

**Vermont Health Data
Infrastructure Workgroup
Subcommittee on Data
Warehousing Materials**



PROJECT NO.

14-237

PREPARED FOR:

**Health Data Infrastructure Work Group
Vermont Health Care Innovation Project
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Vermont Health Data Infrastructure Workgroup Subcommittee on Data Warehousing Materials

Document Title

Vermont Health Data Infrastructure Workgroup Subcommittee on Data Warehousing Materials

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1. Introduction

The Vermont Health Care Innovation Project Program's (VCHIP) Health Data Infrastructure (HDI) Work Group charged Stone Environmental and its subcontractors Rachel Block and Larry Sandage to staff and support their Subcommittee on Data Warehousing. Two meetings were held. This report contains the meeting agenda and notes, the materials presented and discussed at the two meeting of the sub-committee. The subcommittee was disbanded after two meetings.



Appendix A: Glossary of Terms



GLOSSARY OF HEALTH CARE ACRONYMS

ACC – Accountable Care Community	IFS – Integrated Family Services
ACG – Adjusted Clinical Groups	INTERACT – Interventions to Reduce Acute Care Transfers
ACH – Accountable Communities for Health	IOM – Institute of Medicine
ACO – Accountable Care Organization	IT – Information Technology
ACS-NSQIP – American College of Surgeons National Surgical Quality Improvement Program	LS – Learning Session
ADAP – Alcohol and Drug Abuse Programs	LTSS – Long-Term Services and Supports
AHS – Agency of Human Services	MA – Medical Assistant
AOA – Agency of Administration	MD – Medical Doctor
APM – All-Payer Model	MPI – Master Patient Index
APMH – Advanced Practice Medical Home	NAACO – National Association of ACO’s
BHN – Behavioral Health Network	NIST – National Institute of Standards and Technology
BRFSS – Behavioral Risk Factor Surveillance System	NMC – Northwestern Medical Center
CAGR – Cumulative Average Growth Rate	NPI – National Provider Identifier
CAHPS – Consumer Assessment of Healthcare Providers and Systems	NQF – National Quality Forum
CBC – Complete Blood Count	OCR – The Office for Civil Rights within HHS
CCHL – Community Committee on Healthy Lifestyle	OCV – OneCare Vermont
CCIO – The Center for Consumer Information & Insurance Oversight	ONC – The Office of the National Coordinator for HIT w/in HHS
CCMR – Care Coordination Medical Record	OS – Operating System
CCT – Community Care Team	P4P – Pay for Performance
CD – Clinical Director	PCMH – Patient Centered Medical Home
CDM – Chronic Disease Management	PCP – Primary Care Physician
CHA – Community Health Advocate	PDF – Portable Document Format
CHAC – Community Health Accountable Care, LLC	PHI – Protected Health Information
CHF – Congestive Heart Failure	PPS – Prospective Payment System
CHIP – Children’s Health Insurance Program	PRG – Pharmacy Risk Grouper
CHT – Community Health Team	QCCM – Quality and Care Coordination Manager
CMMI – Center for Medicare and Medicaid Innovation	QI – Quality Improvement
CMO – Chief Medical Officer	RFP – Request for Proposal
CMS – Centers for Medicare and Medicaid Services	RN – Registered Nurse
COPD – Chronic Obstructive Pulmonary Disease	RUI – Resource Use Index
CSA – Community Supported Agriculture	SAS – Statistical Analysis System
DAIL – Department of Disabilities, Aging, and Independent Living	SBIRT – Screening, Brief Intervention, and Referral to Treatment
DAs – Designated (mental health) Agencies	SC – Surgical Champion
DHMC – Dartmouth Hitchcock Medical Center	SCR – Surgical Care Reviewers
DID – Difference in differences	SCÜP – Shared Care Plan/Universal Transfer Protocol
DLTSS – Disability and Long Term Services and Supports	SIM – State Innovation Model
DUA – Data Use Agreement	SMHP - State Medicaid Health Information Technology Plan
DVHA – Department of Vermont Health Access	SMS – Short Message Service
ED – Emergency Department	SOV – State of Vermont
EHR – Electronic Health Record	SPA – State Plan Amendment
EMR – Electronic Medical Record	SPC – Statistical Process Control
EMT – Emergency Medical Technician	SRA Tool – Security Risk Assessment Tool
EOC – Episodes of Care	SSA – Specialized Service Agency
ePHI – Electronic Protected Health Information	SSCPC – Statewide Surgical Collaborative Project Coordinator
ERG – Episode Risk Grouper	SSP – Shared Savings Program
FAHC – Fletcher Allen Health Care	SVHC – Southwestern Vermont Health Care
FEDU – Frequent ED Use	SVMC – Southwestern Vermont Medical Center
FICA – Federal Insurance Contributions Act	SW – Social Worker
FQHC – Federally Qualified Health Center	SWOT – Strengths, Weaknesses, Opportunities, and Threats
FTE – Full Time Equivalent	TACO – Totally Accountable Care Organization
GMCB – Green Mountain Care Board	TBD – To be determined
HC – Health Care	TCI – Total Cost Index
HCM – Health Confidence Measures	TCM – Transitional Care Model
HDI – Health Data Infrastructure	TCN – Transitional Care Nurse
HF – Healthfirst	TCOC – Total Cost of Care
HH – Health Home	TCRRV – Total Care Relative Resource Value
HHS – U.S. Department of Health and Human Services	UCC – Unified Community Collaborative
HIE – Health Information Exchange	VCN – Vermont Care Network
HIPAA – Health Insurance Portability and Accountability Act of 1996	VCP – Vermont Care Partners
HIPPA – Health Insurance Portability and Accountability Act	VCP – Vermont Collaborative Physicians
HIT – Health Information Technology	VDH – Vermont Department of Health
HITECH Health Information Technology for Economic and Clinical Health Act	VHCIP – Vermont Health Care Innovation Project
HP – Hospital Readmissions	VHCURES – Vermont Healthcare Claims Uniform Reporting & Evaluation System
HPA – Health Promotion Advocate	VHIE – Vermont’s Health Information Exchange
HRQL – Health Related Quality of Life	VITL – Vermont Information Technology Leaders
HSA – Health Service Area	VPQHC – Vermont Program for Quality in Health Care
HSE – Health Services Enterprise	VT – Vermont
IBNR – Incurred But Not Reported	WRFP – White River Family Practice
IFS – Integrated Family Services	XSSP – Commercial Shared Savings Program

