NIAMS IRP DATA DISCOVERY AND ANALYSIS (DnA)

National Institutes of Arthritis and Musculoskeletal and Skin Diseases (NIAMS)

Christine Winchester — IRP Liaison

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NIH

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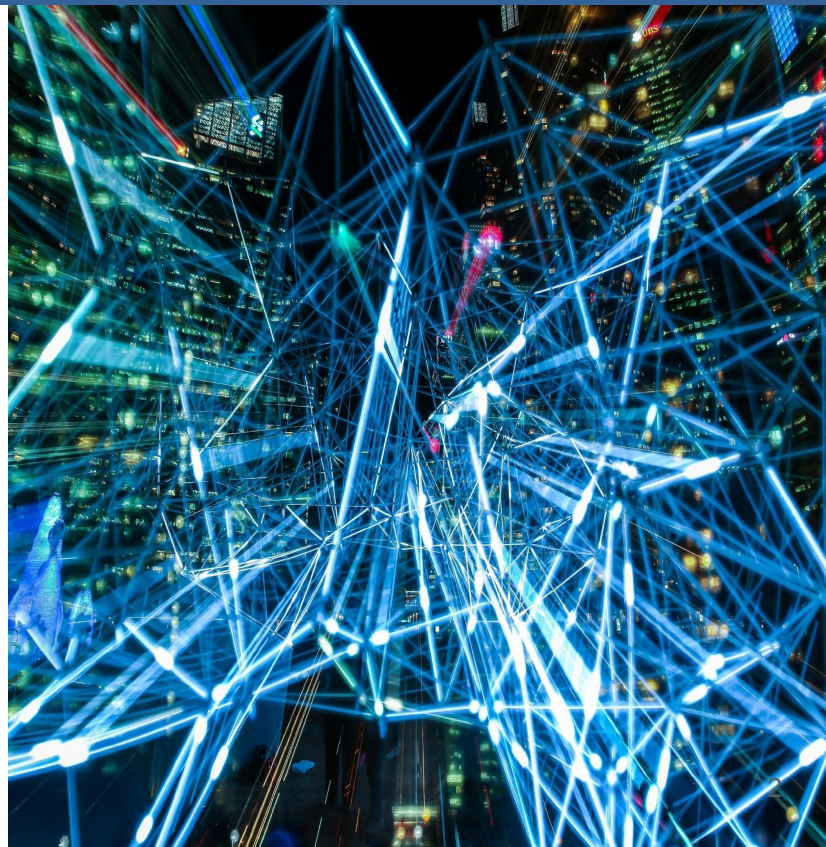
Public Policy + CS

BACKGROUND

- NIAMS IRP Scientific research in genomics, flow cytometry, microscopy, and other experiments generate a large amount of data
    - 10 TB of data generated monthly
    - Over 1 PB of data currently stored on-premise
- There is currently no disciplined approach for managing data as an asset



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OUR CHALLENGE

Establish an approach for managing NIAMS data that:

- Can be implemented incrementally
- Incorporates the different goals/needs of various stakeholders
- Will support the NIAMS mission and evolving research needs
- Encourages researchers to realize the value and benefits of good data management

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TIMELINE

- **Weeks 1-2:** Understanding existing policies, practices, and procedures and how they shape the current data environment

- **Weeks 3-6:** Data collection, surveys & interviews

- **Weeks 7-9:** Analysis and review data/research findings, preparing presentations to management/leadership

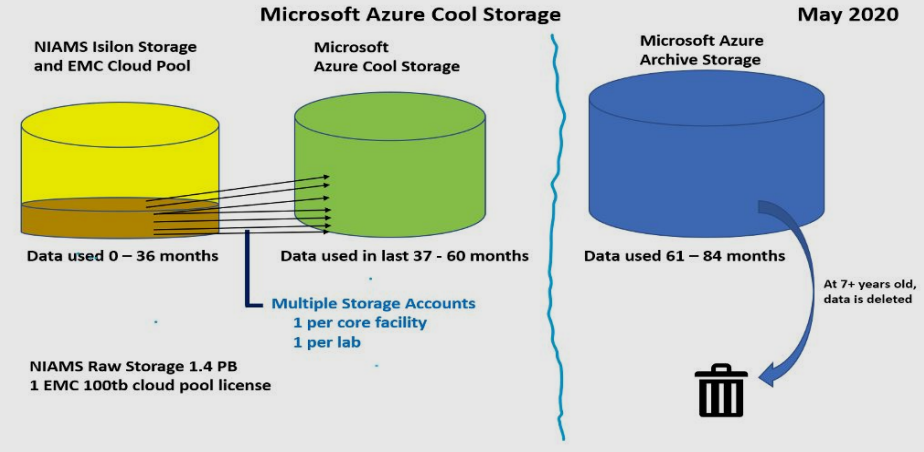
- **Week 10:** Wrapping up, next steps!

