The Reality of Information Governance Deployment at the National Institutes of Health

ABSTRACT----------

Successful implementation of Information Governance promises the much sought after integrative collaboration of business and IT to achieve enterprise goals and lead to better decision-making. Nevertheless, its design is technically complex, organizationally challenging, and, above all, politically sensitive.

NIH is a Federal agency that spans 27 separate institutes and centers involved in highly complex medical research. Within this, information serves as the bloodline linking everything together. NIH is a highly federated and semantically segmented environment where data quality and consistency are of paramount value, and needs of multiple stakeholders must be balanced and met. This presentation draws upon the experience of institutionalizing federated information governance at NIH, facilitated by the Enterprise Architect.

- What are the complex dynamics and political realities involved?
- What was proposed?
- What is the creative "structure" implemented as an outcome of the study?

BIOGRAPHY----------

Helen McCulloch Schmitz
Acting Chief Information Technology (IT) Architect
National Institutes of Health (NIH).

Ms. Schmitz has been with the NIH Enterprise Architecture program for seven years, three as Acting Enterprise Architect. She has over twenty years IT experience, providing leadership in support of large, complex enterprises in the private sector and the Federal Government, including the Department of Defense and civilian agencies. She worked with the American City Business Journals then the Resolution Trust Corporation. While working with EDS for seven years, she supported the Army, the Pentagon and NASD.

She earned a Bachelor of Arts degree in zoology from Connecticut College, then worked as a lab technician in microbiology at Wayne State Medical School, in Detroit, Michigan.
Her results have been achieved through the collaborative development of NIH Enterprise Architecture and sponsorship of technology transformation initiatives with demonstrated value to NIH. She sees her role as a liaison between NIH's scientific and business organizations and those that provide IT support.

NATIONAL INSTITUTES OF HEALTH
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The Reality of Information Governance Deployment at the National Institutes of Health

Helen M. Schmitz

NIH Chief IT Architect (Acting)

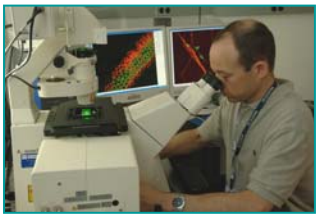
Agenda

- About NIH
- Approach
- Information Governance Frameworks
- Artifacts
- Lessons Learned

About NIH

NIH: The Nation's Medical Research Agency

"Science in pursuit of fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to extend healthy life and reduce the burdens of illness and disability."



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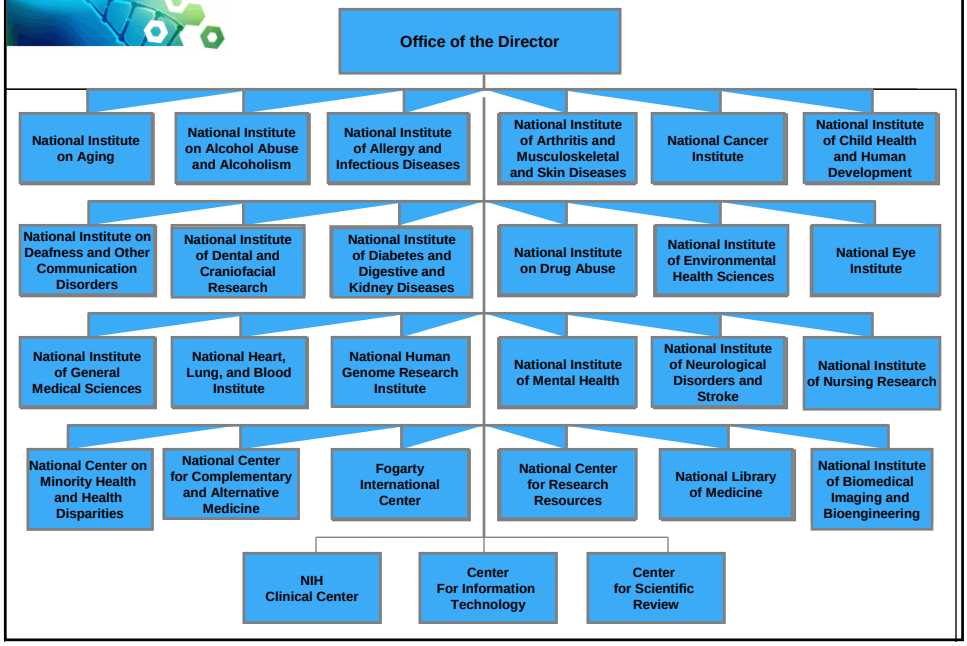
National Institutes of Health



