

ciitizen

Privacy Policy & Patient Access to (and Control of) Their Health Information

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Ciitizen: Who We Are

Helping cancer patients, using their HIPAA Right of Access, to collect and control all of their health information, so they can use it and share it to meet their needs.

- Get second opinions, seek clinical trial options
- Coordinate with caregivers
- Donate to researchers



Individuals as “HIEs of One”

The HIPAA Privacy Rule **requires** covered entities to share health information in a “designated record set” with individuals **upon request** (except in rare circumstances).

Once individuals have their health information, they can **share it with whomever they please**.

How easy is it for individuals to get their health information?

- Harder than it should be – but **improving**
- Access to **complete** records through application programming interfaces (APIs) of certified electronic health records is years away.
- Still a need for greater compliance with HIPAA Right of Access

Patient Record Scorecard and Survey

- OCR released extensive guidance on the Right of Access in 2016* - but patients still struggle to get their health information
- Recently OCR announced **more robust enforcement** of the Right of Access.
 - OCR settled two cases in 2019 in their new Right of Access enforcement initiative
- We want to **raise the bar on compliance** with the Right of Access – and get processes improved before OCR knocks on the door.
- We're taking a page out of the **quality measurement playbook** – what gets measured and publicly reported gets improved.

* <https://www.hhs.gov/hipaa/for-professionals/privacy/guidance/access/index.html>

The Patient Record Scorecard

The Patient Record Scorecard Process



Request Records

We sent medical record and radiology requests to 210 healthcare providers, based on actual requests from Ciitizen users - patientrecordscorecard.com



Patient Requests Copy

All patients requested digital copies to be populated into their Ciitizen personal health record accounts (options to send through an encrypted portal or by e-mail for text, and CD for images).



Rating

We rated medical providers from 1-5 stars based on their responses.



Scoring

Score is based on the latest request (not averaged) - many scores based on only one request

Four Key Right of Access Components

1

Accepts requests by email or fax.

Providers may not create a barrier to access by requiring patients to submit requests in person or by mail

2

Sent in format requested.

The provider sends the records in the format the patient requests, which is in digital form by email for text (option for secure portal), CD for images.

3

Sent within 30 days.

The provider responds to the request within 30 days of receipt (or provides notice of delay and responds within 60 days).

4

No unreasonable fees.

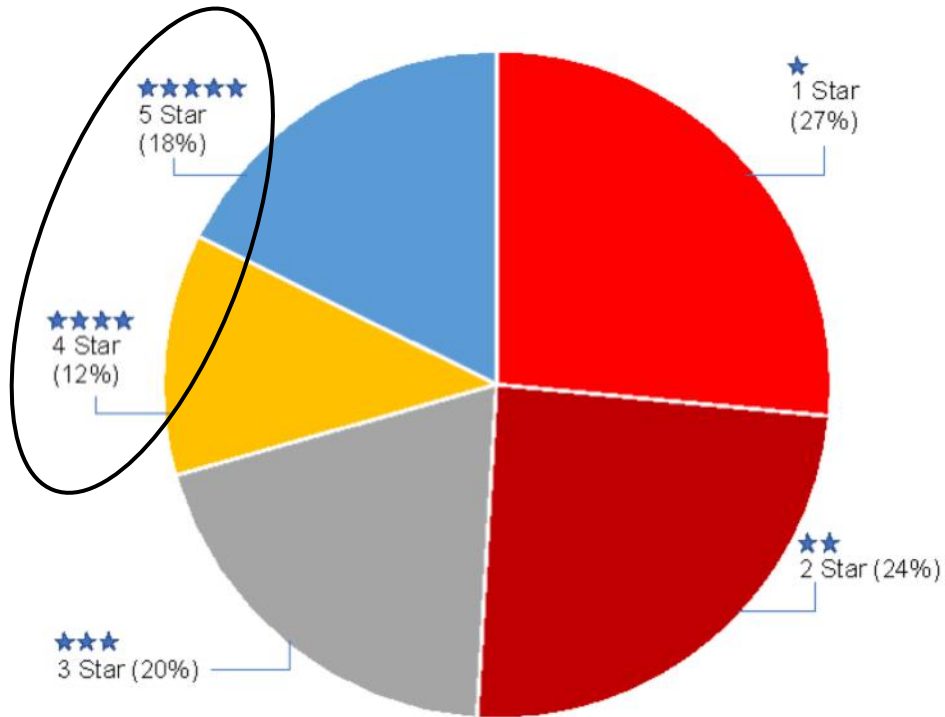
For copies requested by the patient for his/her use, providers may only charge reasonable, cost-based fees for labor of making copy, plus associated supplies

