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

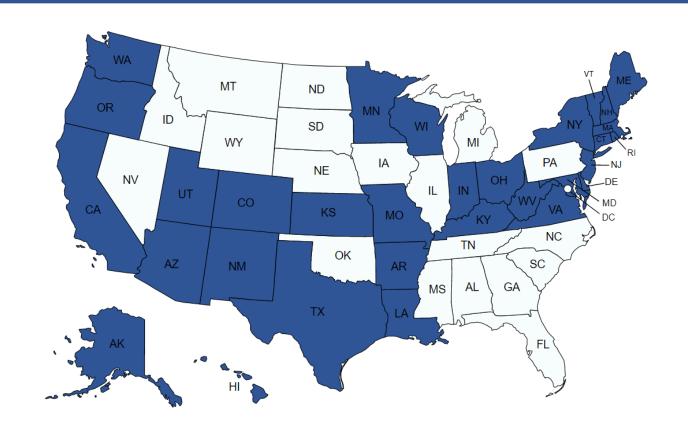
Data Governance is About People: Essential Roles & Responsibilities

Jonathan Mathieu, Senior Consultant Marissa Smith, 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



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Data Governance is about People

Agenda

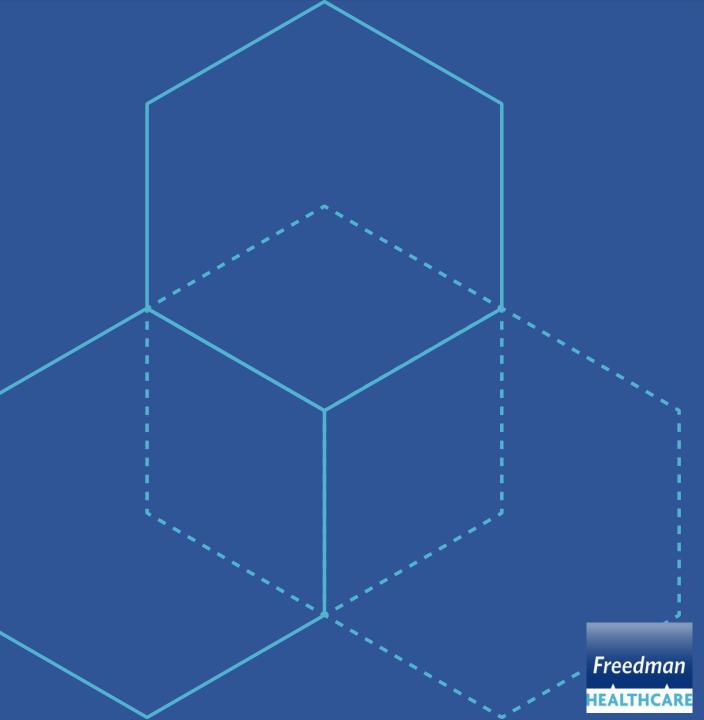


Internal & External Stakeholders



Best Practices & Lessons Learned

Recap:
Data Governance
Foundations



Good data governance is essential for timely and informed decision-making. Decisions that support...

Performance Management



Program Evaluation & Improvement



Policy Making & Strategic Planning



Data Governance Lifecycle

Data Intake

- Standardization: File & data field formats and definitions
- Quality checks: Focus on accuracy & completeness
- Timeliness: Fix problems early to avoid delays

Data Processing

- Flags & enhancements for greater usability
- Quality checks: "Fitness for use" determination
- Compliance: Privacy & security requirements

Data Use

- Policies: What data is available, for what uses, by whom
- Procedures: For access, request & approval
- Terms & conditions for data use



Documentation

Start Small & Build DG Over Time



What is your current DG status/state?

Understand

What are you already doing that you can codify?

Formalize

What are the **most** important issues, areas of need?

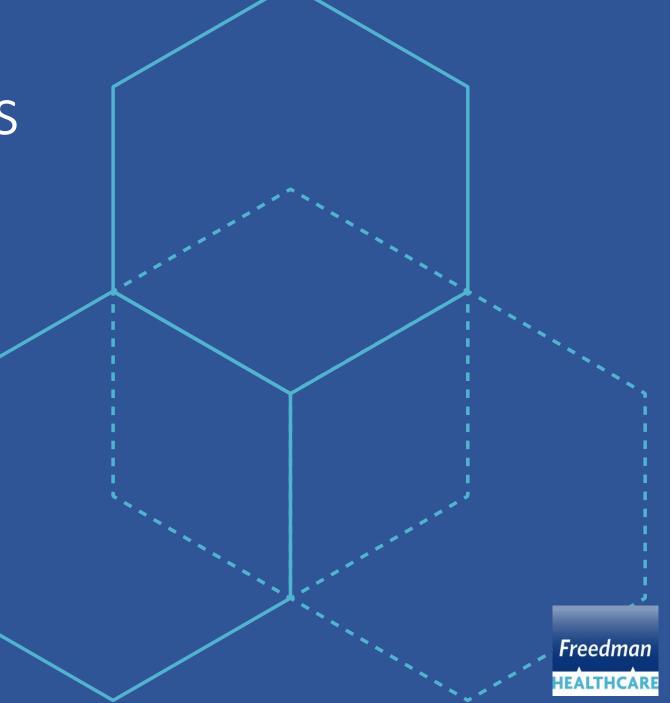
Choose a Use Case

What is the next priority?

