

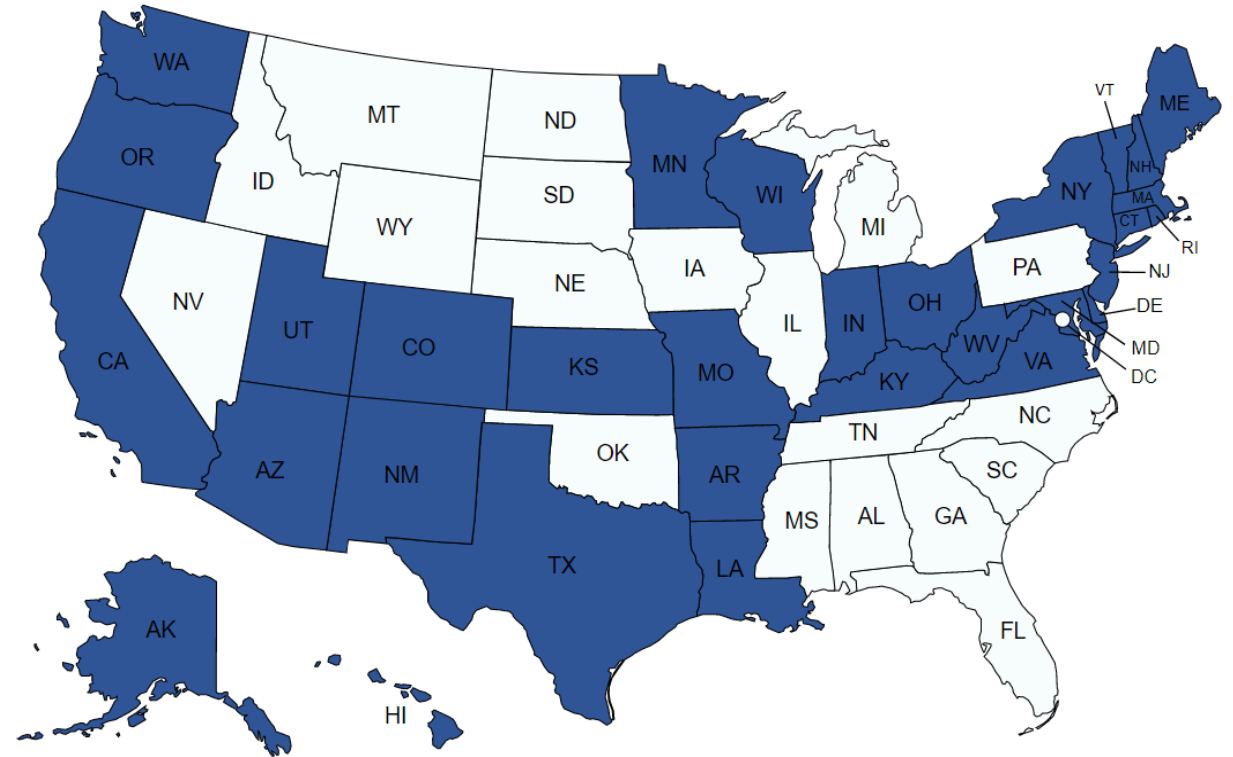
# Data Governance: Essential for Timely Decisions in an Era of Changing Social Policy

Rules of the Road for Data  
Use: How to Create Value  
& Manage Risk

Jonathan Mathieu, PhD  
*Senior Consultant*  
Marissa Smith, MPH  
*Project Associate*

# About Freedman HealthCare

- Founded in 2005
- Focus on state and nonprofit health data initiatives
- Experienced APCD managers and data scientists
- APCD and Integrated Data System lifecycle expertise:
  - Stakeholder engagement
  - Statutes & rules
  - Data Management Vendor SOWs
  - Quality & validation
  - Analytics & reporting
  - Access & use policies
  - Funding & sustainability



FHC has experience in more than 30 states

# FHC Team



**John Freedman, MD**

President



**Linda Green, MPA**

Executive Vice  
President



**Jonathan Mathieu, PhD**

Senior Health Care  
Data/Policy Consultant



**Marissa Smith, MPH**

Project Associate



**Summer Preg**

Project Manager

# Agenda for Today



Creating Value with Data



Managing Risks



Lessons Learned

# Recap: Data Governance Foundations



# Foundations

The approach must be informed by agency needs, priorities, and current state.

