectful of my privacy choices. That is because once listed as a provider to a patient, the doctors remain listed as such in the portal for three years regardless of the circumstances. I have found that a deterrent to using the patient portals.

Sometimes a patient in seeking a new doctor, decides right away on the first visit that the doctor is not a good fit and does not continue or really establish care with the doctor. The patient might not want to share all records at the outset not only because the patient does not know if he or she will choose the doctor but also because the visit may be for another opinion which the patient does not want prejudiced by the opinions of previous doctors.

I do not have access to images from imaging in any of those portals. Access to those is important in that I am a not-cured rare cancer patient with complex imaging needs.

Sometimes radiologists have missed seeing things that appear on my imaging. I have gotten some of my best care in the past from providers who want to look at images or have images reviewed by their radiologists rather than rely on reports.

I do have images on disk that I requested by going to radiology film libraries at the hospitals where the imaging was done from about 2005 to around 2020. The disks would usually be available for pickup the same day.

However I can no longer access those images on my computer as I have an older operating system that is no longer compatible with that software. Not all patients can afford to buy new mobile or electronic devices that keep up with the current technology. Patient access to their electronic health data should support older systems and technology.

I do not have most of the imaging on disk that has been done since 2020 because there is no longer a radiology film library or medical records office that one can physically go to at the hospital where I have had some of that imaging. When I last inquired, the hospital offered to mail the disks to me with a possible turnaround of a couple of weeks after they get the request. I did not make the request because it was

unclear that it would get to me by mail. I was having trouble with mail delivery at the time. I didn't want something like that with my health information on it lost somewhere.

I do have fairly complete paper copies (Five boxes of them.) of my medical records from the decade or so from before EMR sharing of medical records between hospitals really started to come into use around 2010 or so.

The medical records from that pre-EMR period are among my most important. I had my cancer diagnosis and surgery and identification of other rare or uncommon medical issues during that period. Markers and anatomy to be followed by imaging were determined during that period. Some of the anomalies to be followed that were identified back then are small. They were missed by some radiologists in the past. I have been told they could potentially be missed in the future by radiologists unaware of them or with improper acquisition protocol. The imaging and reports from back then were to be compared to future imaging to identify changes over time.

Prior to that, I had a long road to just my diagnosis. Symptoms of my rare lung cancer and syndrome accompanying it started to appear well over a decade before my diagnosis. I was a postdoctoral scientific researcher when crushing fatigue became one of the growing list of my symptoms. I was no longer able to continue to work. Undiagnosed, that ended my career.

I was diagnosed with my lung cancer years later at a local hospital only after I began to cough up blood.

It took a few more years to begin to get to appropriate care at tertiary care Center A.

There I got diagnoses of additional rare or uncommon conditions which necessitated getting care at another tertiary care -- Center B -- where I had my lung surgery to remove the primary tumor of my cancer.

I began to request copies of my medical records during those years. I would usually get complete records on paper when I requested them. I found having the records helpful and necessary to keep track. My care got to be so complex and scattered among different places and doctors on multidisciplinary teams, that I was just about the only person who had an overall understanding of my care.

When I saw new doctors, I would extract the important points from my record and present them in an outline summary to the doctor so he could then find and confirm the facts in the actual records. Having seen the whole record, I knew what the new doctor would see when he got it. If there were errors in the records I could see them

and at the very least note them to doctors. At the request of one of my doctors, I started to make tables of my lab values by consolidating them from different places so my doctors could see the trends from the values taken everywhere. The doctor said that helped him. Having the records also helped me form questions for my doctors. That sometimes lead to more discovery and helped me make decisions about my care.

I learned during those years that not all imaging is created equal, and different radiologists have different levels of expertise. Having the images on disk lead to new discoveries on old imaging when I would take the old imaging to a new center.

It also allowed me to send imaging to a friend who was a radiologist. At the first center, Center A I mentioned that a neurologist had discovered I had a pituitary adenoma years back. He had instructed me to mention it to future doctors.