Refine and Expand

Continuous Stakeholder Engagement

Data Governance is About People



Data Governance is About People

"The right people, doing the right things, at the right time."

Internal Team External Stakeholders , Public/Data Users

They are already doing some DG; seize the opportunity to redefine and expand current roles.

Obtain explicit permission to use & share data. Emphasize mutual benefits. Provide opportunity to share perspectives & concerns.

Reichental, *Data Governance* for *Dummies*, pp. 121

Identify and address concerns & pain points. What information is needed for better informed decisions & outcomes?

Essential Internal DG Roles

Program Sponsor



"Executive Producer"
Sets the tone and drives the program.

Data Owner



"Director"
Accountable for data quality, compliance.

Data Steward



"Stage Manager"
Responsible for daily
operations & decisions.

Data Custodian



"Set Designer"
Responsible for DG
technical aspects.

Defining clear roles and responsibilities is essential for effective Data Governance

Program Sponsor



Who - "Executive Producer"

- Senior leader from the responsible agency or department, e.g., Executive Director
- Accountable for creating value consistent with agency mission & program goals
- Serves as DG champion internally & externally; sets the tone, drives the program

Role

- Responsible for creating value = information to inform decision-making and policy
- Communicates the importance of DG to achieving mission & goals
- Manages relationships with agency, internal staff & external stakeholders
- Accountable to entities with statutory/regulatory authority

Data Owner



Who – "Director"

- Member of the management team, e.g., Director, Department Lead, etc.
- Accountable & ultimately responsible for data quality & compliance
- Knowledgeable and familiar with all aspects of Data Governance

Role

- Accountable for data quality, accuracy & completeness; privacy & security; oversight of data use, request & approval processes
- Leads multistakeholder process to create DG policies & procedures
- Responsible for Data Governance oversight throughout the life cycle

Data Steward



Who – "Stage Manager"

- Member of the Management Team, plays the active "hands-on" role
- Director/Manager of Data Operations, Research, Compliance, etc.
- Understands the details & works directly with data

Role

- Manages day-to-day Data Governance and database operations
- Works with stakeholders to maintain DG policies & procedures over time
- Resolves data quality & access issues, monitors compliance
- Facilitates data use, request & approval processes

Data Custodian



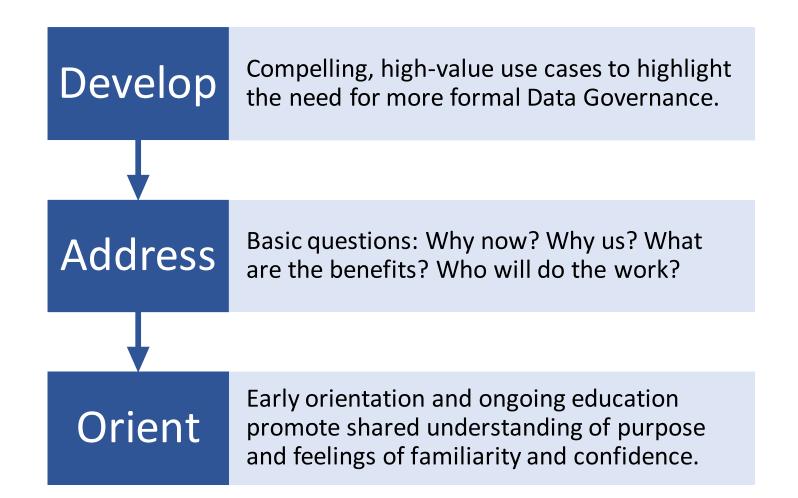
Who – "Set Designer"

- Director of IT, Database Administrator or Manager
- Responsible for the technical aspects of Data Governance and management
- IT role. Some functions may be assigned to a contracted data manager

Role

- Oversees technical implementation of Data Governance
- Responsible for day-to-day IT operations
- Manages technology that allows appropriate use, protects data privacy & security
- Maintains a secure storage environment throughout the life cycle