One size doesn't fit all



This is an ongoing effort, not a one-off project. Iterate and improve.

It's a program, not a project



A modest start and steady progress will get results.

Go slow to go fast



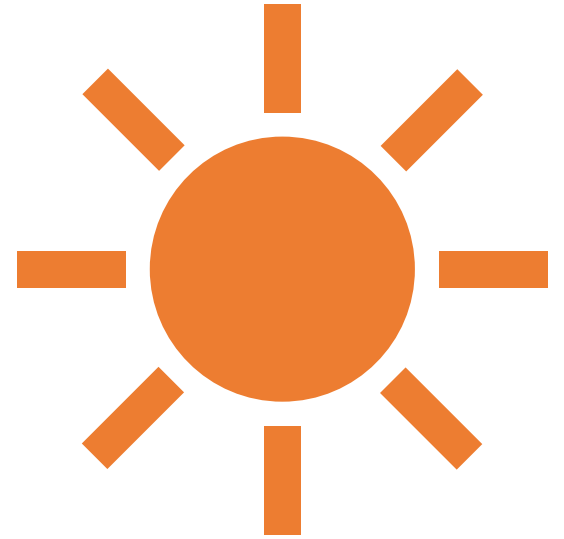
***Don't let perfect be the enemy of good***

# Best Practices & Lessons Learned



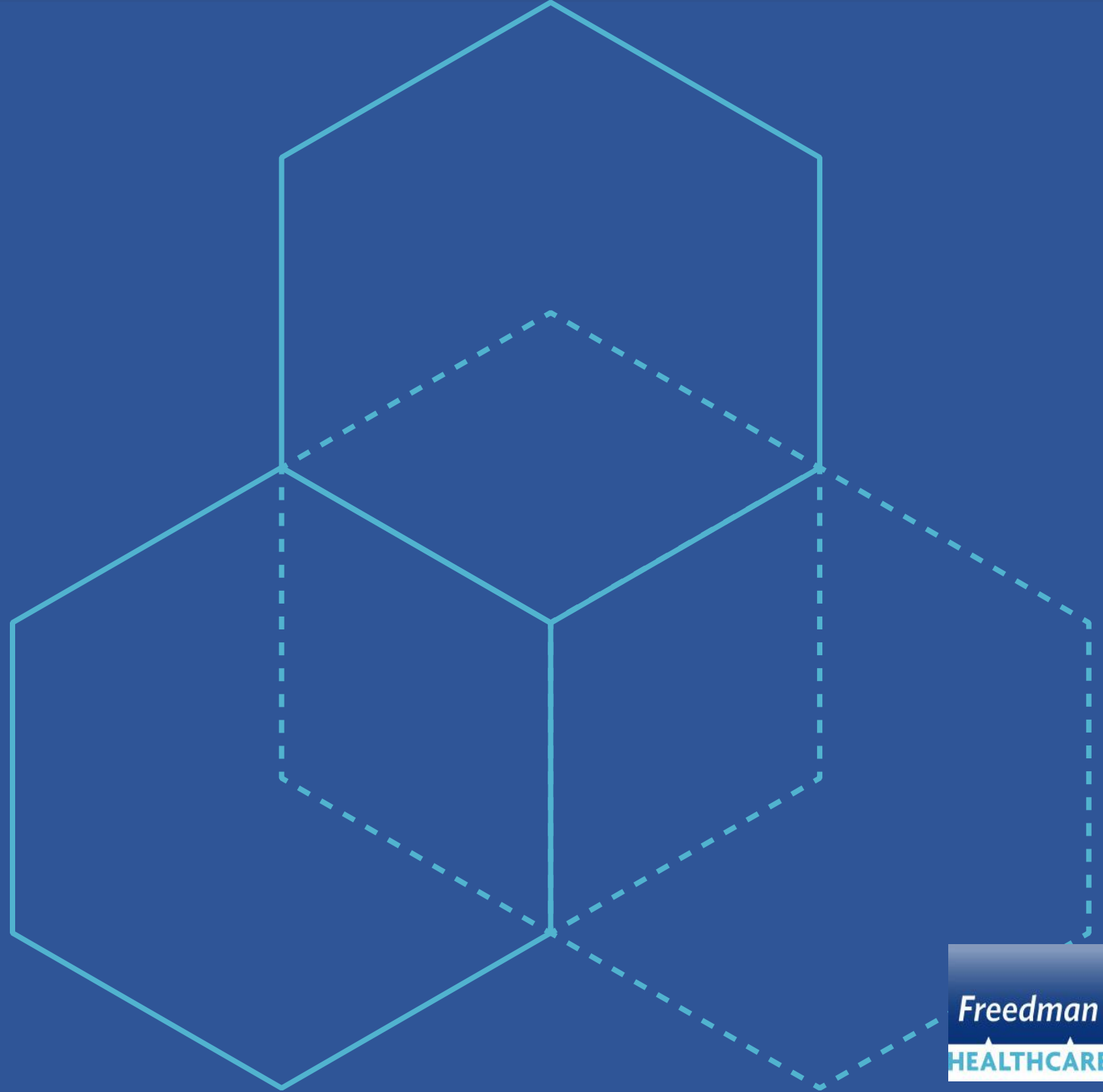
- Stakeholders have unique perspectives, concerns and information needs that must be recognized in developing an effective DG approach
- Early, frequent and ongoing engagement contributes to buy-in and builds stakeholder willingness to participate, confidence and trust
- Multiple avenues exist for stakeholder engagement including advisory committees and public comment opportunities
- Qualifications and experience should be considered in identifying advisory committee members based on specific roles and needs.