I had tried to get the imaging and records for that diagnosis from years back but they were unavailable. The hospital where they were had gotten rid of them after they were no longer required to keep them. That became another reason why it was important to get my complete medical records – they might not be there in the future.

Imaging for the pituitary adenoma was ordered at Center A but the radiologists there reported nothing was there. When I sent the images to a radiologist I know, he found. The adenoma. He sent a photo pointing to it so that the Center A radiologists could see it. I then had a diagnosis of pituitary adenoma which lead to more.

I had my lung surgery to remove my primary tumor at the next center, Center B where Doctor X, my main specialist there for the cancer was also my specialist for the pituitary adenoma and other conditions because of the unique fit of his specialties to my case. Soon after my lung surgery, my medical care was seriously disrupted after Center B removed Doctor X from my care without good explanation as to why exactly. Whatever it was, it was clear, it was a legal situation.

I was sent to other doctors but the ball got dropped on a lot including the pituitary adenoma, which before his expulsion from my care, Dr. X had postulated in a visit note in my medical record might be a rare neuroendocrine pituitary tumor and a source of my remaining disease.

I continued some treatment at the previous center, Center A, under the care of my oncologist there but the imaging there missed what was picked up at Center B.

I eventually started to get care at Center C. It had excellent imaging and a specialist Doctor Y who could fill Doctor X's role in my care. Center C however was hundreds of miles away.

I did not involve Center B in arranging that or getting my records to Center C. At Center C I placed restrictions on sharing my medical records, prohibiting sharing them

with Center B. I brought my previous imaging on disk and a box full of my main record -- which in copying costs alone cost me a bit -- to Doctor Y at Center C. When he looked at the box of records he said he wasn't looking through all that.

I then pulled out an outline of my medical history, my surgery report, and Excel sheets in which I had organized all my labs across centers from information in my records. It took me about a week to put all that together. I hoped that there would be an easy way to do that a couple of years or so later when I saw the first presentation on a concept called Blue Button at Patients 2.0 in 2011. That description envisioned a patient having all of their medical records with easy ability to share and choice in sharing them.

Doctor Y, an endocrinologist, was especially pleased to see the Excel sheet. It summarized the most important things he needed. We then started to talk. My care for much that had been neglected since the exit of Dr. X resumed.

That worked out for a while but then around 2011 inexplicably I started to have trouble scheduling my imaging at Center C -- which is something that happened at Center B before Doctor X was ousted from my care.

I got a call one day from someone at Medicaid in my state. Medicaid had just approved covering the MRI's I was to have at Center C, but Center C cancelled the scans immediately after that. The Medicaid person advised I get a new doctor. I mentioned how hard it was to find a doctor for what I had. Medicaid personnel then took some extraordinary steps to get things back on track for me with the MRI's. I had them and saw Dr. Y again but it was not the same. The MRI of the chest results indicated I needed a repeat under a different specified protocol to better see something that showed up. Dr. Y did not order it. He barely placed orders for a brain MRI to resume followup of the pituitary adenoma. I did not return after I had extraordinary difficulty later with scheduling that.

Seeing Dr. Y worked for a while while I could choose who among my providers could and could not see my medical record. Years later I realized that it was around 2010 or 2011 that sharing by EMR between centers really began and of some of the sharing that could be done between providers without the patient's knowledge or permission after that.

I continued to just receive treatment for the endocrine condition that accompanied my cancer at Center A without much imaging or monitoring for my cancer, etc.

In 2016 I returned to Center B because there was a clinical trial of a special whole body PET/CT scan for my cancer there.

I saw one of my previous doctors Doctor Z at Center B to order the scan there. Years earlier, after Dr. X was removed from my care, I could also soon no longer see other

doctors who could most help me there including Doctor Z. However, I could see him when I went there for the clinical trial scan.

