Today, the consumer’s experience with the healthcare system is dreadful, exacerbated by the pandemic. Scheduling an appointment with a new physician takes months and sometimes proves impossible. Emergency rooms have become crowded and dreary basements designed to discourage use. This is despite the fact that the ED and some urgent care clinics are the only open doors to patients who need health care now. A full day of waiting in a crowded room of sick and injured people is an experience we all share and dread repeating.

These distressing encounters with the health system, the deep inequities they reveal, and the suffering patients experience because of them guide us at MHDC to build a better health data ecosystem where apps on personal digital devices or similar mechanisms will create a welcoming front door for patients and members, each of whom has unique health, equity, and accommodation needs. We are driven by the power that an individual wields when they control how their information is shared and used, especially for purposes secondary to direct patient care.

These secondary purposes include population health management, health system planning, quality control, public health monitoring, program evaluation, and research. Sometimes a patient’s health information will be “de-identified” or “anonymized” before it is used for these secondary purposes, sometimes it won’t be. Some of these uses, such as public health monitoring are required by law, but most aren’t.

These unregulated uses of a person’s health data are dictated by institutional priorities and not by the duty of care that guides informed consent. Signing a document that states that my health care entails risk and that I consent to care knowing those risks exist is the letter and spirit of informed consent. When the same contract expands my health care consent to uses of my health data that have nothing to do with my care or the common good, we have a problem.

Fast forward to 2027. Personal digital applications powered by data that conform to rigorous standards and are accessible by application programming interfaces, or APIs, will enable patients and their designees, with their health plan and primary care provider, to use their health data to find, schedule, and consent to the care they need and determine when, where, and how that care will be delivered. Patient consent will become granular, meaning one can grant and withdraw consent to specific data being shared for some uses and not for others.

Or not.
Shoshana Zuboff, author of *The Age of Surveillance Capitalism*, describes surveillance capitalism as the dominant economic institution of our time. Today all apps and software, no matter how benign they appear, are designed to maximize data extraction.

If we are to prevent the health data economy from committing and exacerbating the social harms caused by surveillance capitalism, we must regulate against the threat that this secret extraction of information presents to our most prized data and trusted relationships. No secret extraction means no illegitimate concentrations of knowledge about people. No concentrations of knowledge mean no targeting algorithms. No targeting means that corporations can no longer control and curate information flows and social speech or shape human behavior to favor their interests. Regulating extraction would eliminate the surveillance dividend and with it the financial incentives for surveillance. This affects both data outside of HIPAA and the standard 18 data elements included in HIPAA within the health system - consent should be a key driver of all interoperability and data use moving forward.

We have a lot of work to do.

Denny Brennan, Executive Director

Email us at newsletter@mahealthdata.org with your thoughts about this newsletter. Thank you for your continued support and participation!

**MHDC Events**

Meetings through February:

- The Forum (formerly CIO Forum): February 9, 8-9:15am
- DGC Working Group: February 2, 9, 16, 23 11am-12:30pm
- DGC Steering Committee: February 9, 3-4:30pm
- NEHEN Business Users: February 3, 9-10am
- Spotlight Users Meeting: February 22, 2-3pm - POSTPONED

Want to learn more about any of these meetings? Email info@mahealthdata.org

**MHDC Webinars**

Join us for our upcoming webinars:
The Forum: Discussion with Micky Tripathi on February 9 at 8am.

The Imperative Facing Every Tech Leader Agility + Efficiency + Compliance presented by Ruby Raley of Axway on March 1 from 11am-12:30pm.

Missed any of our webinars in 2021? Click here to see what you've missed!

Interested in holding an MHDC webinar or have an interesting topic you'd like to present? Contact us at webinars@mahealthdata.org

Arleen Coletti

Our long time Membership Director, Arleen Coletti, is retiring this month. Since joining MHDC in 2000 she's been the face of the consortium to most folks interacting with us. Arleen will be missed by all and we know she is all but irreplaceable, but MHDC will do its best to fill a tiny portion of her many roles - please let us know if we come up short.

Spotlight Analytics Update

Spotlight Business Analytics helps healthcare organizations run custom analytics on health data including market share, patient origin, disease prevalence, cost of care, and comparative costs and outcomes for acute care hospitals.

