

## **Testimony of Christine Bechtel; Coordinator, GetMyHealthData Campaign**

*“It makes sense to me as a patient to have my data and use it to empower myself to know my body through the data.” – Bon S., GMHD Tracer patient*

**GetMyHealthData** is a national campaign focused on enabling consumers to demand and use their health information electronically.<sup>1</sup> We provide patients with resources that help them understand why and how to get their health data from providers and others, and help them troubleshoot along the way. We believe that a concentrated “tug on the rope” from consumers can help unravel health care information silos.

Right now, in the early days of the campaign, one of our central goals is to learn from patients and providers about the realities of requesting, providing and using digital health data so we can advocate for advancements in policy and practice. We rely on cadre of volunteer patients who serve as test cases, or “Tracers,” to track and record their experience requesting their health data. The policies we most often promote to facilitate data access are 1) the HIPAA right of electronic access and 2) Meaningful Use-enabled View, Download and Transmit (V/D/T). Thus far, Tracer experiences reveal several problems with current policies and practices. In my comments below, I draw from their experiences and also provide excerpts of their stories to illustrate key points.

1. Is an electronic file size an appropriate proxy for “pages” in setting fees for electronic access, or is it simply a substitute for a per-page proxy? If file size is appropriate, how should cost be calculated, particularly considering the questions below? If not, what is a better proxy for calculating labor costs for electronic access?

**The law does not permit charges based on file size. File size as a proxy could also introduce significant unintended consequences and unnecessary barriers to patient access.**

At a minimum, neither per-page fees nor file size-based fees for electronic data are permissible under HITECH. In fact, allowing providers to charge for file size would likely become a new and serious barrier to patient access, and should be expressly forbidden. The HITECH law authorizes the categories of costs for which providers can charge: *“any fee that the covered entity may impose for providing such individual with a copy of such information ...in an electronic form shall not be greater than the entity’s labor costs in responding to the request for the copy....”* The law does not recognize “file size,” “number of pages,” or anything other than labor. The Access Rule does recognize the cost of portable media such as USB or CD, and while we are not convinced that OCR’s expansion of the fee structure to allow charges for such supplies either conformed to Congressional intent or was in the best interest of patients, what is unquestionable is that OCR intended only for marginal copying and supply costs to be chargeable to patients. Under no

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<sup>1</sup> Coordinated by the National Partnership for Women & Families, a non-profit consumer organization, founding collaborators include AHIMA, Amida, Code for America, Flip the Clinic, the Genetic Alliance, Health Data Consortium, NATE, former National Coordinator for Health IT Farzad Mostashari, and former Chief Technology Officer of the United States, Aneesh Chopra.

circumstances would or should such costs include per-page or per-gigabyte charges, nor retrieval fees, administrative and processing fees, etc.

Fees based on file sizes could also backfire by creating even more severe access impediments than we already have with HIPAA records requests today. First, due to the sheer (and growing) quantity of data that could be provided in response to a patient request (consider imaging data for example), it would be harmful to patients to create a new incentive for providers to produce excessively voluminous reports as a way of obtaining additional revenue. Second, as our Tracers have documented, there is no way to know in advance how much or how little data they will receive as a result of their request. There is also no way to pre-select only the data consumers want (as opposed to the entire record). Thus, there would be no way to control (or even estimate) costs patients are charged. In addition, charging based on file size would likely put already-vulnerable patients with complex conditions or diseases at a significant financial disadvantage.

**A new paradigm for medical records requests: technology enabled self-management and care coordination in an era of health reform.**

Dramatic advances in data availability, technology and mobile applications (apps) since the passage of HIPAA and HITECH has created a new context for records requests. Our Tracers thus far report they want their records all in one place so they can do things such as manage their care using an app, facilitate information sharing between providers, and donate data for research. Combined with a new era of delivery system reform that relies heavily on patient and family engagement, and where patient access to data is a key element of patient activation, we believe providers should be discouraged from charging fees at all. Patients cannot possibly effectively manage their health and health care, participate in research, or support interoperability when they face barriers to accessible and convenient information about their diagnoses and treatment received. It is **their** information about **their** health and the health care services they have bought, and they should have ready, barrier-free access to it. At the same time, providers cannot succeed under new models of care without activated and engaged patients.

We recognize, of course, that certain fees for medical records are permissible under the HITECH statute. In light of that, we believe that OCR and ONC should make a clear statement that the best practice for providers is, in their opinion, to charge *no* fees for medical records whatsoever, because fees for essential information about one's one medical conditions and care is an impediment to the Triple Aim of better care, smarter spending, and healthier people. Where fees are nonetheless permissible, we encourage OCR to set strict on the amount of fees, narrowly limiting them to the marginal labor costs set by Congress in HITECH.

We further recommend that labor fees should only apply in cases where significant staff time is required to compile older records, and/or records not readily producible by the current EHR or other electronics system. This construct is common to other industries. Banks typically charge nothing for current copies of statements, often extending one year to several years into the past.

But if a consumer needs a bank statement from 10 years ago, the bank will likely charge additional fees.

We also encourage OCR/ONC to be clear that they expect many providers will continue to provide electronic copies without fees, as many are today, recognizing that electronic copies ultimately save providers money by avoiding having to print on paper, use toner, and mail reams of paper.

**The way that fees are being charged today is highly problematic.**

We have learned with GetMyHealthData that not only is cost a barrier to patients receiving their medical records and other health data, there are significant practical problems associated with the ability to charge fees for records requests:

- A.** Patients are routinely required to sign forms up front in which they agree in advance to pay an unknown sum to receive their health records, often without even being given an estimate of the total costs that the consumer will be obligated to. Imagine if consumers were required to agree to let a mechanic fix a car, with no estimate of financial liability. However, when it comes to medical records, patients are frequently required to agree in advance to a blank check.