- If your organization manages data, you are already doing some data governance
- Laws and rules provide guardrails and a starting place
- Subject matter experts and stakeholders can & will help
- Stakeholder engagement builds trust and buy-in for the program
- Effective DG creates value by expanding appropriate data use while managing risk





# Creating Value with Data



# Data - Information Cycle

## Data

- Raw
- Not useful in isolation
- Without context
- Must be processed, analyzed & transformed to create value

Effective data governance & management enable users to create information

Information derived from data informs opportunities to expand uses & create additional value

## Information

- Useful alone
- Context specific
- Valuable & supports:
  - Data-driven decisions
  - Policy development
  - Program design, evaluation & improvement

Good governance  
leads to useful data  
and meaningful  
information.

Useful data is...



High quality  
(accurate, complete)



Convenient, timely, relevant

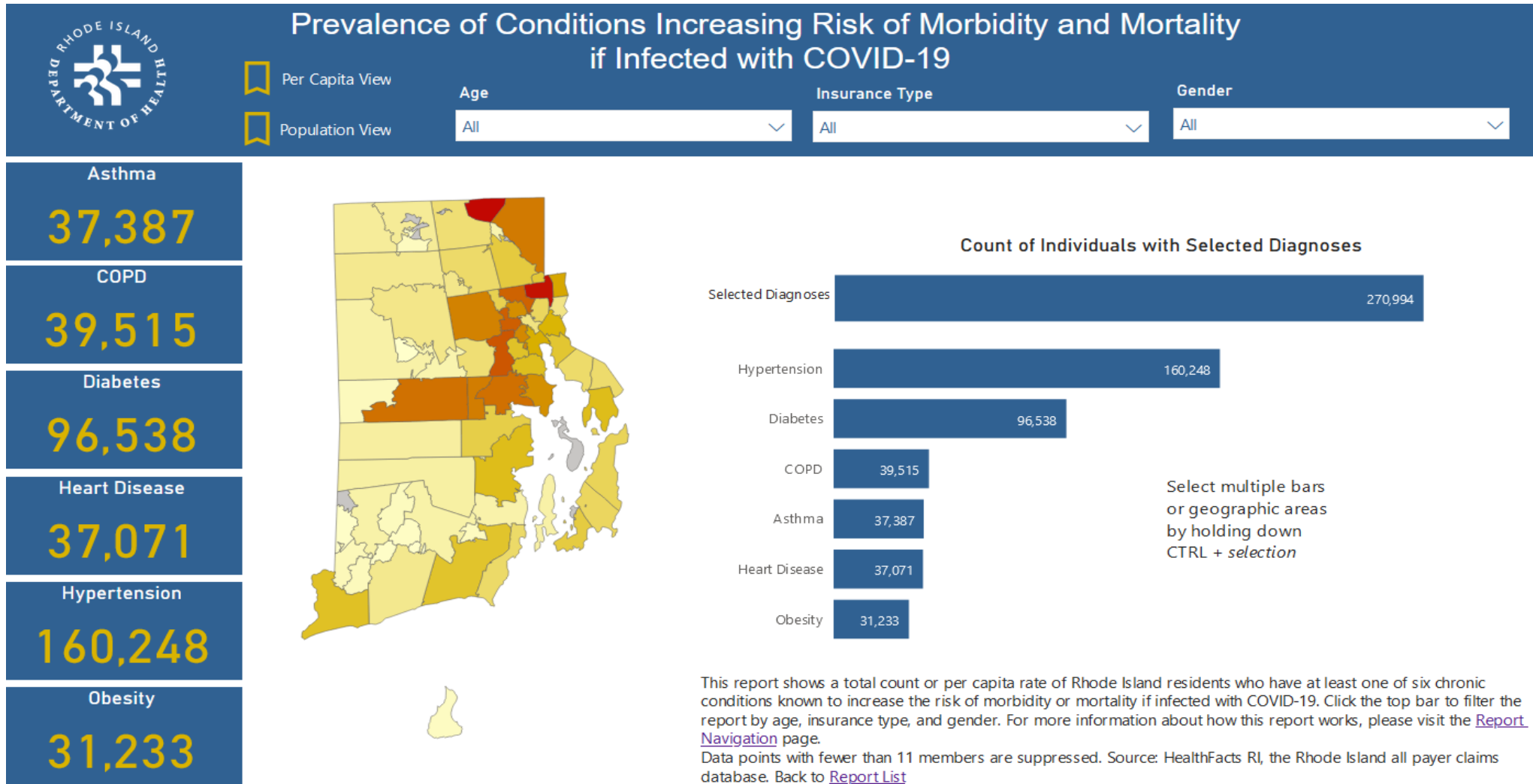


Low risk  
(private, secure, protected)

# Having Data is not Enough

- **Value**
  - Created when data supports analysis that drives informed decision making & policy
  - Derived from information addressing priority issues that meets the needs of diverse users with different skill sets