We are pleased to announce our partnership with the Lown Institute to add civic and care leadership measures to Spotlight. Augmenting Spotlight’s market share, disease prevalence, and demographic analyses with the Institute’s equity, value, and outcomes measures will provide Spotlight subscribers with a more comprehensive and relevant view of health system performance. We are working on and getting closer to having these new datasets incorporated into Spotlight for use, stay tuned
for more information. We are postponing the planned Spotlight Users Group meeting previously scheduled on Tuesday, Feb 22 at 2pm until we have the Lown data integrated and available to demo - we'll let you know when it is rescheduled.

The current data status is:

Loaded & available for use:

- Massachusetts Hospital Inpatient Discharge Data FY20
- Massachusetts Emergency Department Visit Data FY20
- Massachusetts Observation Data FY20
- Rhode Island Hospital Inpatient Discharge Data FY20

Received & ready for use soon:

- Lown Institute measures

Future planned data:

- New Hampshire Facility Discharge Data Sets (Application pending)
- Maine Hospital Inpatient and Outpatient Data (Application pending)

Please feel free to drop us a line with any questions or comments at spotlight@mahealthdata.org. In the meantime, thank you for being a Spotlight Analytics user and a member of this community! Feel free to visit our Spotlight Business Analytics page or email us at the address above for more information.

**DGC Update**

The Data Governance Collaborative (DGC) at MHDC is a collection of payers and providers throughout the region exploring ways to better exchange health-related data incorporating industry standards and automation as much as possible.

MHDC is moving to the implementation phase of the code mapping service - now called MHDC CodeMap. It will support exchanging data from one location to another - either inside an organization or between organizations - via RESTful APIs as well as allow data to conform to USCDI, FHIR, and FHIR IG requirements. For example, it can be used to align data from a quality measures store to risk analysis management within a payer's organization or to provide information about an encounter to a patient app or send clinical data supporting prior authorization requests from providers to payers. DGC members get a discount, but this service will be available to anyone who wants to use it.

We held our latest deep dive on SDOH questionnaires and learned quite a bit about SDOH questionnaires, how they and their resulting answers might be stored in medical data, and privacy and consent issues around SDOH data collected via
questionnaires and otherwise. Regulations are still a priority in our regular meetings, and we've also been reviewing several recent industry events. We've also been exploring several special projects with our Steering Committee - watch this space for more information as those projects progress.

Membership in the DGC is open to any payer or provider with business in Massachusetts - big or small, general or specialist, traditional or alternative. Want to know more? Email datagovernance@mahealthdata.org

NEHEN Update

NEHEN reduces administrative burden through the adoption of standardized transactions. It is a cornerstone service for payer and provider trading partners wishing to exchange industry standard X12, HIPAA compliant transactions in a real-time, integrated manner using APIs. Because of our unique governance, non-profit status, and membership-based model, NEHEN is able to offer very competitively priced services relative to the market.

NEHEN did not hold a January Business User’s meeting because of the New Years holiday. Happy New Year to all!

2022 is starting off with a flurry of industry activity. Most pertinent to this group, ONC has issued a request for information (RFI) seeking input on electronic prior authorization (ePA) and what certification requirements should be placed on EHR developers to support it (MHDC will be responding to the RFI with our recommendations). See the ePA section of this newsletter for more information on the RFI. For more information on other industry activity, see our main article in this issue covering all sorts of (mostly governmental) activity since mid-November.

The ePA prototype project has officially launched with Blue Cross Blue Shield of Massachusetts and New England Baptist Hospital. If you’re interested in learning more about it or interested in participating in the project please read the ePA section of this issue and contact us at epa@mahealthdata.org. In future issues ePA updates will be provided under NEHEN instead of separately.

For information about NEHEN please contact us at members@nehen.org.

Electronic Prior Authorization (ePA) Initiative

This project is a prototype implementation that automates prior authorization transactions using the industry standard, open platform methods developed by the HL7 DaVinci Prior Authorization workgroup. This project will be compliant with the three related implementation guides which utilize open, FHIR based API exchange methods. This will allow payers and providers to implement a single prior
authorization process and format for exchange so long as all of their exchange partners adhere to the same standards.

We are happy to announce the signing of participation agreements with both Blue Cross Blue Shield of Massachusetts and New England Baptist Hospital for a prototype implementation of electronic Prior Authorization (ePA) following the DaVinci Implementation Guide standards. The project will formally kick off meetings shortly and we expect it to last 12 months.