Source: VT HIT Plan & HHS Terms



Appendix B: Vermont Health Data Infrastructure Workgroup Subcommittee on Data Warehousing, Members, Agendas and Minutes

Background Paper

Member List

May 24, 2016 Agenda and Notes

July 14, 2016 Agenda and Notes



Vermont Health Data Warehouse Background on Vermont Health Data Warehouse Project¹

VHCIP provides resources for specific investments to improve Vermont's health data infrastructure. Many of these investments are addressing important short-term needs, but the program is also focused on longer-range goals. This work group has been established to flesh out the potential scope for a Vermont health data warehouse to be operated by the state for the benefit of all Vermonters. Key activities to develop this scope include:

- (1) Baseline assessment of current capabilities;
- (2) Outline future state vision and capabilities;
- (3) Identify priority business needs and use cases considering strategic and tactical perspectives;
- (4) Develop draft proposal for next steps – short and long term

Goals for the work group:

- Represent the key state agency stakeholders; facilitate input from key external partners – resulting in a multi-sector, multi-disciplinary perspective
- Develop shared understanding and consensus on:
 - Strategic goals and priority needs closely aligned with ongoing health reform plans and initiatives
 - Match priority needs with short term resources and sustainable funding
 - Initial scope framing for 3-5 specific projects that would serve as building blocks for Vermont Health Data Warehouse development – commission project plans to be developed by appropriate agency staff in consultation with internal and external stakeholders

Principles (excerpted from the draft Vermont HIT Plan):

- Need to share data to learn, measure and improve across the health care system (including all relevant state agencies)
- This requires assurance of privacy and security, and rules for access to data
- Need to utilize industry standards and best practices; examples include data governance, interoperability, end user needs, appropriate management resources, leverage existing investments
- To maximum extent possible, data should be considered a public good and operate in a transparent manner

General priorities (also excerpted from draft Vermont HIT Plan):

¹ Prepared by Larry Sandage, Health Information Consultant

- Establish statewide HHS governance model to strengthen policy and operational coordination across projects
- Establish master data management program across all applicable programs (common rules, meta data)
- Provide more efficient and effective tools for provider and program reporting on performance measures
- Develop shared infrastructure and tools to aggregate and analyze data within and across programs and agencies
- Business model to maintain and enhance infrastructure (organizational, functional, resources, timeline)