Dual Nature of NIH…

NIH INTRAMURAL RESEARCH

NIH is an institution

Supports:
- **Over 10,000 scientists and research personnel**
- **15.8% of NIH budget- $4.7 B**
- **Primary location: Bethesda, MD**
- **A few labs throughout U.S.**

NIH EXTRAMURAL RESEARCH

Supports:
- **Over 3,000 institutions worldwide**
- **Over 325,000 scientists & research personnel**
- **Awards issued to over 100 countries**
- **Clinical, Basic, & Translational Research**
- **84% of the NIH budget - $24.8 B**

Complexity

- 3 functional areas
  - Intramural
  - Extramural
  - Administrative supporting services
- 27 institutes and centers
- All have own unique needs and requirements – and need to work together

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Approach

Target State

Data is well defined in a consistent and controlled manner. Defined authoritative data sources exist within NIH. Data is provided in a format that is useable to the recipient. Information access and reporting is conducted in an accountable, secure, and consistent manner across NIH. Transparent data responsibilities are established to provide clear and distinct roles and responsibilities for governance bodies. A well defined and comprehensive decision-making framework is instituted that outlines the priorities, criteria and processes that will used in the selection of alternatives and solutions in support of NIH's mission.

Activities To Get There

- Implement governance
- Determine resource requirements
- Conduct Pilot
- Design future processes within each functional area.
- Develop a decision framework
- Recommend list of governance bodies, roles, and responsibilities.
- Identify and work with participants
- Review existing governance bodies, roles and responsibilities

Current State

There is no formal structure for information governance. Changes to data are ad hoc and take too long. Common and consistent definitions and formal enterprise glossaries are needed. Data quality is inconsistent.

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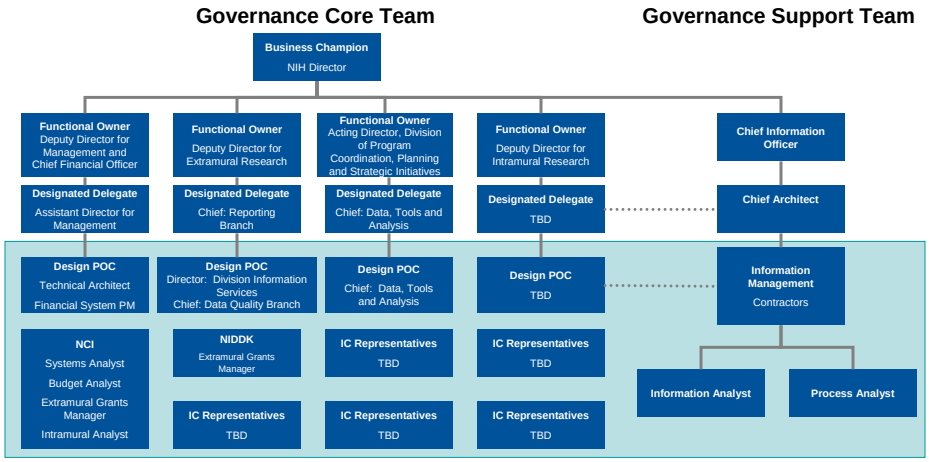
Information Governance Design Team