As part of this work, we are partnering with the Network for Excellence in Health Innovation (NEHI) to capture lessons learned, best practices, challenges and barriers to more widespread adoption of ePA within Massachusetts, New England, and the rest of the country. NEHI will be observing and extracting learnings from the ePA prototype to create a set of recommendations. These recommendations will also be shared with the Health Policy Commission and industry stakeholders to advance the automation and adoption of electronic prior authorizations.

On the regulatory front, ONC recently released a Request for Information (RFI) regarding the readiness of health IT vendors including electronic health record systems (EHRs) to support the standards and workflows defined in the related DaVinci implementation guides and beyond. ONC will use this industry feedback to consider additional health IT certification requirements going forward. The RFI touches on all aspects of the workflow including exchange standards readiness (FHIR, CDS Hooks, X12, C-CDA) and maturity of the proposed mechanisms for performing prior authorization (including the CDS Hooks integration and attachments readiness of EHRs among other things).

ONC focuses on the provider side with the health IT certification program (CHPL) certifying EHRs and other related technology. They are considering the interplay of both administrative and clinical data exchange standards and the best approach overall. We anticipate the gathered responses will be shared and help inform a future CMS interoperability and burden reduction rule covering ePAs.

For more information email us at epa@mahealthdata.org.

Industry Events

Interested in webinars and online conferences in February? Here are some we recommend (they’re free unless otherwise noted):

- **ONC: Annual Meeting**: Feb 2-3
- **Beckers: Managing Security and Threat Landscape in Healthcare**: Feb 7, 1pm
- **AHIP: Meeting Consumer Surge in Demand for Virtual Care: Are You Ready?**: Feb 8, 3pm
- **ONC: PULSE Workshop**: Feb 9, 1pm
- **Infoblox: Quarterly Threat Report: Research and Analysis on Emerging Cyberthreats, Malware, and Ransomware**: Feb 9, 1pm
- **AHIP: Views and Perspectives on Provider Directories for Payers**: Feb 9, 1pm
- **Healthcare Innovation: Consumerism & Healthcare**: Feb 10, 1pm
- **AHIP: State of the Industry: Unpacking the Potential Impact on Health Plans in 2022**: Feb 10, 2pm
- **Health System CIO: Establishing Accurate Patient Identity As the Cornerstone of Your Interoperability Strategy**: Feb 15, 12pm
- **WEDI: Health Equity Summit (fee)**: Feb 16-17
- **AHIP: What is Goal-Driven Member Engagement**: Feb 16, 2pm
- **AHIP: Using Data-Driven Strategies to Drive Success in Value-Based Contracts**: Feb 17, 11:30am
- **Beckers: Improved access is only one piece of the health outcome puzzle**: Feb 17, 1pm
- **Beckers: Accelerating Primary Care’s Strategic Role in Patient Engagement and Retention with Intelligent Automation**: Feb 22, 1pm
- **Beckers: In the trenches with the No Surprises Act — Successes, challenges and preparing for what comes next**: Feb 22, 1pm
- **AHIP: CMS 2023 Advance Notice: What Medicare Advantage Plans Need to Know**: Feb 22, 2pm
- **DaVinci Community Roundtable**: Feb 23, 4pm
- **Beckers: Empowering patients to organize and navigate their care lives**: Feb 24, 2pm
- **Beckers: Lessons in healthcare transformation: How 3 CEOs plan to reshape the patient experience in 2022**: Feb 28, 12pm

We do periodically post webinars we plan to attend on social media, so feel free to follow us on Twitter ([@mahealthdata](https://twitter.com/mahealthdata)) and [LinkedIn](https://www.linkedin.com) for more webinar ideas and for our take on interoperability, data, health equity, telehealth, APIs, and other topics of interest.

Have an upcoming event next month to suggest? Write us at newsletter@mahealthdata.org - no self-promotion please.

**It's Been Busy: Legislation, Regulation, Guidance, and More**
The end of 2021 and beginning of 2022 has been a busy time for healthcare and health IT legislation, regulation, specifications, guidance, tools, requests for information, and reports from various agencies. Before you have a chance to read an announcement or the related details the next one comes out (ONC alone had three major announcements in the same week in mid-January).