Core set of shared services and desired capabilities (topics identified based on first work group meeting feedback):

- Master patient index/identifiers
- Data quality (front and back end)
- Analytic tools
- Data dictionary
- Consent management
- Workforce – building and retaining staff with necessary skill sets

VHIP Health Data Infrastructure Work Group Subcommittee on Data Warehousing

Members

Georgia Maheras, Georgia.Maheras@vermont.gov, Deputy Director for Health Care Reform-Payment and Delivery System Reform at State of Vermont

Craig Jones, Craig.Jones@vermont.gov; Director, Vermont Blueprint for Health

Richard Boes, Richard.Boes@vermont.gov; DII, Chief Information Officer

Casey Cleary, Casey.Cleary@vermont.gov; DII, Information Architect

Darin Prail, darin.prail@vermont.gov; Chief Information Officer at Vermont Agency of Human Services

Heidi Klein, Heidi.Klein@vermont.gov; Director of Health Surveillance at Vermont Department of Health

Susan Barrett, Susan.Barrett@vermont.gov; Executive Director at Green Mountain Care Board

John Stern, Health and Human Services Enterprise, Program Director

Larry Sandage, Larry.Sandage@partner.vermont.gov

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John Rancort, Deputy ?, ONC

Agenda

Vermont Health Data Warehousing Meeting #1

June 8, 2016

Pavilion Office Building

3:30 – 5:00 PM

Members: Georgia Maheras, Craig Jones, Heidi Klein, Susan Barrett, Richard Boes, Casey Cleary, and Darin Prail,

Support: David Healy, Rachel Block and Larry Sandage, (Kate Kiefert, ONC HIT Resource Center Consultant)

Meeting Goal: Reach General Agreement on Desired Outcome--Making data available for analytics and care support (and leveraging existing warehouses)

1. Introduction – Georgia
 - a. Where are we now with these data sources?
 - b. Do we need new tools to meet our goals?
 - c. Relationship to HIT Plan
2. Individual Aspirations & Outcomes (no more than 5 minutes each)
3. Brainstorming - what do you want/need to get out of data?
 - a. Timely? MPI? Evaluation? Forecasting? Other?
4. Next steps and Meeting Date

Minutes
Vermont Health Data Warehousing Subcommittee Meeting #1
June 8, 2016
Pavilion Office Building
3:00 – 4:30 PM

Attendees:

Georgia Maheras, Georgia.Maheras@vermont.gov, Deputy Director for Health Care Reform-Payment and Delivery System Reform at State of Vermont

Craig Jones, Craig.Jones@vermont.gov; Director, Vermont Blueprint for Health

Richard Boes, Richard.Boes@vermont.gov; DII, Chief Information Officer

Casey Cleary, Casey.Cleary@vermont.gov; DII, Information Architect

Darin Prail, darin.prail@vermont.gov; Chief Information Officer at Vermont Agency of Human Services

Heidi Klein, Heidi.Klein@vermont.gov; Director of Health Surveillance at Vermont Department of Health

John Stern, Health and Human Services Enterprise, Program Director (Denise Nagelschmidt attended for him)

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Rachel Block rachelblock13@gmail.com, Health IT Policy Consultant, Part of Stone Team, Project, 518.860.2226

John Rancourt, John.Rancourt@hhs.gov, ONC Resource Consultant, 202.691.2112

Absent: Susan Barrett, Susan.Barrett@vermont.gov; Executive Director at Green Mountain Care Board

Meeting Goal: Reach General Agreement on Desired Outcome--Making data available for analytics and care support (and leveraging existing warehouses)

1. Introduction – Georgia

- Where are we now with these data sources?
- Do we need new tools to meet our goals?
- Relationship to HIT Plan

Georgia Maheras

- There's many questions surrounding data warehousing
- Current draft of health information tech strategic plan – talk of data warehousing and making data available for analyzes
 - Programmatic assessment
 - Monitoring program
 - Trends analysis

- Specific program activities
- Others
- Current data sources – lots of good data; Data Inventory specifies sources, some more accessible than others.
 - Leverage existing things
 - Evaluating approach
- No preconceived notions – brainstorming to see what they have, what can get to, collective aspirations

David Healy

- Facilitating work group
- Rachel is health policy expert
- Would like to hear from everyone