Star Rating Key

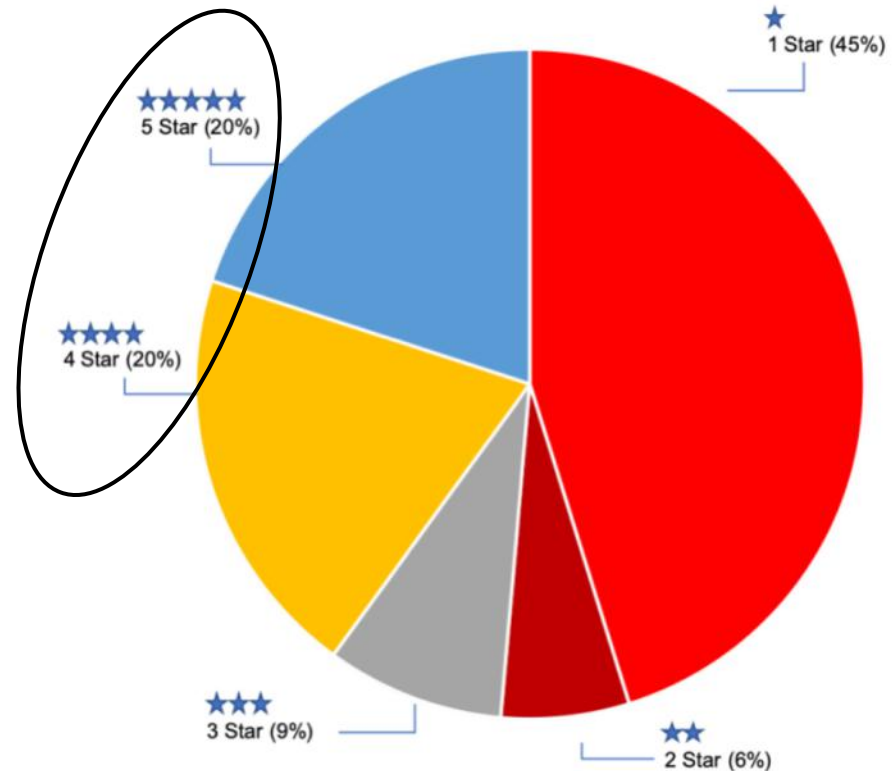
		STAR RATING - Collapse Requirements		
NON-HIPAA COMPLIANT	HIPAA COMPLIANT Substantial Intervention	HIPAA COMPLIANT Minimal Intervention	HIPAA COMPLIANT Seamless Process	HIPAA COMPLIANT Patient Focused
★	★★	★★★	★★★★	★★★★★
Accepts Requests by Email or Fax	Multiple Supervisor Interventions	One Supervisor Intervention	No Supervisor Intervention	No Supervisor Intervention Accepts External Request Forms Sends Records in 5 Days or Less No Fees

Point 1: good news - more providers delivering seamless access to records.