To help keep this onslaught of new stuff straight, we've compiled a list, organized by type of announcement:

- Legislation in Process
- Proposed Rules
- Final Rules
- Specifications
- Guidance
- RFIs
- Reports
- Tools

We can't guarantee we've caught everything of interest (and we deliberately omitted some announcements with no clear bearing on data, interoperability, quality measures, patient access and experience, equity, or SDOH), but we hope this helps you keep up with what's going on.

**Legislation in Process**

Congress is working on a 21st Century Cures Act v2.0 ([overview](#) | [full draft bill](#)). It was introduced in November 2021 and is now working its way through various committees. It's meant to build on the original act, and includes clauses related to public health, patients/caregivers, FDA activities, CMS activities, and research. Among many other things it includes sections on patient experience data, FDA digital health oversight, FDA expedited approval processes, CMS expansion of telehealth and medical device support, better e-prescribing standards, claims data availability requirements, reporting on payment models, ARPA-H funding, and efforts to diversify clinical trials.

The [Social Determinants of Health Data Analysis Act of 2021](#) has passed the House and is in committee review in the Senate as of the last known update. It is mainly a data gathering bill, requiring analysis of privacy implications of SDOH data collection, looking at coordination requirements between HHS and other government entities, and looking at public-private partnership and how to leverage private sector efforts to address SDOH.

The [LINC to Address Social Needs Act](#) directs grant money to states for private-public partnerships to manage referral networks and track health outcomes from SDOH programs. Versions have been introduced in both the House and the Senate; the
Senate version has been sitting dormant for months but the House version was moved to committee in early January.

The **PREVENT Pandemics Act** is starting to wind its way through the Senate. This act, currently in draft, includes a ton of oversight and information collection clauses but also includes some data standardization and interoperability requirements. Some of the measures most relevant to our work include funding for programs to reduce health disparities by addressing SDOH and that use technology to improve coordination, requirements to modernize existing public health data systems (including integration of lab data and electronic exchange of data), a deadline to improve CDC-set public health data exchange standards, requirements for better data exchange between federal agencies, implementation of programs to improve demographic data collection, and an FDA mandate to increase use of digital health and decentralize clinical trials.

A new **Massachusetts Mental Health bill** passed the Senate in November. A version of the bill had already passed the House, but needs to be reconsidered. The Senate version of the bill is currently in the House Ways and Means committee. Among many other things, the current version includes mental health parity requirements, free annual mental health checkups, insurance reforms, standardized release forms, interoperability requirements around continuity of care, and some type of state-wide portal for finding open beds at facilities.

**Proposed Rules**

CMS issued a proposed rule called **Patient Protection and Affordable Care Act** that mostly goes into effect in January 2023 (if finalized). Some of its clauses include prohibiting discrimination based on sexual orientation or gender identity, updates to risk adjustment models and new data reporting for risk, new network adequacy requirements requiring tracking of new metrics, and a request for information on how to incentivize equitable plans and SDOH programs.

CMS issued a proposed rule governing **Medicare Advantage and Medicare Part D drug pricing** that also modifies the way some Stars quality measures are calculated and requires Special Needs Plans to complete SDOH screening for all enrollees on an annual basis among many other requirements.

**Final Rules**

CMS issued a **third Interim Final Rule (IFR)** related to the No Surprises Act in late November. It covers reporting requirements including plan enrollment and premium information, total healthcare spending broken down by type of care, the 50 most frequently dispensed brand prescription drugs, the 50 costliest prescription drugs by total annual spending, the 50 prescription drugs with the greatest increase in plan spending that year, all prescription drug rebates and remuneration paid by drug manufacturers, the 25 drugs yielding the highest amount of rebates, and the impact
of rebates on premiums and out of pocket costs. The rule was effective on December 27, 2021 but enforcement discretion is in place until December 27, 2022.

Specifications

TEFCA v1 was finalized and released on January 18. It consists of two specifications: the Trusted Exchange Framework and the Common Agreement. The Trusted Exchange Framework is a series of non-binding principles to facilitate data exchange among HIEs. The Common Agreement is a binding agreement that outlines the specific rules of operation and required feature support for Qualified Health Information Networks (QHINs) chosen to participate in TEFCA. QHIN selection starts in Q2 and should begin operation by the end of 2022. TEFCA is currently built upon traditional exchange mechanisms and focused on provider access but plans to address wider access and support FHIR at some point in the future.