2. Individual Aspirations & Outcomes (no more than 5 minutes each)

Craig Jones

- Trying to link data sources for program evaluation
- Uses All Payer Claims Database (APCD-VHCURES) to link to claims data, data from provider registry, rules require that medicare data stays in APCD; uses Blueprint registry database; the clinical registry (feeds from medical record systems through VITL), BRFSS from VDH, PCMH CHAPS survey data (patient experience) collected by the Blueprint and GMCB, corrections data, and others.
- The aggregated data (healthcare, social, behavioral) is used to routinely produce performance profiles (practices profiles, health service area profiles) – these profiles are used by participants in service area collaboratives across state as part of the learning network working to improve quality, coordination, and outcomes on key measures.
- The state maintains a wide array of traditionally segregated data systems, and is uniquely positioned to establish a warehouse that links data from these systems (claims data, clinical data, education data, housing data, transportation data, labor data, corrections data, and various registries within VDH such as vital statistics). Linked data can be used for evaluation, comparative performance and variation analyses, and predictive modeling that can be used to fuel an accountable health system.
- Would like to turn this into systematic enterprise routine w/ common identity layer going across all – use all pair claim or other to create linkages and virtual environment accessible by analysts for uses Georgia mentioned and others.
- The Blueprint has been able to demonstrate this type of linkage as proof of concept. The linked data has driven a new data use culture in service areas across the state. It is now time to turn this into a routine production process with broad access and use for learning system activities.
 - Done this with EMR data across state
 - Data quality, identity management, and linking data

Richard Boes

- Set realistic goals
- Role as CIO – don't define programmatic needs but rather facilitate other to meet needs in efficient and effective way
 - Manage data commiserate with risk
 - Build good processes
 - Follow appropriate processes
 - Want business to define what programmatic needs are and then facilitate that

Darin Prail

- Same position as Richard – goal is to support program staff
 - Foster culture of analysis and process improvement, resource assessment and planning, sustainable management, and project success
 - Improving support for AHS business strategies – he doesn't set goals but there's a long-standing (7+) year plan to connect data sources and systems together.
 - Focus on getting base technology in place and getting master index to link all people and all systems with enterprise ID to perform analytics
 - AHS Data governance effort – working with Casey . DII on effort
 - Need to create predictable way of sharing data together and understanding implications of doing so
 - Need to make sure data is classified appropriately.
 - Foster environment of analytics and metrics based decision making
 - Data warehouse to do longitudinal studies
 - Really want an **cdw** to do longitudinal analytics. Had a system that was just dumping all the data in. It was a giant holding cell for all the data (**jitney?**)

Georgia

- Also wants to hear about pace and ability to deliver
- Different types of data
 - Claims
 - Clinical
 - Survey
 - Programmatic analysis and assessment
 - Both identified and de-identified

Denise

- Andrew Lang – goal is to have a way to query data

Heidi

- DOH oversees public health systems

- DOH has just completed a data encyclopedia includes full list of data they collect largely based on legislative requirements
- Make data useful to decisions being made in VT
- Hold most data that's not claims
 - Vital statistics – core
 - Clinical – but don't own portion
 - Surveys
 - Surveillance
 - Census data for population estimates (ACCD large request to compile this info)
 - Holders of most data
 - Others
 - Invested a lot of GIS mapping and coding
- DOH Interests
 - Internally – catching up (SPHINX data warehouse patient tracking portal completed for some)
 - We've created own MPI. Have done that for certain data sets. We could expand that at the record or patient record level.
 - We need to have our internal systems in order, so we can navigate our own requests.
 - We want it easier for you to request data from us and we can share it.
 - Other systems that they could create
 - Want to get this in place to make easier to share
 - Able to maintain certain restrictions but letting everyone view but not edit – questions around data
 - Don't necessarily want to own the warehouse but staff does understand how to handle data
 - Harder to build faster in government - not a lot of time to build up sphinx
 - Faster to do it externally comes with internal costs – significant time for outside data requests,
 - Existing data sources – Blueprint on-point clinical data repository w/ Craig doesn't work for them... need access to underside/backside of the database
 - Have lots of valuable, high-quality data
 - Questions around data governance are critical.
 - Our folks understand cleaning and de-duplicating data. We have whole structure set in place.
 - It is harder to build faster in government. Caution about it is faster and easier to do externally, but don't forget the internal cost associated with that. There is internal investment when we have external vendors.
 - To Craig, I'm thinking about what Blueprint's Onpoint clinical data repository that feels like black box. The questions that our staff is asking for data dictionaries. To be able to view, see and edit. Those things have not been addressed for us. That doesn't work for us. If we are going to be partners, we need to have access to the backend (underside).