Scorecard V1: 51 Providers

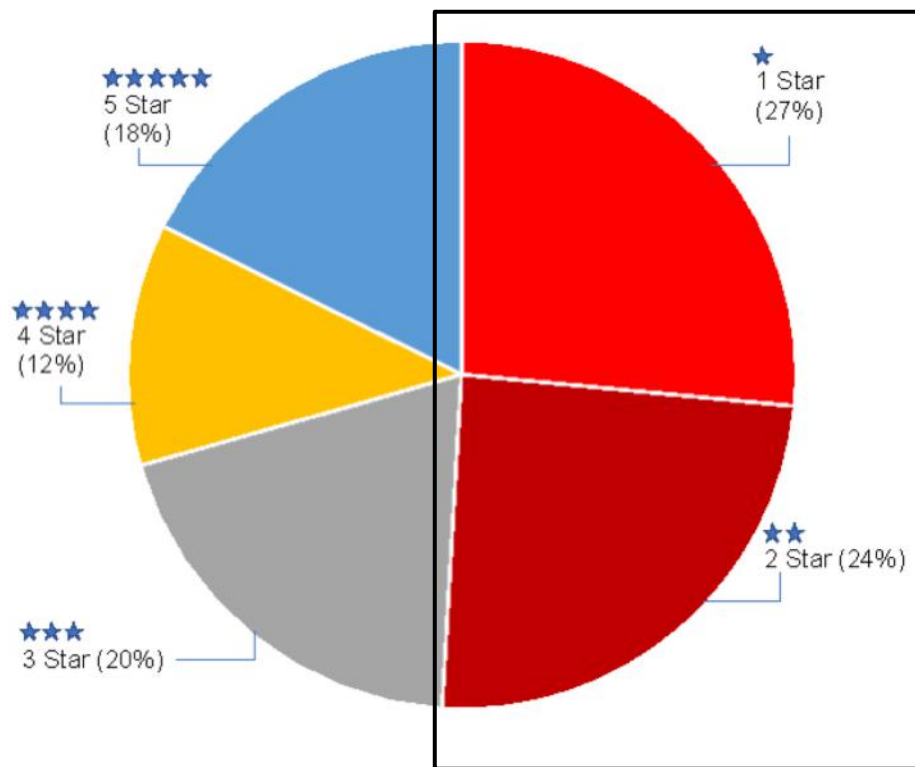


Scorecard V2: 210 Providers

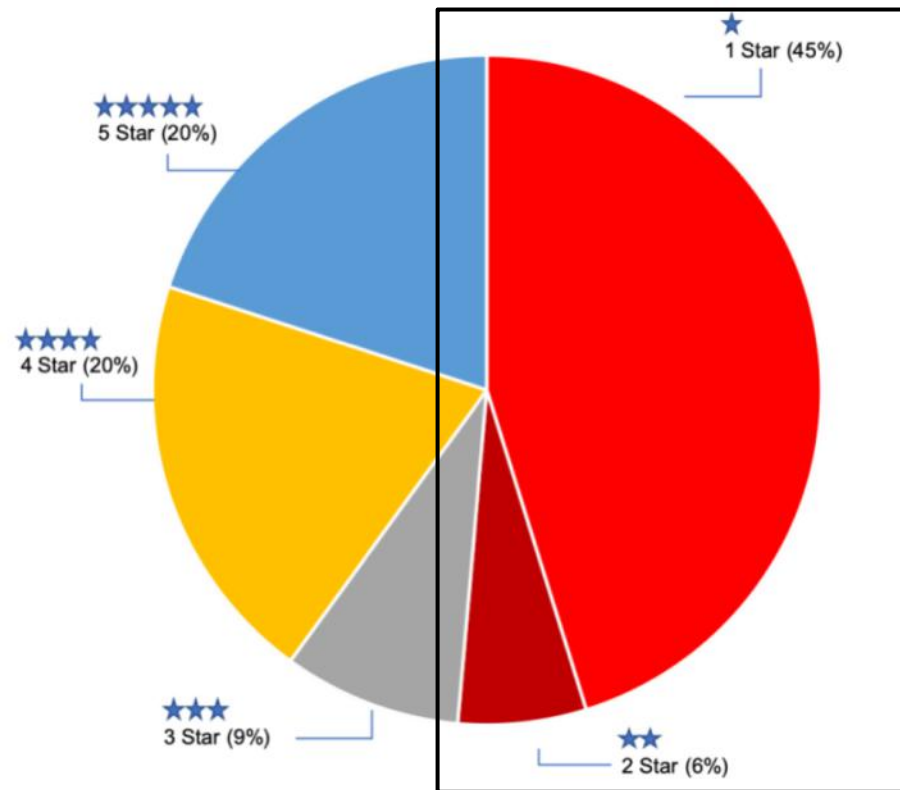


Point 2: bad news - 51% of providers still non-compliant under HIPAA or need significant intervention.