  - Effective data governance & management are prerequisites to value creation
- **Effective Data Governance**
  - Allows appropriate use consistent with law & rule
  - Avoids unnecessary limits & undue burden on potential users
  - Supports alignment with agency mission & program goals





**This analysis:**

- Uses diagnosis codes to identify patients with chronic conditions
- Counts unique individuals
- Does not require a longitudinal analysis of claims, costs, or utilization

# Virginia Price Transparency Report

- Different Services (e.g., Arthroscopic Knee Surgery)
- Supports Greater Price Transparency
- Shows the difference in price based on place of service and region
- Breaks down the potential costs by category

Source: Virginia Health Information

## Arthroscopic Knee Surgery



Arthroscopic knee surgery is done with the help of a miniature camera, inserted into a small incision or cut. The doctor can see images from the camera on a monitor and can thread tiny surgical tools through other small incisions. Arthroscopic knee surgery is used to treat and repair knee injuries. It can also be used to relieve some symptoms of arthritis.

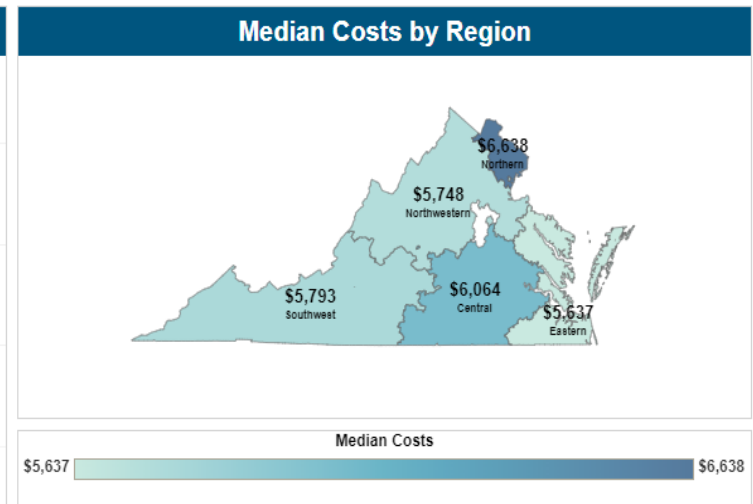
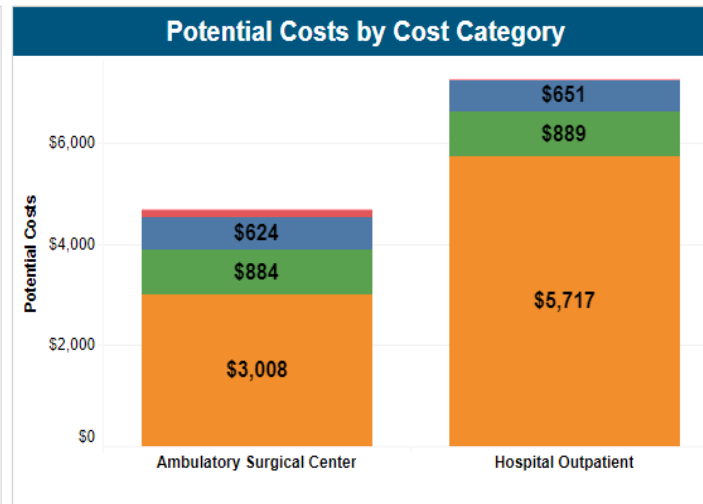
CPT Code(s)- 29881