Casey

- Richard is my boss, gives direction
- Actionable, tangible – have a lot of strategies, good ideas that hasn't been completed, encourages business to own their requirements and data and what they want to do
- Primary push right now is data governance
- AHS prime candidate
- How to treat data initiative up and running, data reuse, interoperability configuration over optimization
- Want the businesses to own and accept their data so they can make knowledgeable decisions.

QUESTION: How big should this be? The audience? Craig mentioned identity management – like better understanding of who's going to access this data. Who is the audience?

- Heidi – made some assumptions to test; data (equal access wanted) and data reporting are two separate things
 - They share data internal and external (public health partners, legislature).
 - Made assumptions that use is across government and separate function for public use data sets
- Casey – could make 2 cases
 - e-government movement
 - specified health and human services data (researches, hospitals, providers) – waiver for protection
- ??--Promote broad use – if need to be in phases
 - First priority – internal use, BIA, contractors
 - But should also keep eye on broad use for other users like Green Mountain Care Board
 - Audience should reflect goals trying to be achieved
- Sustainability – need to look to future and consider uses of unstructured data
 - Unstructured data that parts of EMR
 - Want system or technology for processing this data? Critical choices need to be made based on goals of the project
 - Do we want to have a system or technology that allows for the processing of that unstructured data as well?
 - There are considerably different technologies for unstructured data.
 - There are critical choices that should be made by what are the goals of the project are.
 - What are those in the future? Looking out years in advance.
- Georgia- special place for mental health and other similar types of data issues
- Craig – push for upfront planning for both structured and unstructured data
 - To get to place to do accountable and population health need to deal with both types of data
- Heidi agrees – unstructured would be very useful in tracking spread of infectious diseases
 - Patient goals often unstructured but important for developing care plans

- Unstructured data needed for intelligence and predictive modeling
 - We have sentinel departments reporting to us on diseases that are reportable.
 - If we had EHRs then we would have better reporting (usually those are things that don't fit in the box early). Seems random at first.
3. Brainstorming - what do you want/need to get out of data?
- How to use data
 - Timely?
 - MPI?
 - Evaluation?
 - Forecasting?
 - Other?
 - i. Stewardship
 - Casey – usually few number of employees actually working with data; hard to get business requirements for data use
 - Data governance – develop overarching framework w/ 4-5 blanket policies then can flush out requirements, audience, role-based access, then formulating policies around it
 - Have enough needs
 - Problem is action – hard to implement
 - Heidi – We aren't in a position where other than existing registries where we need to be answering some of the clinical level questions or performance of our medical care system questions..
 - Want to continue to collect data to develop trends of health status overtime, place and subpopulation and want to do more of that.
 - Manages hospital discharge survey, behavioral surveys, but not connected to individuals
 - VDH has responsibility for a lot of data, not just used by them, but others at a state level, as well as for comparison among regions and other entities
 - Hospitals are major users of data
 - Survey of users? Each program does, but don't survey comprehensively. We want a more robust data tracking system.
 - Working on data request tracking system right now
 - Could get to this faster if dealt with data governance before data requests and needs b/c care about ownership and quality
 - Needs platform to engage people – data governance framework
 - Building of actual IT system – does data need to sit somewhere new to allow of interoperability
 - Darin – we have been looking at this on a data governance level. There is: an access control mechanism; a person index to connect disparate systems; and a consent system not to defeat access control of it.
 - Agrees a few policies at top level good starting point
 - They have some clean data, but not a lot standards in other systems
 - Heidi--Data governance is key here