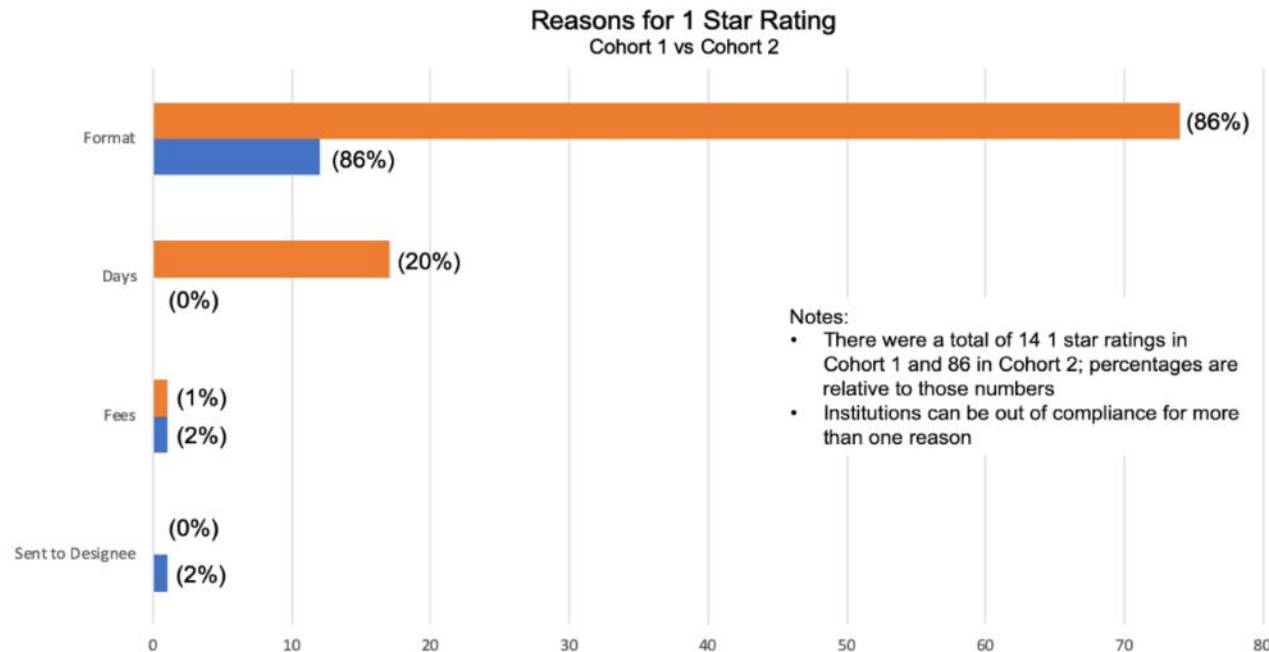
Scorecard V1: 51 Providers



Scorecard V2: 210 Providers



Point 3: w/out intervention, too often records aren't released on time



In this last cohort, we reduced our interventions to providers and saw an immediate increase in number of days it takes providers to send records. Also 20% of non-compliance scores are now associated with providers sending records over 30 days.

Scorecard 1: Too much intervention needed to get records

	Confirmation Calls per Request	Medical Records Office Follow-up Calls per Request	Escalation Calls Per Request	Total Calls Per Request
Average	2	3	2	7
Maximum	6	8	10	24

Without intervention to HIM Supervisors and/or Privacy Officers, 71% of our requests would not have been fulfilled pursuant to HIPAA requirements.

Point 4: call and wait times are too long for sick patients!

Hold and Call Times for Select Providers

Provider	Minutes
Provider A	15
Provider B	15
Provider C	15
Provider D	16
Provider E	16
Provider F	16
Provider G	20
Provider H	21
Provider I	22
Provider J	23
Provider K	25
Provider L	25
Provider M	26
Provider N	27
Provider O	34
Provider P	36
Provider Q	36
Provider R	51
Provider S	157

Point 5: consistency in patient experience an issue

Scores for providers with multiple cases (only most recent reported on Scorecard)

Provider A	3	1			
Provider B	3	4	5		
Provider C	2	5			
Provider D	1	5	1		
Provider E	1	2	4	5	4
Provider F	5	2	5		
Provider G	1	1	1	1	1
Provider H	5	1			
Provider I	3	1	1	1	1
Provider J	1	3			
Provider K	2	1			
Provider L	1	1			
Provider M	2	1			
Provider N	2	1			
Provider O	3	3	3	5	1
Provider P	2	2	2	1	

Majority of providers do not receive the same score for their cases; much variability depending on the HIM representative and potentially other factors.