The draft version of USCDI v3 was released on January 19. While more a high level list than a true specification, USCDI sets the baseline for data exchange standards (all current requirements are still based around USCDI v1). The v3 draft adds insurance information, health status information, additional patient demographics, a referral reason to Procedures, and specimen type and result status to Laboratory data. Comments will be accepted through April 30.

ONC’s Project US@ officially released v1 of its specification to standardize address information across all health data on January 7. The DGC participated in this project and, while a small step toward better patient matching, is happy to see it come to fruition.

Guidance

HHS has released new HIPAA guidance covering emergency firearm protection orders including when to release mental health information without patient consent.

FDA has released draft guidance on remote data acquisition during clinical trials. It provides guidance in a number of areas including the selection of digital health tools suitable for clinical trials, definition and evaluation of clinical endpoints connecting to digital health tools, risk management considerations, and the protection and retention of records. The draft is open for comments until March 22.

CMS has updated its interoperability FAQ site and interoperability guidance page with additional information about Payer => Payer exchange and its enforcement delay (other information may have also been updated). Formal notice of the enforcement delay was published in the Federal Register on December 10.

ONC has released a blog post and fact sheet on electronic health information or EHI. Information blocking regulations move from USCDI v1 to all EHI on October 6, 2022 and full provider export of all EHI is required by December, 2023. These
documents look at the relationship of USCDI, EHI, and the HIPAA designated record set including some examples.

ONC has updated its information blocking FAQs to add additional information about EHI requirements, whether a direct request for information is required for actions to be considered information blocking, which progress notes are covered by USCDI v1, whether information must proactively be made available in patient portals, rules around fees for paper or CD/DVD copies of requested information, and whether PDF files are considered a machine-readable format by the information blocking rules.

RFIs

As noted above, the CMS Patient Protection and Affordable Care Act proposed rule includes a request for information on how to incentivize equitable plans and SDOH programs.

ONC released an RFI on January 24 asking for information on electronic prior authorization. Some of the areas they’re looking for comment on include electronic prior authorization standards, implementation specifications and certification criteria that could be adopted within the ONC Health IT Certification Program, the use of attachments in prior authorization, and reducing burden on clinicians and patients. As many of you know, MHDC is standing up a prototype electronic prior authorization project using FHIR and the three Da Vinci implementation guides. We plan to comment on the RFI before the March 25 deadline.

Reports

The United States Preventative Services Task Force Annual Report to Congress outlined some additional recommended research, screenings, and data collection to improve care and equity in chronic diseases including hypertension, diabetes, cancer, and cardiovascular disease.

ONC published submitted Health Outcomes 2030 public statements of what people think should be possible by 2030 thanks to increased interoperability. MHDC submitted several ideas that we hope will guide future interoperability regulations.

AHRQ published its 2021 National Healthcare Quality and Disparity Report with data on 6 sets of measures related to quality of care (person centered care, patient safety, care coordination, affordable care, effective treatment, and healthy living) and 4 related to equity (race and ethnicity, income, insurance status, and residence location).

CMS published a report on the status of provider digital contact data in NPPES. This report is a requirement of the CMS Interoperability Rule from May 2020 and will be updated quarterly from now on. It consists of a list of names and NPI numbers of practitioners without digital contact information on data.cms.gov. This is essentially a dictionary of FHIR and other endpoints associated with providers. As of December
21, 2021 the list contained nearly 3 million providers without any type of digital contact information, making provider interoperability more difficult.

The ASPE Medicare 2020 Telehealth Usage Report looks at Medicare Fee for Service usage in 2020 by location, modality (~70% was audio-only), specialty, and various demographic metrics including race/ethnicity and geographic location.

The Center for Democracy and Technology and American Association of People with Disabilities has released a report on how technology can discriminate against people with disabilities. It covers a variety of topics including digital accessibility practices, equal employment and education access, data privacy, and algorithmic bias to name just a few. This one's not from the government like most of our other listings, but we thought it was important to highlight anyway.

Tools

HHS has a new website providing cybersecurity information to healthcare professionals and organizations. It includes educational materials, best practice guidance, and materials aimed at preventing specific types of attacks (including ransomware, phishing, loss and theft, attacks via connected medical devices, and more).