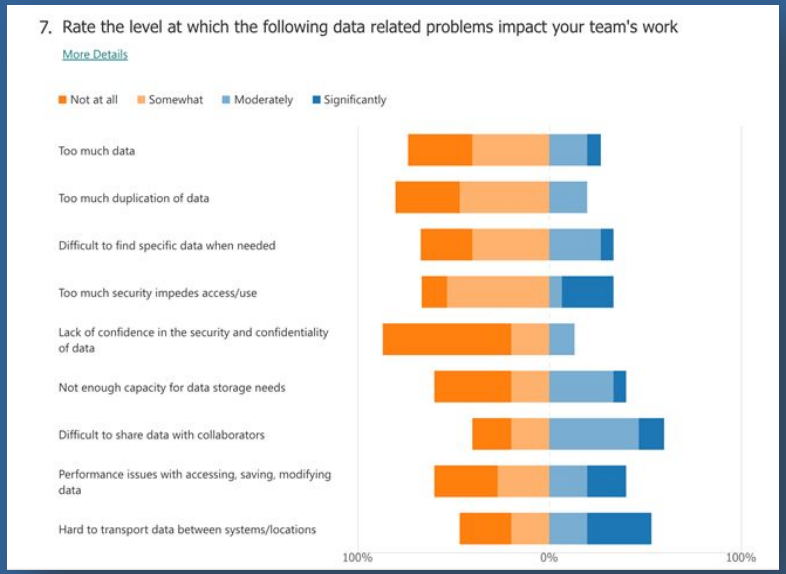
DISCOVERY

NIH/NIAMS POLICY

- Conduct of Research in the IRP at NIH
- NEW NIH Policy on Data Management and Sharing (effective January 25, 2023)