Engaging the Internal Team

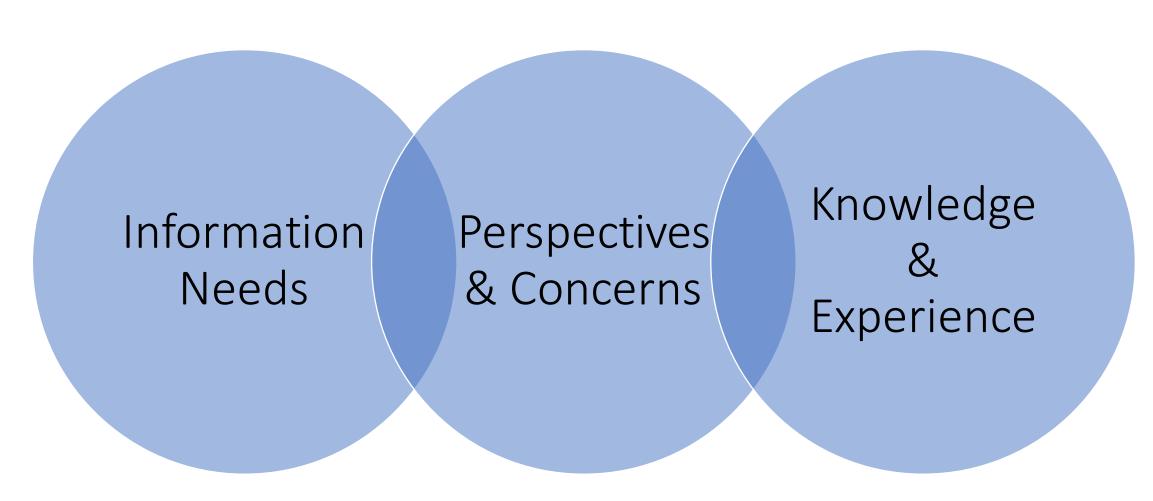




Building
Relationships with
External
Stakeholders



Stakeholders Matter



Who are the External Stakeholders?

External stakeholders have unique perspectives, concerns, and needs that must be recognized



Data Sources

Payers, HIEs, Public Health, Social Services

Role: Understand and inform how data they provide will be protected and used



Providers

Hospitals, Health Systems, Provider Groups

<u>Role</u>: Understand opportunities to use data to improve operations and better coordinate care



Data Users

Researchers, Payers, Employers, Purchasers, Advocacy Groups, Government, Legislature, etc.



Subject Matter Experts, Public

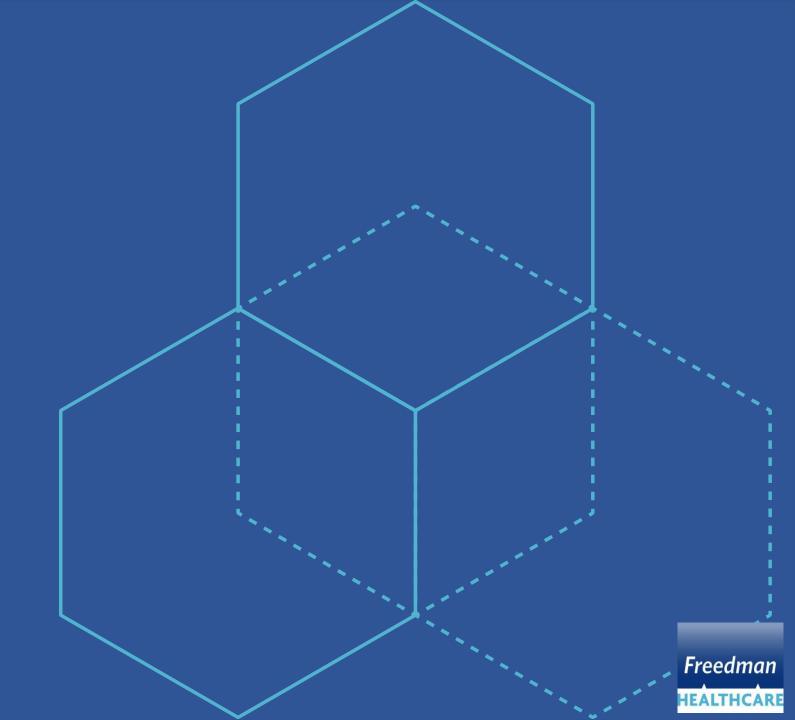
People with expertise on specific DG topics.

<u>Role</u>: Express unique perspectives, needs & concerns. Contribute to development of policies & procedures

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Engaging External Stakeholders



Committee Participation

Advisory/Policy Committees

- Role: Advise on policy alignment with law/rule & program goals. Provide input on public reporting principles, information needs and priorities
- Knowledge Base: Diverse health policy & program experience, public & private
- **Members**: May include state agency partners, health care associations, data sources, providers, researchers, advocacy groups, legislators.

