

# Legislative Briefing on Privacy Developments

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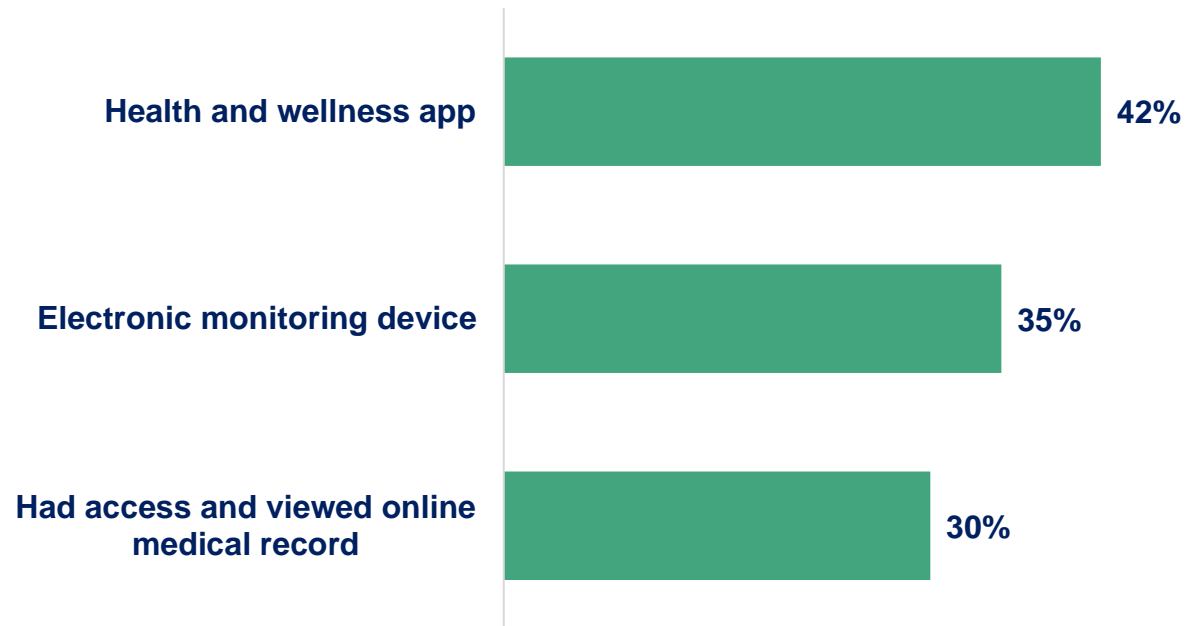


# Importance of Improving HIPAA

- Scope of health information has expanded
- Increasing number of consumer-facing technologies, applications, products, and services not covered by HIPAA
- With the expanding world of big data and data analytics, entities are amassing large data sets from sources within and beyond HIPAA
- Patchwork of state and federal laws governing health information. Variability has made it difficult for HI professionals to navigate to ensure compliance.