Statewide Median:  
Statewide Range:

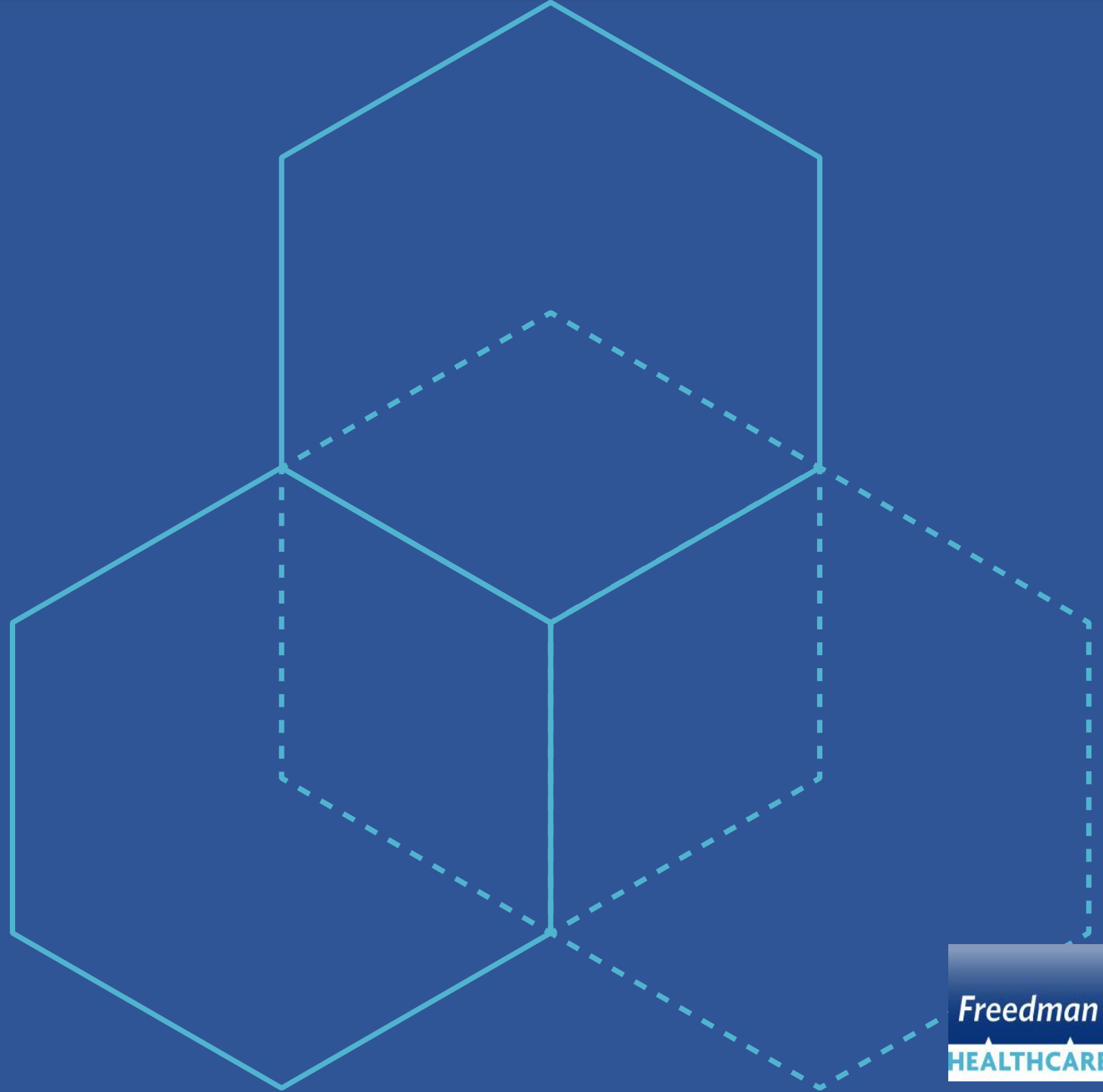
Place of Service	
Ambulatory Surgical Center	Hospital Outpatient
<b>\$4,558</b> (\$3,509 - \$6,126)	<b>\$7,270</b> (\$5,373 - \$9,690)