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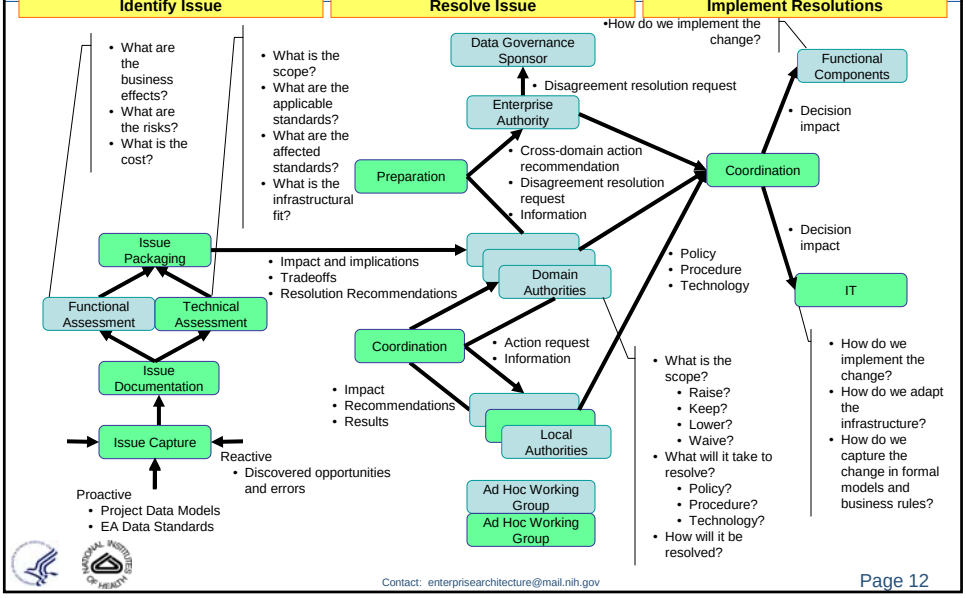
Information Governance Frameworks

Generic Governance Framework Proposed



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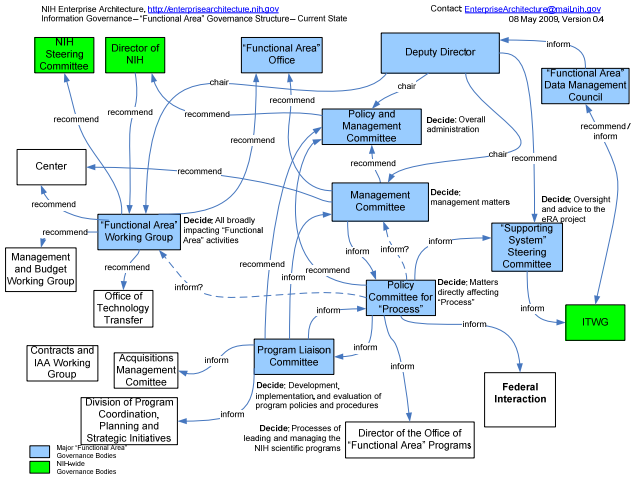
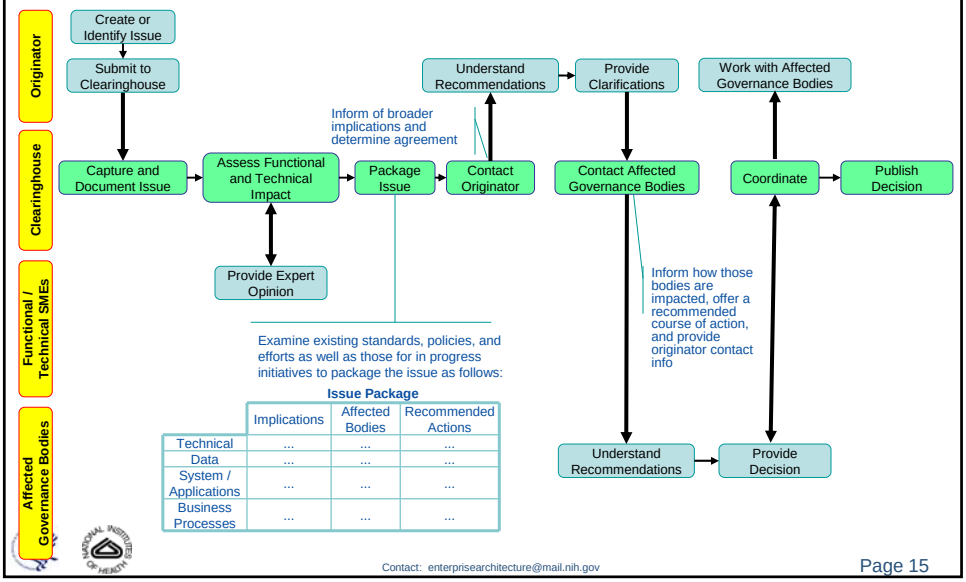
Current Governance Bodies Relationships Functional Area