After the scan, Dr. Z's office cancelled my appointment to go over the results soon after it delaying it to an unknown point in the future. I did see the report in my portal there – a spot on my liver and my thyroid were all that were mentioned. I had trouble arranging the MRI that was to follow up on the spot on my liver.

In the meantime at Center A's eye center, I had been found to have a cataract and was to have surgery for it. Just after I had the whole body scan at Center B, the eye doctor at Center A cancelled my cataract surgery. No one there would do it instead. Something the eye doctor's staff had said indicated that the Center A eye doctor might have been in touch with Center B.

As I tried to seek care elsewhere to get my cataract surgery strange things happened in my eye care, which had previously been problem free. My local eye doctor of ten years would not see me. So much more.

The government was paying for and wasting money on medical visits that provided little care to me but lots of frustration and runaround. There was to be much more of that to come as I tried to get needed care in the next year or so, especially eye care and for what I was to find did appear on that clinical trial scan that was not mentioned in the report.

With the sudden trouble with my eye care. I began to wonder if something that was not in the report showed up on my head in that whole body scan at Center B.

I called Doctor Z's office at Center B and insisted on a visit soon to go over the scan and see the images. At the visit he did not show me the whole body images but mainly covered the thyroid telling me I needed surgery to remove it right away.

- I subsequently had appointments toward the thyroid surgery in which I saw mention in my newly emerging records then at Center B of things about my thyroid nodules that were not true – like that they were hot when the assays that had been done for that in the past had showed that they were cold. I was told Dr. Z had put that in the record. I dropped plans to go ahead with the thyroid surgery. I wasn't having it where my surgeon couldn't even keep the facts straight on it. I still have my thyroid now more than eight years later.
- I also had MRI of chest, abdomen and pelvis ordered by Doctor Z at Center B the fall of 2016. Only after I had the MRI did I see that I got the wrong contrast for assessing the spot on the liver. The protocol for the chest MRI was not that suggested at Center C years earlier. The reports for the new MRI's ( and also for the whole body scan) mentioned no comparison to previous scans or the lesions identified to be followed years before.



- The new care that I was getting at Center C was going into an electronic medical record there – whereas my previous records there were paper records. Center B had the paper records electronically in their system but had not put them in my electronic medical record there. That radiologist who read the MRI's did not compare them to the old scans or know what to look for because he could not see that there were old scans there. All he could see was the electronic medical record and the old scans were not in it at the time. That was never subsequently addressed.
- When I got a new oncologist a couple of years later at center A after my oncologist of many years retired, she showed no interest in following what was to be followed after my lung surgery – because the last MRI's I had were those here mentioned at Center B. the reports of which essentially erased much of my imaging history for my cancer.
- Other things that happened after my return to Center B, which I won't go into, for that whole body clinical trial scan indicated that I was receiving care there to rewrite my medical history there replacing fact with fiction.

Going back to the visit to go over the results of the whole body scan:

Right after the visit I headed to the radiology film library at Center B. I requested the images for the clinical trial whole body scan. I put the disk into my laptop when I got it. I then exclaimed, what's that spot near my pituitary behind my bad eye that's not supposed to be there and that's not mentioned in the report?

I made another appointment to see Dr. Z specifically about that and to ask him to order an eye orbit MRI ( I had not yet had the above mentioned MRI's). He admitted the spot was there and referred me to neurosurgeon Dr. W. whom he said could order the MRI.