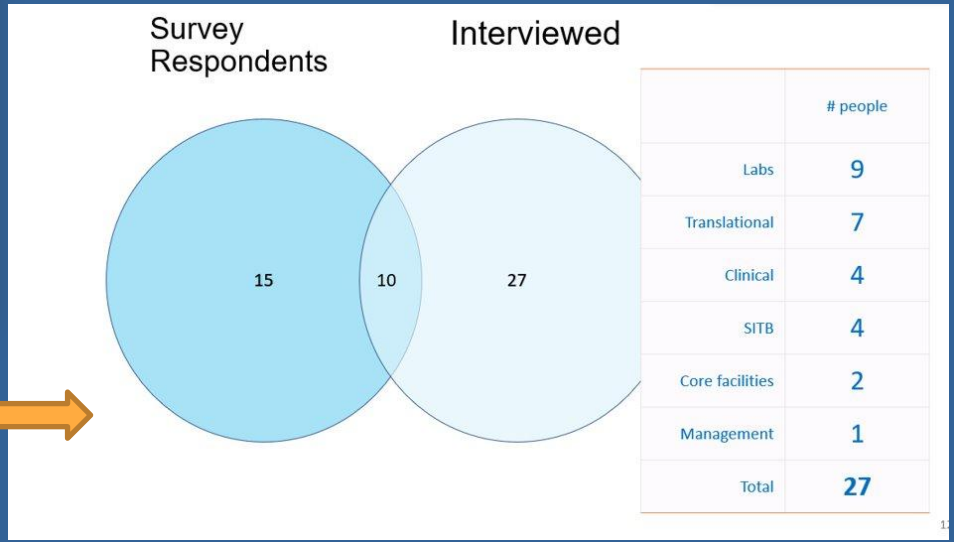
IT PROJECTS & INFRASTRUCTURE





Sample Question From Survey

Stakeholder Interview Composition



	# people
Labs	9
Translational	7
Clinical	4
SITB	4
Core facilities	2
Management	1
Total	27

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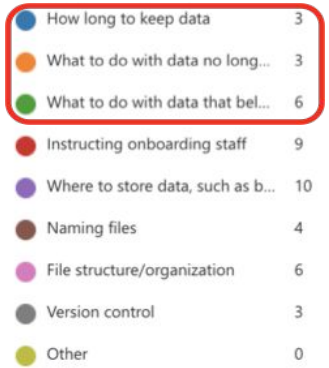
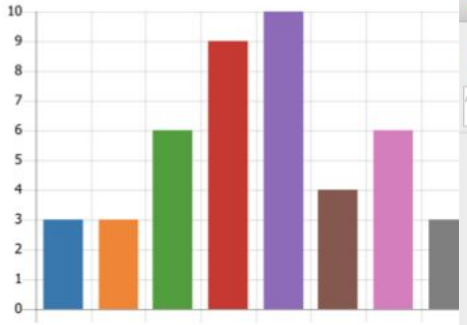
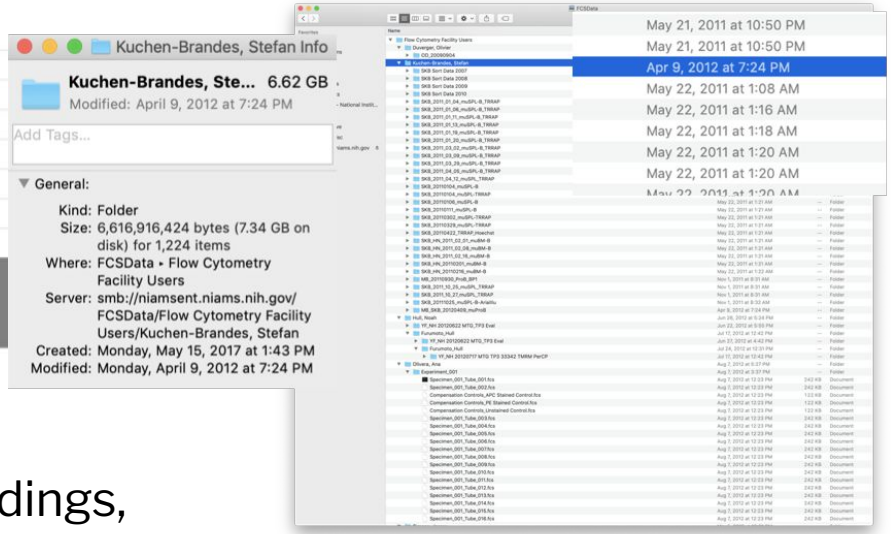
ANALYSIS







Reviewing our survey and interview findings, comparing qualitative and quantitative data

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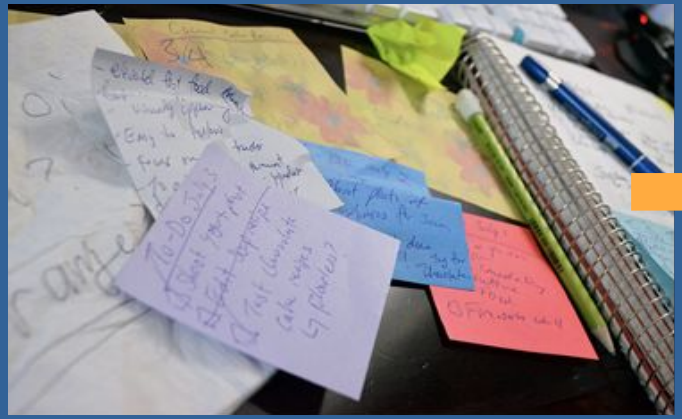