Cost Category

- Prescription Drug
- Other
- Anesthesiologist
- Surgeon
- Facility



# What are the Potential Risks?



# Potential Risks & Outcomes

Category	Potential Risk	Possible Outcomes
Privacy & Confidentiality	Personal information is used to reidentify or contact individuals	Legal action, fines
Data Security	Data is accessed or used by unauthorized persons, e.g., data breach	Legal action, fines
Incorrect Data or Information	Data is not fit for use. Results are not consistent with other sources of similar information	Impacts value, stakeholder confidence & trust
Reporting	Published results allow reidentification of individuals or include information that is confidential, sensitive or protected ( <i>topic of FHC webinar 4</i> )	Confidential, sensitive or protected information is inappropriately used or shared
Data Linkages	Links to other sources that include personal data increase reidentification risks	Potential Privacy & Confidentiality concerns

***Effective Data Governance helps avoid potential risks & outcomes***



# Considerations for Data Access & Use

## Who is the data user? What is their purpose?

- State Agency, Researcher, Payer, Provider, Purchaser, etc.
- Uses: Cost transparency, quality improvement, access to/continuity of care

## How will the data be accessed?

- Secure Analytic Environment or Enclave (Internal Control)
- Direct File Transfer (External Use)

## Sensitive Information

- Protected Health Information (PHI)
- Entity & Financial Information (EFI)
- Sensitive diagnoses/procedures, information on providers of those services, e.g., reproductive health, abortion, gender affirming care, substance use...

# Additional Considerations

## Complete & Accurate Data

- Develop data quality standards & processes for all lifecycle phases
- Phases: Intake, Standardization, Processing
- Quality is documented, data is timely & fit for use

## Accurate Information

- Reasonableness: Compare results with other sources of similar information
- Develop Policies & procedures for review / approval of:
  - Internal analyses & public reports
  - Reports, presentations, etc. produced by *external users* prior to release
  - Prevent release of confidential, sensitive or protected information

- Develop consensus policies & procedures consistent with law & rule
- Apply data quality & review in all phases of the lifecycle: Intake, Processing, Reporting
- Data Request/Application:
  - Require justification for confidential, sensitive or protected data
  - Limit personal information to the minimum necessary
  - Permit linkages only if required
- Review results, reports, etc. prior to public release for confidential, sensitive or protected information



- Data Use Agreement (DUA)
  - Prohibits use of data to reidentify individuals
  - Limits use to the purpose described in the approved application
  - Restricts access to identified project team members
  - Includes specific safeguards to protect privacy & security:
    - Data management plan
    - Requirements for encryption, secure transmission & storage
- Require certification of destruction at the end of projects



