Ensuring Interoperability and Information Sharing

21st Century Cures Act and Open Notes

FAQs

What is the 21st Century Cures Act?
It is a law passed by Congress and signed by President Obama. It recently went through its final regulatory rule making. Implementation of key features of the 21st Century Cures Act are now upon us. As of November 2, 2020, it is unlawful to do anything that interferes with the transmission of health data (patient-authorized health data), including transmitting records to the patient.

UCDH already shares the majority of the data set that is required to be shared in November. It is working on making the rest of the information available for sharing by November 16, 2020, together with the Epic quarterly upgrade.

Why did they pass this law?
Studies have found that patients are more engaged, likely to have better adherence, and are able to engage their families in their care when they can understand ‘why’ various tests and treatments are being recommended. More important, patients have the rights to their own health information as defined in HIPAA. The new requirements don’t add to what patients can access. The 21st Century Cures Act rule only makes it easier for patients to access the data they already have a right to see.

What’s going to be shared with patients?
Eventually, almost everything in Epic and other electronic systems (see “Are there exceptions to the 21st Century Cures Act?” below) will be shared. In November, the requirements mainly involve most Epic information. Many of the requirements are for data UC Davis Health already shares via the MyUCDavisHealth patient portal, such as medications, health concerns and problems, and immunizations.

Will notes and test results be shared?
Yes. All notes going forward, with rare exceptions, will be released when you close your outpatient encounter, or when the Inpatient and ED note is signed. Trainee notes including those written by Residents and Medical Students need to be co-signed by an attending first. Almost all results will be released to patients without delay regardless if they were performed in the ED, Inpatient, or Ambulatory setting.

Will encounters be shared?
Yes. Almost all encounters will be listed in MyUCDavisHealth. If an after-visit summary or a note is attached to the encounter, the patient will be able to view that information.
Are there exceptions to the 21st Century Cures Act?
There are only a few exceptions in the regulation, and there is very little latitude for clinical input.

- Exceptions for notes: Psychotherapy notes, used only by the psychiatrists and written as sensitive notes, will not be shared via MyUCDavisHealth.

Additionally, providers can un-share individual notes if the information in it would do the following:
  - Would likely put a patient or other individual at risk of physical or “substantial” harm
  - Would violate privacy (e.g., you can’t separate out information, such as a teen’s reproductive health information or information about other people/family members in the note).

The Preventing Harm and Privacy exceptions include:
  - Preventing Harm: Physical harm to patient or others
  - Preventing Harm: Risk of releasing inaccurate information
  - Privacy: Other law allows blocking/delaying this information
  - Privacy: Patient or Legally Authorized Representative (LAR) requested information to not be shared with the patient and/or others
  - Privacy: Treatment provided to incarcerated individual at direction of correctional institution
  - Privacy: Information obtained from confidential source

When invoking an exception, a provider must document why they decided to not share the information by using the following Smartphrase in the note that they are not sharing: notsharingnote.

- Exceptions for results: California law requires discussion with patients about new cancer diagnoses (Pathology results not including Dermatology), HIV, hepatitis, drug abuse labs before they can be released. Automatic release will therefore be delayed for 14 days for these results, allowing providers time to communicate and contextualize life-changing diagnoses. Genetic results don’t have the same State of California requirements for delayed release.

- If a provider needs more time before releasing a result, they can do so on a case-by-case basis by using the MyUCDavisHealth results-release activity or selecting “Manual Release” at the time of placing the order. Detailed instructions for this workflow will be disseminated soon.

- Transplant donor results are not released to MyUCDavisHealth.

What about data from my research?
For most clinical research studies, study documentation has routinely occurred in the same Epic clinical note types used for care and treatment. In order to help protect the clinical research record when the study prohibits sharing research notes with subjects, a specific Research note type is being developed.
Research information should be documented within this new Research note type and not in the Progress note. Research notes will be manually, not automatically, released when permitted by the study protocol. Principal investigators are encouraged to manually release the notes during the study as permitted by the protocol. Ultimately, all Research Notes withheld during the study will need to be manually released at the conclusion of the study, unless a harm or privacy exception to release (outlined above) applies at that time.

Research test results that are associated with a research diagnosis code at the time of ordering will not be auto released. However, as with research notes, principal investigators are encouraged to manually release the test results as permitted by the protocol to support patient care, and they must manually release the results once the study is over.

Who else might this data be shared with?
Anyone the patient wants to share it with. HIPAA makes it clear that health data belongs to patients. Information will be viewable by a patient’s full-access proxy, and patients can also allow third-party apps to have access to their data.

Is this going to make my work harder?
There is a lot of literature, as well as local data, that shows sharing notes has minimal impact on providers.

How should I change my practice?
- **Set patient expectations:** Let patients know they can read your notes. The benefits of better understanding and engagement won’t happen if they don’t.

- **Writing notes:** Hopefully, writing notes should not have to change at all. If your comments are professional, studies show that patients have a good understanding of most notes.
  - UC Davis Health policy states that the medical record should only contain facts and clinical opinions that are relevant to the diagnosis and treatment of the patient, and that personal opinions, assumptions and conjecture should be avoided. Charting should be free of emotional feelings, and not contain statements that blame, accuse or compromise the hospital, other care givers, the patient or their family.
  - As for jargon, let patients know that Medline Plus Common Medical Abbreviations is available in MyUCDavisHealth (https://medlineplus.gov/appendixb.html) for patients to use as a reference, or encourage them to consult a healthcare professional.

- **Signature Block:** remove your pager number and other contact info; consider removing any images of your handwritten signature.

- **Results:** When ordering, manage patient expectations by letting them know that they’ll receive results perhaps even before you see them, and that anything needing comments will happen later, via MyUCDavisHealth or a phone call, as appropriate.
Will patients complain or ask for changes to their notes?
From time to time patients will catch important errors that should be corrected.

Patients can request corrections to their PHI under HIPAA Patient Amendment law and California Addendum law. The form is available for patients to download via a hyperlink in MyUCDavisHealth and on the UC Davis Health website. If you would like to request that an HIM subject matter expert present this process at your department or practice meeting, please send an email to hs-him@ucdavis.edu.

Experience to date at UC Davis Health has shown a small, manageable number of patients do request changes. Most of those requests have been reasonable.

What about staff messages, routing and result comments?
These will not be shared yet. However, message and comments may be shared in 2022. Result comments will be shared.

What special considerations should I have around adolescents?
Make sure teens know not to share their passwords, otherwise parents will be able to see private reproductive and other health information. If there is confidential information that families think should be in the child’s record, but don’t want the child to know about yet (e.g., genetic conditions, adoptions), note authors can write a separate confidential note with that information and un-share that note.

Teens will see the same information that adults see in their MyUCDavisHealth. Legally Authorized Representatives (i.e., parents, guardians) can access their child’s PHI through the HIM Release of Information process. This will allow HIM to ensure the representative is only able to access information they are legally entitled to view.

Parents/Guardians (proxies) of teens will continue to be granted medium (limited) access to their teen’s MyUCDavisHealth. For more information click here: MyUCDavisHealth For Teens and Parents/Guardians

What about breast biopsies?
Radiology will call with positives as pathology that is addended to biopsy procedure notes and will be released immediately.

What about STDs and partner violence or child/domestic/elder abuse?
You can block the release of the note if sharing the note is likely to put a patient or other individual at risk of physical or “substantial” harm.