Access Right – Request Process

- Covered entity **may require written request**
- Can be **electronic**
- Entity must take reasonable steps to **verify identity**.
- **BUT cannot create barrier** to or unreasonably delay access

For example:

Cannot require individual to make separate trip to office to request access

Cannot require individuals to mail in requests (creates delay)

Form, Format & Manner

- Individual has right to copy **in form and format requested** if “readily producible.”
 - If PHI maintained electronically, **at least one type of electronic format** must be accessible by individual.
 - Depends on **capabilities**, not willingness
 - Scope of this right includes **requested mode** of transmission/transfer of copy
 - **Right to copy by e-mail (or mail)**, including unsecure e-mail if requested by individual (plus light warning about security risks)
 - Other modes if within capabilities of entity and mode would not present unacceptable security risks to PHI on entity’s systems

Timeliness & Fees

- Access must be provided **within 30 days** (one 30-day extension permitted) BUT expectation that entities can respond much sooner
- **Limited** fees may be charged for copy for patient's own use
 - Reasonable, cost-based fee for labor for copying (and creating summary or explanation, if applicable), plus applicable costs for supplies and postage
 - Grabbing info from "portal" (via API) must be free
 - No search and retrieval or other costs, even if authorized by State law
 - Entities strongly encouraged to provide free copies
 - Must inform individual in advance of approximate fee

Right to Direct to Third Parties?

- Prior to 1/27/2020 - Individual's right of access includes **directing a covered entity to transmit PHI directly to another person**, in writing, signed, designating the person and where to send a copy (45 CFR 164.524(c)(3)(ii)).
- OCR opined that fee limitations applied to requests from patients directed to third parties.
- Opinion in CIOX Health LLC v. Alex Azar et al. issued 2/27/2020

Right to Direct to Third Parties?

- Opinion in *CIOX Health LLC v. Alex Azar et al.* issued 1/27/2020
 - Vacated scope of “third party directive” regulation in 45 CFR 164.524 (because it went beyond HITECH)
 - Held that HHS had impermissibly established fee requirements for “third party directives” through guidance
 - Directed HHS to establish fee provisions to implement HITECH third party directive provisions through notice and comment rulemaking.
- HHS statement: “The right of individuals to access their own records and the fee limitations that apply when exercising this right are undisturbed and remain in effect.”
<https://www.hhs.gov/hipaa/court-order-right-of-access/index.html>

Relevant HITECH (2009) statutory language

- HITECH provision (Section 13405(e):
 - In the case that a covered entity maintains an “electronic health record” (broadly defined), the individual has a right to get a copy of such information in an electronic format, and to direct the copy to be transmitted to an entity or person designated by the individual.
 - The fee for providing the individual with a copy of such information “shall not be greater than the entity’s labor costs.”
 - Electronic health record defined as an electronic record of health-related information on an individual that is created, gathered, managed & consulted by health care clinicians and staff

21st Century Cures (2016) statutory language

- Section 4006(e) – Empowering Patients and Improving Patient Access to their Electronic Health Information (EHI)
 - Secretary, in consultation with ONC, “shall promote policies to ensure a patient’s EHI is accessible to the patient *and the patient’s designees*” in a manner that facilitates communication w/ the patient’s providers and other individuals, including researchers, with the patient’s consent.
 - “To promote awareness that an individual has a right of access to inspect, obtain a copy of, and transmit to a third party a copy of the individual’s [PHI] pursuant to [HIPAA regulations],” OCR is required to help individuals and providers understand this right, including “best practices for requesting personal health information in a computable format, including using patient portals or third-party apps....”

Next Steps

- Obtaining records is a lot of work – personal health record services can help patients exercise their right of access. Key is when are they mere conduits for third party access to data.
- Clarifying guidance from OCR re: when a patient is requesting his/her own information where an app or service is involved in assisting the patient would help.
- Ciitizen will continue to do the scorecard but will evaluate how to report information on how providers (and vendors working on their behalf) respond to patient requests