# What is Health Information?

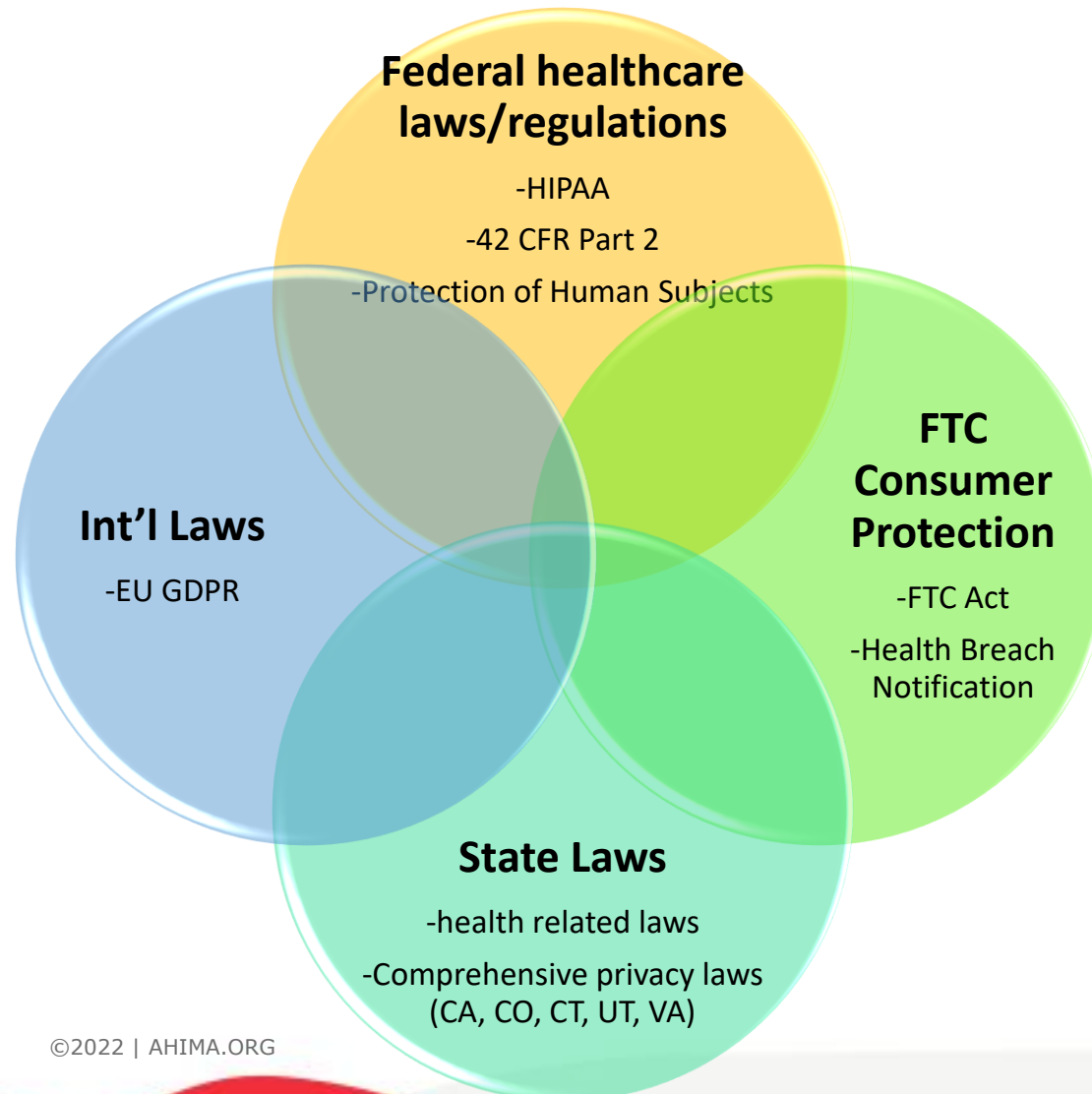
## Share of Individuals using online tools, pre-pandemic



Source: ONC Data Brief No. 48, May 2019.

Increasingly, health information is generated outside of HIPAA and is shared with non-covered entities at the request of the patient.

# Policy Developments Related to Privacy



How would a new federal comprehensive privacy law fit into this landscape?

# Other Policies Related to the Use and Sharing of Health Information

- CMS
  - Promoting Interoperability Program
  - Interoperability and Patient Access Rule
- ONC – 21<sup>st</sup> Century Cures Act / Information Blocking
- HHS - No Surprises Act and related regulations that focus on Price Transparency by providers and health plans

HHS policies since 2011 have promoted increased access to and sharing of information held by providers and payers.

# American Data Privacy Protection Act

- Growing interest in comprehensive privacy bills in the 116<sup>th</sup> and 117<sup>th</sup> Congress
  - Broad applicability, with FTC enforcement
  - HIPAA carve outs
- HR 8152 - American Data Privacy and Protection Act
  - Referred to the House Energy and Commerce Committee (markup scheduled for Wednesday, July 20)
  - Amendment in the Nature of a Substitute
  - Bipartisan, bicameral
  - Key sections:
    - Title I – Duty of Loyalty
    - Title II – Consumer Data Rights
    - Title III – Corporate Accountability
    - Title IV – Enforcement, Applicability, and Misc.
- Key areas of negotiation:
  - Federal preemption of state laws
  - Private right of action

# American Data Privacy and Protection Act

- Addresses all data, not just health data
- Health data identified as “sensitive covered data”
- Carve-out for covered data subject to other federal data protection laws deemed to be in compliance
- Addresses gaps in privacy and security protections of consumer-facing technologies
- Excludes de-identified data from covered data
- Preempts many state laws governing privacy and security with exceptions
- Other aspects addressed (e.g.—enforcement by FTC, private right of action, etc.)

# Opportunities for further inquiry by NCVHS

- Enhance understanding of how HIPAA interacts with broader privacy laws under consideration
- Focus on approaches to de-identification
- Continue focus on availability of data for public health purposes



# Resources

- [HR 8152, American Data Privacy and Protection Act](#)
- [Amendment in the Nature of a Substitute to HR 8152](#)
- [US Federal Privacy Legislation Tracker \(iapp.org\)](#)

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