*"I received the medical records from my father's hospital admission, and an unexpected bill for \$500."*

– (Patient wishes to remain anonymous.)

*"I completed a long form to request data from one visit. It was denied because they couldn't find the visit in the system because they did not read the form I filled out carefully enough. The denial came back to me in the mail 4 weeks later. I resubmitted, this time simply asking for all of the information in the system. A denial came back because they needed a credit card on file."*

– Sarah T.

*"[In] one instance, they sent me a BILL for sending my records to my new doctor. Ninety dollars! I didn't pay it, so I suppose it will go to collections, but I just couldn't write that check. Arrrggghh!"*

– Jennifer W.

We believe this common pattern of requiring patients to make an open-ended commitment to pay an indeterminate and undisclosed amount of money to obtain copies of their medical records, or surprising them with an unanticipated bill, is a violation of the fundamental tenets of consumer protection laws. Specifically, we think it is an unfair business practice under both section five of the FTC Act and state consumer protection laws barring unfair and deceptive business practices. It is unconscionable to require consumers to obligate themselves to pay an unknown amount of money for the privilege of receiving essential medical information about themselves.

- B.** There is substantial confusion among providers about what fees may be charged in general, and what may be charged for paper vs. eCopy: The Omnibus Rule promulgated by OCR

expanded this by allowing for the charging of (i) Labor for copying PHI, whether in paper or electronic form; and (ii) Supplies for creating the paper copy or electronic media ...”.

HIPAA and state laws allow for per-page charges for paper records. These limitations and distinctions are not well understood by providers. We have seen many instances of Tracer volunteers being charged sums for retrieval costs, for the per-page costs of a PDF generated by an electronicsystem, and even a general \$50 “administrative” fee.

C. Fees should imply value. Yet our Tracer volunteers often are provided data in formats that are not valuable. Sometimes they are charged, and other times not.

*“After some discussion, the best they could offer was a CD that they could either mail to me or I could come pick it up. I received it shortly thereafter in the mail - it is a 47 page PDF of many things and of varying sizes and resolutions - many super small images relative to the others, that I had to expand a thousand percent to read. Incomplete at best. Nothing readable or computable in blue button or any other format. To their credit, they did not charge me for this. I also now have access their patient portal, but have had trouble extracting anything of more value from it. – Jeff T.*

We urge OCR and ONC to issue Guidance that requires covered entities to estimate fees up front, and clearly disclose the available formats and types of data, so that consumers can make informed decisions about whether to proceed.

While we appreciate that providers may incur some labor costs in creating electronic copies of patient’s health data, so does every other business that supplies information to its customers about the services rendered. Businesses that cannot charge for supplying paperwork have found ways to innovate, providing useful data at lower cost. Thus, again, providers should strongly be encouraged to charge no fees, and they should be permitted by regulation to charge only the lowest cost-based fees that don’t discourage patients from requesting and receiving their records.

2. One of the objectives of Stage 2 of the Meaningful Use EHR Incentive Program is to provide individuals the ability to view, download and transmit their health information. Therefore, should the producible form and format of the electronic copy the individual requests affect how the individual is charged? ...

Again, HITECH permits only labor costs, which are not incurred by the provider when a patient facilities their own download or transmit. What’s more, the Meaningful Use program has already paid doctors and hospitals to establish the automated systems that provide this data to patients who, as taxpayers, have paid to fund this federal program.

Further, CMS provides in an FAQ (and we agree) that: *“We do not believe it would be appropriate for the EP or hospital to charge the patient a fee to access the Certified EHR Technology solution regardless of whether the solution is in the form of a provider-specific portal, an online personal health record, community portal or some other solution.”*

3. If, due to interoperability issues between an EHR where the requested information is maintained, and the software used to create the copy for the individual ... the business associate must download the file from the EHR, and subsequently upload it to the business associate's software before generating an electronic copy for an individual, should labor costs associated with this process be charged to the individual? Why or why not? If so, how should they be calculated? Additionally, .....

No. Labor costs should not be considered reasonable in this case; the patient should not be penalized because of a business decision to maintain an inefficient patchwork of systems.

4. Similarly, if information from an EHR has to be printed on paper (therefore paginated) and then scanned and uploaded to a different software program used to create and/or send the copy for/to the individual, should the individual be charged, and if so, how should the cost be calculated?

This scenario is difficult to imagine, except in case of non-MU certified EHR. However, again— labor costs should not be considered reasonable in this case because the patient should not be penalized by a business decision to cling to an inefficient patchwork of systems.

5. Would you answer anything differently if the copy of the data from the designated record set were being transmitted to a non-HIPAA covered business, such as a PHR vendor compared to another HIPAA covered entity or that organization's business associate?

No. Patients have a right under HITECH to direct a covered entity to transmit their data to a third party, which can include an individual, another provider, a PHR, or another app that the patient selects. Further, OCR has clarified that patients can have eCopies sent to them via unsecure email. Many apps today are able to receive care summaries via a Direct email, so we see no material difference between these delivery mechanisms or destinations of the patient's choice.

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In summary, meaningful, convenient, transparent and cost-free patient access to information about their health status and their health care is a fundamental right. It is crucial for patients to be able to manage their healthcare options, control costs, and take charge of their health and their future. It is also a critical need for providers if they are to succeed under new models of care. We are asking OCR and ONC to make a statement that the current best practice is to not charge patients at all for copies of this crucially needed information. To the extent that charging fees is, unfortunately, going to remain legally permissible for the time being, we would strongly encourage OCR to constrain fees to the absolute minimum labor-based charges with a particular focus on cases where significant staff time is required to compile older records, and records not readily producible by the current EHR or other electronic system.

Feel free to contact me with any additional questions.