Data Access Committees

- Role: Advise on data access/use policies. Review requests, make approval recommendations
- Knowledge Base: Expertise in health care data analysis, research, privacy & security
- **Members**: May include payers (public, private), health systems/hospitals, physician and non-physician providers, researchers, policy experts, advocacy groups (consumer, privacy).

Committee Formation & Role

- Statute and Rule:
 - Often mandate creation of advisory and other multistakeholder committees
 - Specify that membership includes specific stakeholder groups to ensure diverse perspectives, needs & concerns are represented.
- Committees typically serve in an Advisory Role:
 - Review and provide input on draft Policies regarding:
 - Alignment with statutory purpose, legislative intent and regulatory requirements
 - Mission and goals of the Agency and program
 - Public information needs and priorities

Opportunities for Public Input

Regulations Development

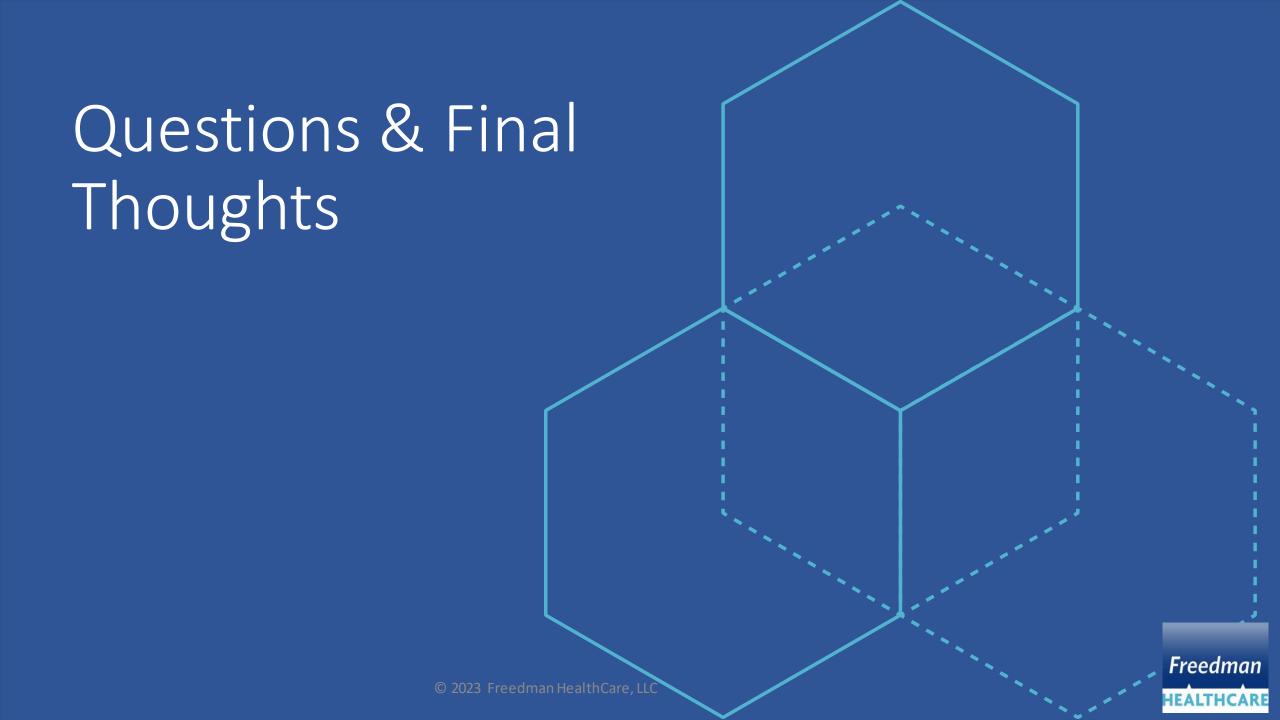
- The review and comment period allows the public to share unique perspectives, needs & concerns.
- This contributes to feelings of inclusion, transparency, buy-in and trust.

Advisory Committee Meetings

- Many committee meetings are open & allow members of the public to comment or ask questions.
- Publishing agendas & other materials in advance creates additional opportunities for public input.

Best Practices & Lessons Learned

- Stakeholders have unique perspectives, concerns and information needs that must be recognized in developing an effective Data Governance 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 and data access committees and other, less formal opportunities
- Qualifications and experience should be considered in identifying committee members based on specific roles and needs.



Upcoming Webinars in this Series

Date	Topic
June 28	Rules of the Road for Data Use: How to Maximize Value & Manage Risk
July 26	A Plan for the Future: Considerations for Growth & Securing Federal Funding

Register at: https://us02web.zoom.us/webinar/register/WN d-sofKILR1m5jM6IRc41Cg
Watch for our follow-up email with slides and registration information.

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