In the meantime I had arranged referral to eye care at tertiary care Center D. I had an local optometrist who was out of the loop with all the other doctors make the referral. That lead to referral to a specialist at Center D to evaluate me for my optic nerve damage and cataracts. I scheduled my visit with Dr. W. at Center B for the day after the Center D visit. What happened at the visit with Dr. W. at Center B is summarized in the abstract for the break out panel discussionit inspired that I lead at Healthdatapalooza 2019:

***From Everything about Me without Me to Nothing about Me without Me: EMR and Patient Empowerment and Engagement, Where We Are and Where We Could Go***

*The patient was at her long awaited appointment with the neurologist. Her cancer doctor had referred her for the spot the patient had found on the scan behind her bad eye. Her heart sank when the neurologist said: "I trust our radiologists. If it's not in the report, I won't discuss it.*

*And symptoms?” “Vision,” the patient answered. The doctor shot back: “Oh, I am now pulling up the notes of the eye visit you had at (Center B) yesterday.” Stunned, the patient asked how the neurologist got the record – which she, incidentally, was not to get when she requested all of her records from Center B soon after. The patient started to describe her long history of vision issues. The neurologist cut her off. “Be quiet!” he said. He had to “read what the doctor had to say”.*

*That is how the patient soon learned that the large medical centers where she’d received care were part of a health information exchange (HIE) through which doctors could access records without the patient’s authorization or knowledge. She had to dig to learn that she had automatically been opted in at each center without her knowledge but had the option to opt out. When she chose to opt out, it didn’t work the first time at Center B. Apparently Center B didn’t have much experience with patients opting out. – maybe patients didn’t know they could. Where was the meaningful use?*

*The patient, a rare cancer patient who had long been a chronic user of the health care system and had found patient engagement, choice in where her records could go and who was involved in her care important to her well being, now understood why, when she had begun seeing new specialists then for the first time since the move to electronic medical records (EMR) began, no one was asking her for records or asking her much about her health. Doctors were looking at the record and talking to other doctors but not talking to her. She did not know what they had seen, what errors they relied on or what had or had not been entered from paper into the EMR about her cancer.*

*The patient will describe that and more that she observed – including how easily it seemed that doctors she had never seen or chosen to see could appear on her care team in MyChart portals - - that made it seem that the move to EMR as implemented was creating an “everything about me without me” world in health care.*

*Years earlier as EMR was about to be implemented, the patient looked forward to its potential of empowering the patient with easier access, control of and perhaps ability to add to the patient’s health record. It seemed not to be happening. Instead, it seemed that in the move to EMR the patient had less privacy, control of her data and choice of who was involved in her care. EMR was making it harder rather than easier for patient rights to be more than just a list on clinic walls. It was not empowering her.*

*Data is about what is going on with the patient. If the patient is no longer a part of generating that data, how meaningful is it? If it cannot be questioned, errors can proliferate. Then how good is it? How good are conclusions or policy based on analysis of it? How good or safe is the care based on it?*

*EMR has such potential to empower the patient. What can we do to shift its implementation from “everything about me without me” to “nothing about me without me” for the patient?*

There is much more that followed that is similar in the above story and additional

points about how medical records sharing between providers without the patient's knowledge or permission can be used to harm the patient's care rather than enrich it.

Such presents a threat to patient safety.

To this day I have not been able to receive care or answers regarding that spot behind my bad eye on the scan, to receive good medical care for my vision which is not getting better, or to get the followup care for my cancer that I should have.

**PC-3. Are you aware of health management, care navigation, or personal health record apps that would be useful to Medicare beneficiaries and their caregivers?**

I just came across some that presently exist when I searched last night. I don't know how the patient's data is transferred to them and am not sure that the data from my provider's could be transferred to them.

It seems that my providers only provide the patient's health information to the patient electronically through their patient portals where the patient does not have good control over who sees the data.

**PC-4. What features are missing from apps you use or that you are aware of today?**

- a. What apps should exist but do not yet? Why do you believe they do not exist yet?
- b. What set of workflows do you believe CMS is uniquely positioned to offer?

An app which I believe should exist is one that allows a patient to get their complete medical records, including images, from all their providers, which keeps the records from each provider separate but has features to easily organize the data from some or all together when that is needed or helpful. The app should also allow the patient to easily and securely share the data with other apps and others of their choosing. There should be a cloudless way of backing up the data in case something happens to the device that it is on.