# An Effective Data Governance Framework

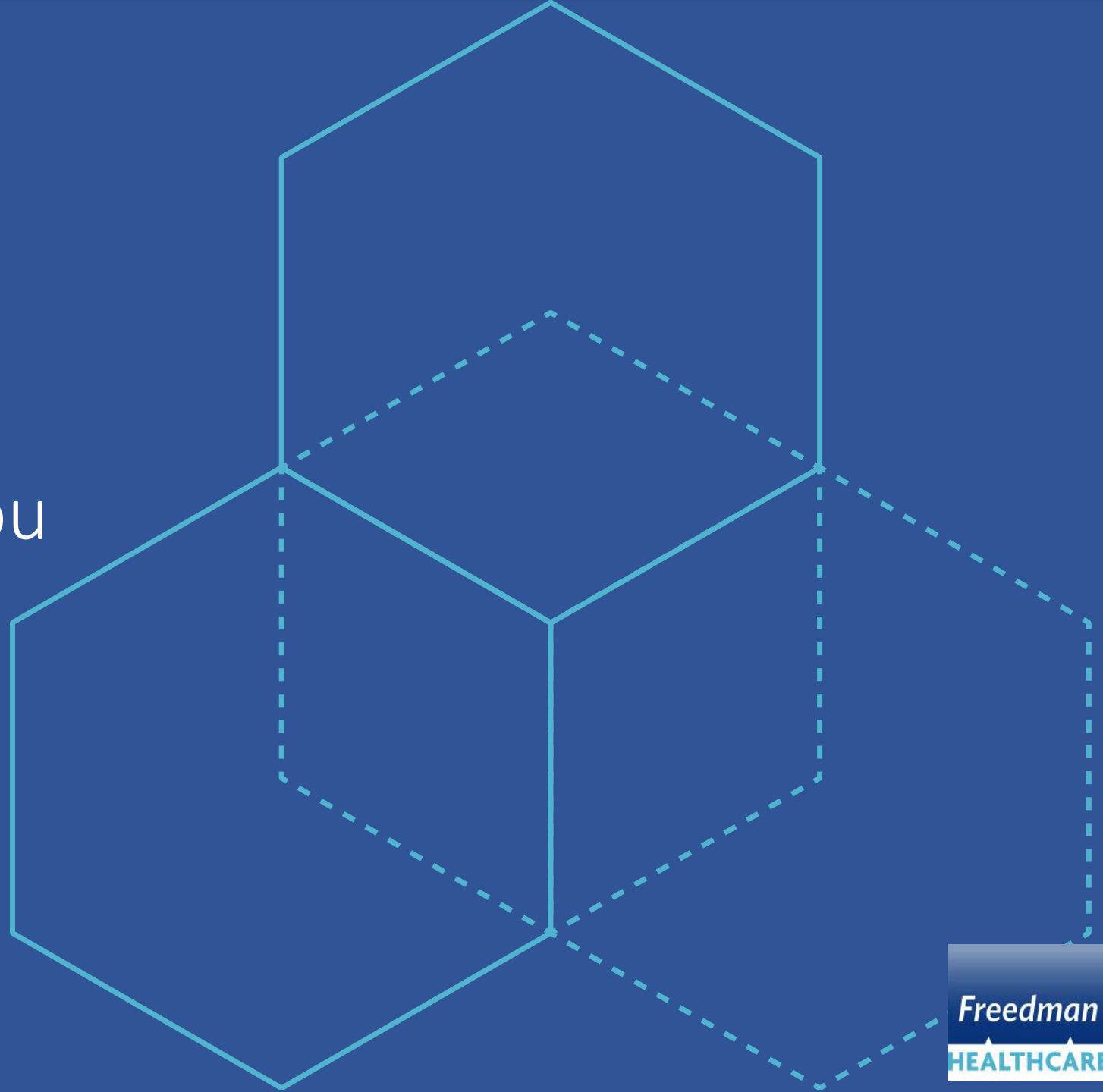


- Is essential for accurate data & information
- Reduces & manages risks associated with use
- Supports appropriate use of data to create value and achieve program goals
- Defines what is possible/allowable
- Establishes clear policies and procedures
- Contributes to agency and program operational efficiency

***Periodic review identifies opportunities to create additional value***

# Getting Started

(or improving what you  
already have...)



# Essential Elements

- Identify key personnel, assign clear roles & responsibilities
- Develop flexible policies and procedures (consistent with law & rule) keeping future needs and expansion in mind
- Collaborate w/external stakeholders to understand unique information needs & concerns
- Create information appropriate for audiences of varying knowledge and sophistication



