



# DATA IN VALUE-BASED HEALTH CARE

Reconciling Data Sharing and  
Privacy Protections

**ROPES & GRAY**

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## CHALLENGES

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graph TD; CHALLENGES --> INTEROPERABILITY; CHALLENGES --> QUALITY_OF_DATA[QUALITY OF DATA]; CHALLENGES --> EFFECTIVE_USE_OF_DATA[EFFECTIVE USE OF DATA]; CHALLENGES --> INDIVIDUAL_PRIVACY_RIGHTS[INDIVIDUAL PRIVACY RIGHTS];
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INTEROPERABILITY

QUALITY OF DATA

EFFECTIVE USE OF  
DATA

INDIVIDUAL  
PRIVACY RIGHTS

# VBHC data challenges

- IT support critical for Value-based Health Care (“VBHC”)
  - Major investments in Electronic Health Records (“EHRs”), but have not met expectations
  - Supporting VBHC Initiatives
  - Need to build for 2020 and beyond
- Grappling with the interoperability millstone – legal and operational challenges
- Seeking high quality data: rethinking the way we organize and support the collection, management and use of the data
  - Capturing and structuring data to support the shift to greater provider accountability

# Quality of data

- Data not effectively captured or measured
- Need for:
  - Effective sharing of data with integrated care team
  - Use of data for benchmarking purposes
  - Support for evidenced-based care planning
  - Support for Clinically Integrated Networks (“CINs”), Risk-bearing Organizations (“RBOs”), Health Information Exchanges (“HIEs”)

# Diabetes as example

## Range of clinical and supplemental needs

- Pre-admission / screening
- In hospital care
- Post acute care
- Physical Therapy
- Diet and exercise
- Patient Engagement through technology
- Ancillary Support Services

# Privacy protections – the counterpoint

- Strong public policy preference: protecting patient privacy and data-use rights
- The conflict: desire to have benefits of big data but reluctance to share personal health information
- Fragmentation of these protections
  - Like EHRs, patient privacy protections built around the legacy fee-for-service health care structure and patient consents and authorizations

# Array of data-use rights & privacy protections

- Legal hurdles
  - Authorizations and consents
    - Non-“treatment” uses and data aggregation
    - Patient compensation for data; blockchain technology?
    - Coordination of consents and authorizations across the care team
    - Authorization of future, unforeseen uses (de-identification, “blanket” consents)
    - Effective data security
- State-specific privacy laws (HIV, mental health, etc.)
- Ongoing compliance with evolving federal standards
  - Office for Civil Rights enforcement
  - Punitive shift in Federal Trade Commission enforcement

# Balancing the values

- Balancing patient privacy legal protections with the data sharing and aggregation required for VBHC:
  - Trusted Exchange Framework (“TEFCA”), a partial answer
    - Pursuant to the 21st Century Cures Act
    - Attempts to create a single “on-ramp” for provider and others’ data exchange
  - CINs
    - Difficult to establish
    - Still require substantial resources devoted to privacy
      - Complex to ascertain needed consents/authorizations
        - Business associate or covered entity status, and when?
      - New York State Medicaid Health Home program
      - Broad state-authored consent and authorization
      - Substantial compliance resources still required



# Balancing the values

- HIEs
  - Exchanges of clinical information between disparate health systems
  - Variety of models (e.g., EHR vendors, consumer controlled, geographic based)
  - Still fundamentally rests upon a concept of consents and authorizations
    - Emerging trends
  - United Health Group
    - Payor provided data analytics and technology
    - Supporting Medicare advanced Bundled Payments for Care Improvement model
  - CVS – Aetna
    - Wellness clinics and pharma services
    - Community-based hub

# Conclusion

- The move to VBHC requires harmonizing competing goals:
  - (1) data sharing and aggregation necessary for VBHC
  - (2) the moral and legal imperatives of patient privacy and control

# Thank you

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