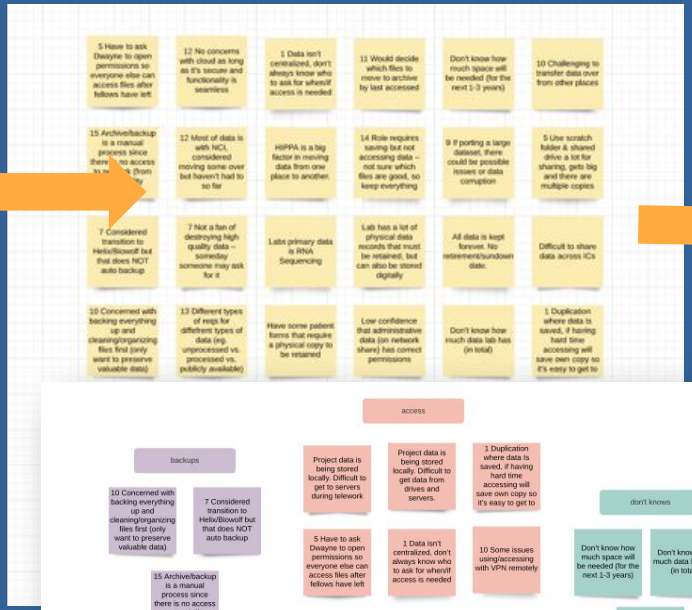

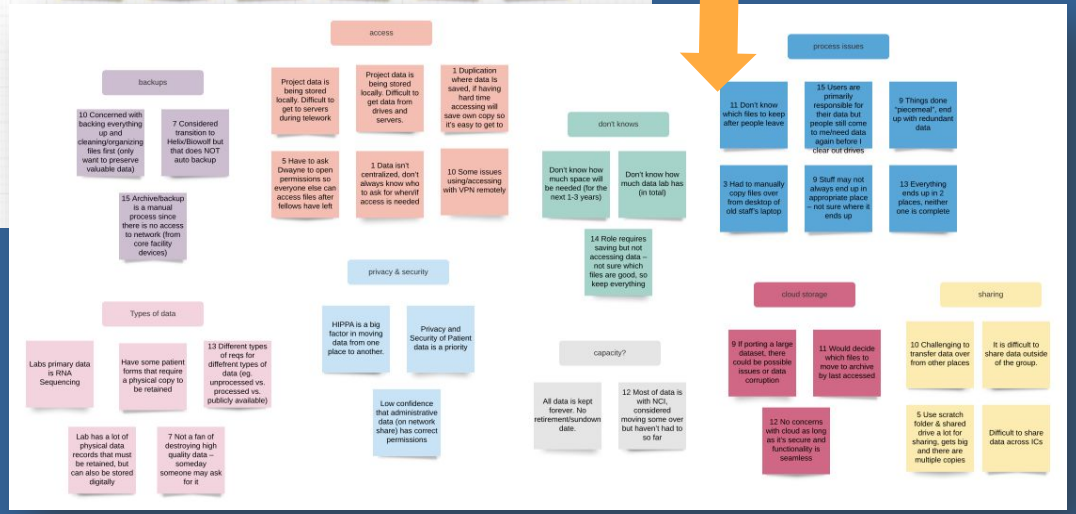

Affinity mapping helped diagnose complicated problems by organizing qualitative data to reveal themes associated with the problems.

Our affinity mapping process

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RESULTS

- The majority of groups don’t delete or archive data
  - “It’s impossible to know - things come back at an unexpected angle. [High quality data], someday someone may ask for it.”
- Some decisions made for convenience, rather than process
  - “...If we have a hard time getting the data, we will save [our] own copy so it's easy to get to"

RECOMMENDATIONS

- **Immediate (Within 3 months)**
  - Data Cleanup Campaign
- **Short-term (3-6 months)**
  - Cloud Archive
  - Educational modules, newsletters
- **Long-term (6 months & beyond)**
  - Feedback loop between SITB and IRP partners

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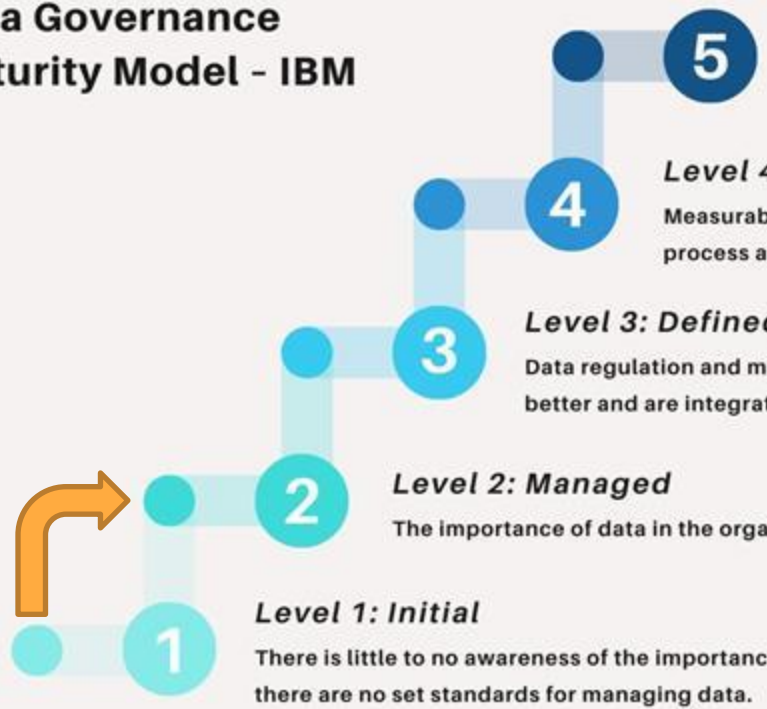
Data Governance Maturity Model - IBM



Level 5: Optimizing

Data governance becomes an enterprise-wide effort that improves productivity and efficacy.

Level 4: Quantitatively managed

Measurable quality goals are set for each project, data process and maintenance.

Level 3: Defined

Data regulation and management guidelines are defined better and are integrated with the company processes.

Level 2: Managed

The importance of data in the organization is realized.

Level 1: Initial

There is little to no awareness of the importance of data and there are no set standards for managing data.

A BIG PICTURE TAKEAWAY

"Supposing is good,
but finding out is better"

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THANK YOU

- **Christine Winchester, La'Tanya Burton, Diana Mungai**, and SITB
- **Jessica Mazerik** and the NIH team
- **Rachel Dodell, Chris Kuang, Ariana Soto** from Coding it Forward
- Mentors **Will Slack** and **Erica Pincus** for their advice/expertise
- Everyone who participated in our survey and interviews
- All the other **Civic Digital Fellows!**

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