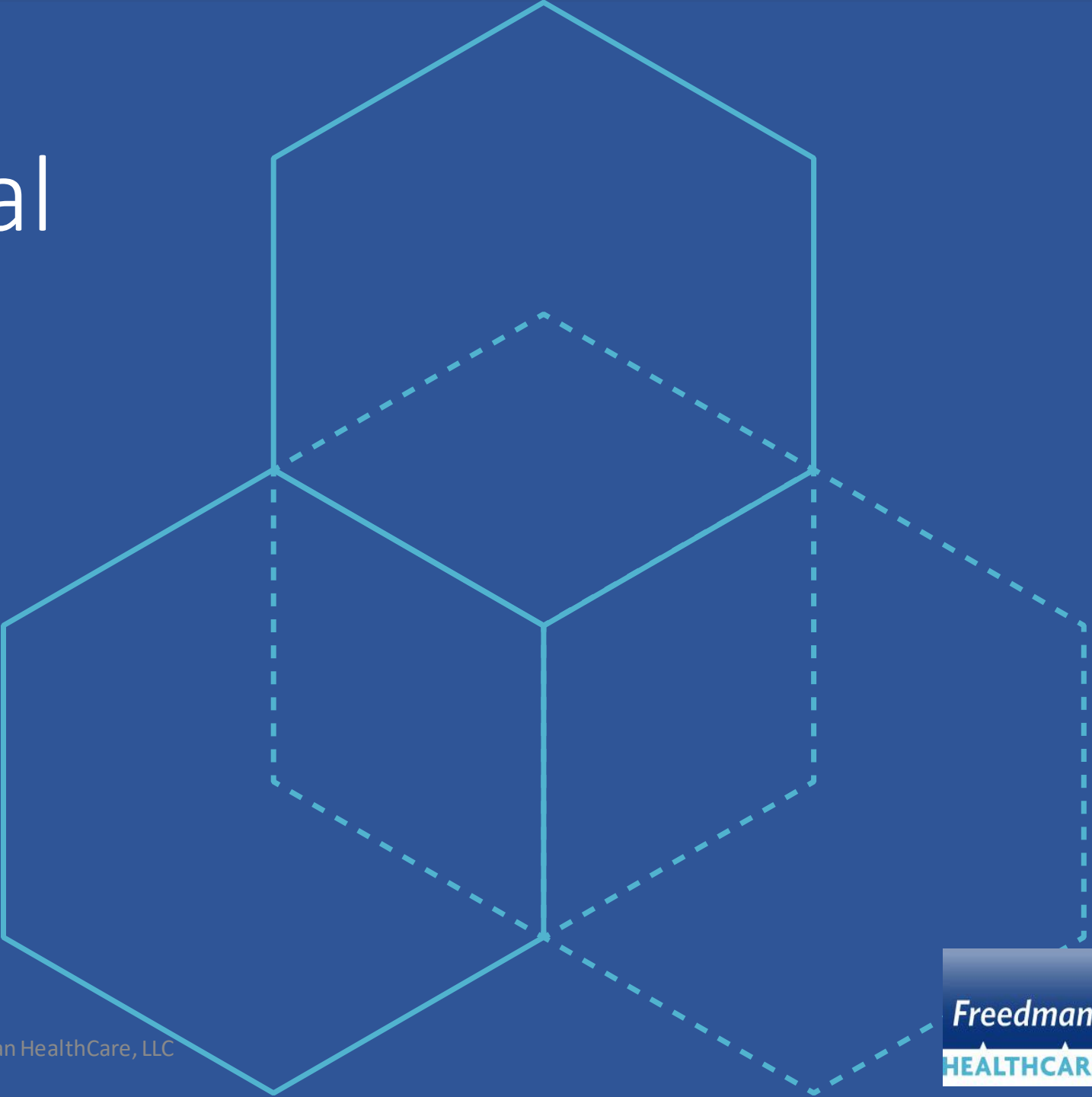
# Where to Start?

- Review current policies & procedures to identify needs & opportunities
- Collaborate with stakeholders to:
  - Understand unmet data and information needs
  - Prioritize new and high-value use cases
  - Identify opportunities to appropriately expand
- Leverage subject matter experts in developing policies & procedures
- Provide stakeholder orientation, education & training to promote participation, acceptance and buy-in





# Questions & Final Thoughts



# Upcoming Webinars in this Series

Date	Topic
July 26	Sensitive Data & Health Equity Components of Data Governance

Register at: [https://us02web.zoom.us/webinar/register/WN\\_d-sofKILR1m5jM6IRc41Cg](https://us02web.zoom.us/webinar/register/WN_d-sofKILR1m5jM6IRc41Cg)  
Watch for our follow-up email with slides and registration information.

**Jonathan Mathieu, PhD**

Senior Consultant

Freedman HealthCare

[jmathieu@freedmanhealthcare.com](mailto:jmathieu@freedmanhealthcare.com)

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Project Associate

Freedman HealthCare

[msmith@freedmanhealthcare.com](mailto:msmith@freedmanhealthcare.com)



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