Aligning Data Initiatives: What You Need to Know

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SLDS Technical Support Team
Agenda

• Discuss the current landscape: The Good, The Bad, The Ugly

• Discuss considerations regarding data: transparency, accountability, & security.

• Review approaches to alignment of data to applicable laws.
The Good

U Penn

Philadelphia
The Good

http://www.youtube.com/watch?v=FLqc_9VxfCE
The Good

• ND established a DS agreement between DOE, Blue Cross/Blue Shied & DOH
  – Each party agrees to use or disclose student educational records and individually identifiable health information only in accordance with and as permitted by the HIPAA privacy rule, 45 C.F.R parts 160 and 164, and FERPA, 34 C.F.R. part 99, and in accordance with all laws and administrative rules of the state of North Dakota.

  – Privacy safeguards employed
    • Technical safeguards by both parties for data in transit
    • Must have security procedures in place
    • Sanctions in place for those who fail to protect data
    • Breach notification requirements

  – Matching conducted by BCBS
The Good: Partnership with Research Agency

- WV DOE created a data sharing agreement under A/E exception under FERPA with a research agency.
  - Data are de-identified
  - Small cell counts are reason for DS agreement.
  - Access limited and defined in agreement
    - Training required for those accessing data along with NDA
    - Publications require review by parties providing data.
    - Random ID’s created in source data
  - Data destroyed after work is done.
“The de-identification and anonymization of the data involves the removal or obscuration of information in individual records so that the remaining information does not identify any individual, and so that there is no reasonable basis to believe the information could be used to identify an individual. To help alleviate privacy concerns, data classified as containing personally identifiable information (PII) in the data inventory phase is de-identified or anonymized before it is included for use in the SLDS by reducing the number of variables on which a match to an individual might be made. All de-identification procedures are implemented with the appropriate physical, technical, and administrative protections in place to minimize risk and ensure regulatory compliance.”

Source: MS Data Governance Manual
The Bad: Data overload
The Bad: Data overload

"Get all the information you can, we'll think of a use for it later."
The Bad: Data Overload
Data Revealed: An EPIC Failure!
Current State

**DATA: BY THE NUMBERS**

- **Number of years to get data:** 3
  - **Yes! Finally!**

- **Number of years to interpret data:** 2
  - **What does it all mean??**

- **Number of years to write about data:** 15
  - **Blah blah blah blah...**

- **Number of slides to present data:** 1
  - **Results: That's it?**

[Source: www.phdcomics.com]
A look at incomplete data
A look at incomplete data

1. EM FIELD MANIPULATION EMITTERS
2. BUSSARD COLLECTOR UPTAKE GRID
3. BUSSARD COLLECTOR ASSEMBLY
4. EM FIELD SENSORS
5. BUSSARD DUMP-PORTS
6. PLASMA DUMP-VENTS
7. PRE-STAGE INTERCOOLER
8. MAINTENANCE ACCESS PANEL
9. MAIN-STAGE INTERCOOLER
10. DORSAL PHOTONIC SPILL-PORTS
A look at complete/linked data
Data vs. Information

Data
- raw facts
- no context
- just numbers and text

Information
- data with context
- processed data
- value-added to data
  - summarized
  - organized
  - analyzed
The Bad: Privacy misunderstood

– Did you know that most people will give away personal information for on average $.99?

– Did you know that in states around the country there are nearly 40 privacy bills focused on the protection of student information?
The Bad: Privacy misunderstood
Transparency

• In the absence of information, people tend to assume the worst
• Be open about what you’re doing
• Highlight your successes
The Ugly: Bad Communication
The Ugly: Bad Communication
The Ugly: In the news: Email

Just Wanted To Let You Know

I'm On To You
The Ugly: Data Breaches
What can we do to move data forward in this environment?

- Let parents know what information you’re collecting, and why you’re collecting it
- Keep (and publish) a data inventory
- Inform parents about your data governance and information security practices
- Be open about who you share data with, and why. (Post your data sharing contracts and MOUs)
- Value! Value! Value! (Explain what’s in it for the parents/children)
Data Visualization: What’s this?
Data Visualization: Easier now?
Let’s discuss an approach to figure out what applies here in Hawaii!!
Why do we need to Map?

• Understanding data flows/sources/elements helps determine which laws apply:
  • Privacy Protections
  • Security Requirements
  • Breach Notification Requirements
  • Consent Requirements

• Gives you a better understanding of your data systems and assists you with internal & external communications
High Level Mapping Steps

1. Involve many agencies, early in the conversation.
2. Identify which data types will be shared—especially which PII will be shared.
3. Ensure compliance with federal, state, and local laws.
4. Map the data flow visually.
Data Mapping: Key Steps

- Identify the key policy questions
  - Align to district, gubernatorial, legislative, executive leadership goals.

- Identify data types/elements needed to answer those questions.
  - Do you have multi-agency governance?
    - Yes = Document the process; No = institute multi-agency governance
  - Agencies involved?
  - What level of data is needed at the input **AND** output level?
Data Mapping: Key Steps

- Review applicable state, federal, & local laws.
  - Current/pending privacy bills? Impact?
  - Compliance is the bar, not the ceiling.. You may want MORE stringent controls.

- Review current privacy policies in EACH agency involved with data integration.
  - Alignment with applicable laws above?
  - Do policies meet multi-agency governance needs of LINKED data?
Data Mapping: Key Steps

✓ Identify the key policy questions
  • Align to district, gubernatorial, legislative, executive leadership goals.

✓ Identify data types/elements needed to answer those questions.
  • Do you have multi-agency governance?
  • Yes=Document the process; No=institute multi-agency governance
Mapping Process...

- Map data flow in a visual format
  - Where information resides (agency/system), where it will go, and what the output (aggregate, PII, de-identified) of the combined data will be?

- Verify governance covers all data sets and actors
  - Ownership of input data
  - Ownership of LINKED data
  - Accountability
  - Collection
Mapping Process...

✓ Verify data sharing agreements needed and/or in place currently

✓ Look at visual data flows/agencies involved to determine which laws/FERPA exception applies.
  ✓ Workforce: Definition (state) of a public official?
  ✓ Audit/Evaluation Exception: Determination of “Education Program”
  ✓ Audit/Evaluation Exception: Designating an “Authorized Representative”

✓ Best practices for Data Sharing Agreements
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<th>Family Policy Compliance Office</th>
<th>Privacy Technical Assistance Center</th>
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<tr>
<td><strong>Telephone:</strong> (202) 260-3887</td>
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<td><strong>Email:</strong> <a href="mailto:FERPA@ed.gov">FERPA@ed.gov</a></td>
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