Proposed NIH Information Governance Clearinghouse Concept

- Clearinghouse Concept: A collection point within NIH to which information-related issues and their resolutions are submitted then published and disseminated. Stakeholders throughout NIH can evaluate issues and identify potential impacts beyond the original scope and intent, then provide feedback. Feedback is then collated and either re-published or forwarded through the appropriate governance.
- Benefits of a clearinghouse:
  - Transparency: Proactively connect and inform stakeholders, minimizing reliance on personal relationships.
  - Based on successful standard development process: documented process to publish for input of interested parties.
  - Collaboration: Reduce the time-to-resolution by reusing solutions, leveraging experiences, or even combining resources to close unresolved issues.
  - Non-Invasive: Issue publication simply informs others; evaluation and resolution follow existing processes.
  - Issue Support: Independent support to maintain the clearinghouse, and that support can also assist with issue identification, evaluation, impact analysis, and resolution.

NIH Information Governance Clearinghouse Concept



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Information Governance Artifacts

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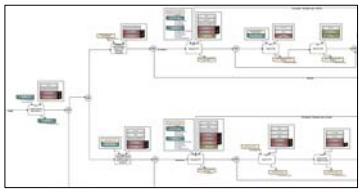
Information Governance Artifacts

Decision & Responsibility Matrix

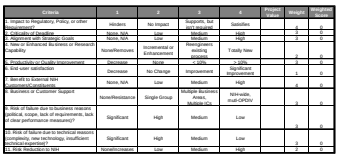
Charters

- Function
- Authority
- Responsibilities
- Relationships
- Composition
- Quorum
- Operation
- Disposition

Processes



Decision Frameworks



Lessons Learned

- Governance is complex and difficult in a federated organization.
- Strong leadership and sponsorship is critical for success.
- Keep structures and processes simple.
- There is contradictory direction because this is a new process, and people's expectations are defined by their unique perspective.
- Communication is critical to get buy-in.
- People respond better if they see an artifact they can alter, rather than start an artifact from scratch.

Contact Information

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NIH Enterprise Architecture Community

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Extra Slides

Sample Decision Matrix

Decision / Participant	IM Strategy	Business Policy Issues	Enterprise Information Standards	Enterprise Information Policy	Data Standards (Quality, Security, Retention)	Enforce/ Implement Data Standards	Data Definition Changes	Governance Processes
NIH Steering Committee	Decide	Decide						
Enterprise Information Management Committee (EIMC)	Decide	Decide? Recommend?	Decide	Decide	Decide	Resolve Issues	Decide	Resolve Issues
Architecture Review Board (ARB)			Decide					Define
Functional Data Committees (EDC, ADC, IDC)		Recommend	Recommend		Recommend	Execute	Recommend	Recommend
ITMC EA Subcommittee			Recommend					
Enterprise Architecture (Governance Administration)	Define		Recommend, Define	Recommend, Define		Execute	Execute	Execute
Working Groups and Domain Teams	Define		Define	Define				
Business Owners					Recommend	Execute	Recommend	
IT Stewards						Execute	Recommend	