CMS has released its list of approved Independent Dispute Resolution (IDR) Entities for use in No Surprises Act dispute resolution. The list includes name, website, and pricing for each approved IDR. Payers and providers engaged in disputes must agree on one of these entities to settle their disagreement.

Wrapping Up

As you can see, there's a lot going on - and there's no sign that things will slow down at all. Did we miss something you think is important? Let us know at newsletter@mahealthdata.org. If you're a payer or provider interested in regular updates of new announcements about and deep dives into specific laws, rules, guidance, and reports consider joining the DGC. Email datagovernance@mahealthdata.org for more information.

Looking Forward at 2022 Crossword Answer Key

For those of you who played along, here's the answer key to our Looking Forward at 2022 crossword. How'd you do? Let us know at newsletter@mahealthdata.org.
ACROSS
2. They’re at the center of everything
3. Healthcare API framework
5. ONC is doing it by design
7. Uses data to predict outcomes
10. Know the cost
13. Chairman of the Board

DOWN
1. They oversee privacy and security of third party apps
2. Get permission for a service from a payer
4. Translating the vocabulary of healthcare from one standard to another
6. Our new analytics partner
8. She’s retiring and we’ll miss her
9. All outcomes are known
10. CMS regulated exchange starting in 2022
11. Our exchange services arm
12. Food insecurity, homelessness, etc.

Black History Month

Black History Month is one of the many ways in which we honor and remember the achievements, significance, and sacrifices of individuals and events from the black community, past and present. This month is special because through discussion and remembrance we can honor and learn about the roles of those who have helped shape the landscape of today. You may not know where to begin or what to do to celebrate but we encourage you to start by checking out some of these links below and participate where you can.

- Some general history, resources, and events: [Black History Month](#)
- The story behind why Black History Month is in February: [Here’s the story behind Black History Month — and why it’s celebrated in February - WABE](#)
- Some older but still very relevant and great articles and resources on racial healthcare disparity, implicit bias in healthcare, notable black nurses through history, and young black healthcare professionals: [Black History Month 2021 - Honoring Black Healthcare Leaders - Trusted Health](#)
- Some publications and resources regarding Black History Month 2022's theme of Black health and wellness: [2022 Black History Month – Black Health and Wellness](#)
A few health-related Black History Month Events from HHS: [Black History Month](#)

10 Black Pioneers in Healthcare: [Black History Month: celebrating 10 pioneers in healthcare](#)

Have a favorite article or event of your own? Let us know at newsletter@mahealthdata.org.

Wrapping Up

Before we go, here's a reminder of upcoming health data exchange deadlines including those from ONC and CMS (including the CMS rule that's currently frozen, as noted by *):
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<th>Date</th>
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<td>JAN 1</td>
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<td>NO SURPRISES ACT (NSA) ENFORCEMENT BEGINS</td>
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<td>• GOOD FAITH ESTIMATES FOR UNINSURED/SELF-PAY PATIENTS COVERING A SINGLE PROVIDER/FACILITY</td>
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<td><strong>INCREASING THE FREQUENCY OF FEDERAL-STATE DATA EXCHANGE (ENFORCED)</strong></td>
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<td>OCT 6</td>
<td><strong>INFORMATION BLOCKING USES EHI (NO LONGER LIMITED TO USCDI)</strong></td>
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<tr>
<td>DEC 27</td>
<td><strong>NSA: REPORTING REQUIREMENTS FOR PLAN AND PHARMACY DATA (ENFORCED)</strong></td>
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<td>DEC 31</td>
<td><strong>PROVIDER FHIR APIs</strong></td>
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<td>2023</td>
<td><strong>NSA: CONSOLIDATED GOOD FAITH ESTIMATES FOR UNINSURED/SELF-PAY CONTAINING ALL PROVIDERS/FACILITIES FOR A SINGLE SERVICE</strong></td>
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<td>DEC 31</td>
<td><strong>FULL EHI EXPORT SUPPORT</strong></td>
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* CMS RULE THAT'S CURRENTLY FROZEN
And that's it, folks. Loved it? Hated it? Have an idea for next time? Send us feedback and suggestions about this newsletter at newsletter@mahealthdata.org or send us feedback and suggestions about anything else at info@mahealthdata.org.

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