ciitizen

- Platform enabling patients – beginning with cancer patients – to gather, use and share their comprehensive health information
  - Information, once in the Ciitizen profile, is under the control of the individual – who can share, or not, as they please
- Leverage the HIPAA Right of Access to obtain information for the Ciitizen profile
- Need more data than is available through portals and APIs (for ex., notes, images, path reports, genomic/genetic test data)
  - So requests need to be routed through medical record offices

State of HIPAA Access Compliance

- Ciitizen recently released scorecard & survey measuring compliance (and potential compliance) with the HIPAA Right of Access
  - Scorecard based on responses to actual patient requests (>200 institutions)
  - Survey based on telephone responses to questions about access processes (@3000 hospitals)
- **Goal is to improve patient's ability to seamlessly access their health information**
- www.ciitizen/scorecard (white paper at https://www.medrxiv.org/content/10.1101/19004291v1)

THE
PATIENT
RECORD
SCORECARD

The majority of medical record providers are not compliant with the HIPAA Right of Access.

Survey of ~3,000 top medical record facilities from August 2018-May 2019.

VIEW SCORECARD

ciituzen

State of HIPAA Access Compliance

- Scorecard & Survey reveals more than 50% noncompliant – or potentially noncompliant)
  - Most common issue (both scorecard and survey): failure to send in form/format requested by patients, to designated third party
  - Fees also potential area of noncompliance (state law reliance misplaced) (but only on survey – scorecard experience was largely positive on fees)
- Front line staff (employed by provider and at records vendors) who deal directly with requests often not well informed of HIPAA obligations
- Challenges to distinguishing between third party requests and those from patients seeking to send to designee (such as an app or personal health record service)

State of HIPAA Access Compliance

- Greater enforcement – two cases settled in 2019
- Willful neglect penalties were not affected by OCR new penalty tier approach
- **More widespread use of APIs to enable patient access (see proposed ONC & CMS rules) will help providers (and health plans) gain greater compliance with HIPAA Right of Access**
  - Will need to expand USCDI to incorporate more data
  - Otherwise will be years before entire "designated record set" (what patients are entitled to under HIPAA) is available thru APIs