Decision Framework

Focus Area	Issue	Process	Artifacts
Strategy and Alignment	• Informational to Business Goals Alignment • **Effort Selection and Prioritization** • **Policy Development and Approval** • **Entity Formation and Assignment** • Stewardship Assignment • **Cross-Functional Dispute Resolution**	• Goal Decomposition and Mapping • **Project Assessment and Evaluation** • Funding source identification and assignment • **Decision rights establishment** • Resource Allocations • **Issue escalation and resolution**	• **Strategy Maps** • **Evaluation Factors Worksheet** • Costing Models • Recourse Estimation Worksheet • **Issue Capture Template**
Architecture, Standards, and Integration	• **Data Definition and Business Rules Capture and Adoption** • **Data and Metadata Standards and Conventions Development and Approval** • **Process and Data Modeling Standards Development and Approval** • **Data Storage, Transport, and Delivery Technical Standards Development and Approval** • Cross-Functional Effort Coordination	• **Vocabulary Term Submission and Acceptance** • **New System Development and Data Use** • **Change and Configuration Management** • New Technology Introduction	• **Term Validation Methodology** • **Definition Quality Checklist** • **Data and Architecture Models** • **Patterns and Bricks** • Roadmaps
Data Quality	• **Data Valuation** • **Data Metrics Determination and Monitoring** • **Data Audit and Stewardship Assignment**	• **Data Metric Determination** • **Stewardship Reporting**	• **Data Quality Dimensions Guidelines** • **Stewardship Requirements and Skills Guidelines**
Data Access and Reporting	• **Roles and Permissions Establishment and Assignment** • **Logical and Physical Authoritative Data Store Identification** • **Data Usage Guidelines and Policy Development** • **Backup and Archiving Policy Development and Approval** • Retention and Disposition Policy Development and Approval	• **Authoritative data Source Certification** • **Reporting Request Evaluation**	• **Data Access Matrix** • **Authoritative Data Source Characteristics List** • Data Inventorying and Categorization Guidelines
Security, Privacy, and Compliance	• **Security and Compliance Policy Development and Enforcement** • Risk Assessment and Control Valuation • Incidents and Breach Response Determination	• **Compliance Assurance and Audit** • Breach Response	• **Anticipated Compliance Issues** • Statutory Compliance Impact Statements • Risk Analysis Worksheet • **Data Classification Guidelines** • **Response Decision Flowchart**

Decision Factors - Sample

Criteria	1	2	3	4	Project Value	Weight	Weighted Score
1. Impact to Regulatory, Policy, or other Requirement?	Hinders	No Impact	Supports, but isn't required	Satisifies		4	0
2. Criticality of Deadline	None, N/A	Low	Medium	High		3	0
3. Alignment with Strategic Goals	None, N/A	Low	Medium	High		3	0
4. New or Enhanced Business or Research Capability	None/Removes	Incremental or Enhancement	Reengineers existing process	Totally New		2	0
5. Productivity or Quality Improvement	Decrease	None	< 10%	> 10%		3	0
6. End-user satisfaction	Decrease	No Change	Improvement	Significant Improvement		1	0
7. Benefit to External NIH Customers/Constituents	None, N/A	Low	Medium	High		4	0
8. Business or Customer Support	None/Resistance	Single Group	Multiple Business Areas, Multiple ICs	NIH-wide, mutl-OPDIV		3	0
9. Risk of failure due to business reasons (political, scope, lack of requirements, lack of clear performance measures)?	Significant	High	Medium	Low		3	0
10. Risk of failure due to technical reasons (complexity, new technology, insufficient technical expertise)?	Significant	High	Medium	Low		3	0
11. Risk Reduction to NIH	None/Increases	Low	Medium	High		2	0

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Charter – Template

- Function
  - [A statement describing the top objectives and the highest level decisions that the entity is responsible for.]
- Authority
  - [A statement describing the authority that formed and formally institutionalized the entity.]
- Responsibilities
  - Recommend the overall responsibilities of the entity with respect to information governance.
- Relationships
  - Recommend the relationships to other governance entities.
- Composition
  - Recommend membership, roles, and skills of the constituency of the entity.

Information Governance Project Output

- Quorum
  - [A list of statements describing the minimum set of conditions required to reach a formal decision including participation and/or circumstances (if it is an emergency the president can decide, if it is …)]
- Operation
  - [A list of the frequency, dates, or events that trigger meetings.]
- Disposition
  - [A statement describing the set of conditions that leading to the different disposition alternatives for the entity.]
  - [This is success/failure/stagnate and if we succeed/ then we will evolve/disband/etc]

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