- Sphinx serve as starting point (combo of warehouse and transactional system) – clean data weekly; run weekly reports matching immunization registries, vital statistics data, cancer registry, etc.
- Transactional system – knowledge of changes to families, births and dates
- Darren
 - Agree that would be great place to look
 - Original MPI rules were built off the VDH rules.
 - Not just data warehousing. Then you can use the data for transactional systems: e.g. if someone died in death registry, can take them off the rolls.
- Craig – want to reinforce Casey’s comments on higher level standards; underlying change in the culture around data use.
 - Really need to consider culture changes
 - Vital statistics data is a good example where data held in a registry isn’t being used as it should be. We have used Vital Statistics data to improve the data quality in EHR systems by identifying people who have deceased but are still active in EHR systems. Practices doing panel management were able to stop making calls to people who were deceased. Their denominators for performance measurement were more accurate.
 - Consider potential business use cases – move to set of policies and governance with controls, appropriate access, but creating opportunity where real population analysis can begin
 - Vermont needs a warehouse environment that supports big and unanticipated uses of data, one that fuels innovation and discovery. There needs to be a change in culture, where limited, use case by use case data extraction is done, and done only for pre-defined use cases. This historic approach to data aggregation and data use limits potential and is out of step with data use in today’s world. In addition, we need to make sure that perfection isn’t the enemy of the good. Each of these large data systems may have quality and completeness issues. Part of the work on aggregation and warehousing is to quantify gaps and work with the data sources to improve quality over time. That should not stop work with the data on evaluation and modeling, at whatever level can be supported with current status. The blueprint team has conducted deep data quality work with each the practices and organizations that are transmitting data into the registry. It’s an ongoing process, which did not stop an incremental approach to using the data as completeness and quality steadily improve over time.
 - Governance and standards that envision a very different future
- Heidi
 - We clean data constantly.
 - We are not relying on HER a lot because we have the registry.
- ??
 - When you talk about patients that have died. Assume you go in and mark as dead?

- It's one thing to generate data moving forward. It's another thing if you have disparate systems (VDH other places, etc.), how much do you envision getting Health records from these other systems into data warehouse
- Heidi
 - I would assume we would not.
- Georgia
 - If designing payment model, then you need to see the trends over years
 - Clinicians would want to see outcomes
- Heidi
 - What is in that shared space, vs what is maintained at original data source. I don't understand.
 - I would want a query capability to look back in time.
- Richard
 - If we keep the data in one place, it's easier to keep in one place rather than integrate to every other system, which is daunting task.
 - Georgia: HIE that gets EMR data is so expensive because of that. It is pulling data from so many places.
- Richard: If you want data warehouse to be useful you need some way of importing data into it.
 - Craig: There's advantage to bringing data into a single place and exercise of cleaning, checking data quality, linking, then building forward with updates.
 - To do real modeling, survival analysis...even if someone passed away 3 years ago...their records are key for end of life analysis.
 - It's easier to build iteratively if it is in one place.
 - We would not be able to do what we do if we had to if had to reach out.
 - Using EMR data out there one thing, if it's in a then that's different.
 - Heidi: my question was about where does the data actually live.
- Richard – question on taking historical records and importing into data warehouse
 - Georgia – only use for historical data from programmatic design perspective and a few other
 - Heidi – unclear what would go into shared data warehouse vs. in original database
 - Daunting from technology perspective to have this separate
 - If all in one place, much easier to do all reporting rather than connections to a lot of outside, disparate systems
 - HIE that collects EMR data expensive to maintain b/c pulling info from many places
 - Need to understanding level of import and would actually be imported is necessary
 - Craig – a lot of value of bringing different data into one place, cleaning it up and linking data, then building it up to analyze longitudinal data
 - Much easier to build iteratively and build upon it
 - As data is aggregated and maintained, it is possible to evaluate completeness and quality on an ongoing basis, track patterns, and work with sources to improve.

This is much more difficult as data is maintained in separate settings, and only aggregated for specific use cases. Then, data quality work only addresses those use cases, as opposed to data quality for expanded whole population use.

- Value of aggregating data and managing in a single place
- Heidi – more about how much data is held in particular place and how much is reported
 - Population health requires them to access historical data, but was asking more question of where it should live
 - Patient record needs to be linked with provider
 - Very supportive of master person index
 - Other reasons for tracking data health

4. Next steps and Meeting Date

Georgia – propose that project team create homework assignment:

- Come to a consensus about goals
- Research MPIs - Larry
- What we can do with that and get info from other states data warehousing from other states – Larry can share some info.
- Get a better idea of stewards (governance) and interoperability (technical) systems within state or is in HIT vs - John Rancourt/ create outline what strategic issues.
- Improve understanding the role of governance and standards for data
- Distill out themes trying to tackle
- Define who is your customer to get out what can do and how fast.

Data Governance-what is currently happening?

-Interoperability

Use Cases are missing

What would they like to do that is different than how they do what they do now?

Heidi – two things they're doing that's important for others to know

- Social vulnerability index
 - Coded GIS system with data on housing, economics, education, health data
 - Interested on trends across populations and places
- Resurrecting old community profiles that were developed – created prototype for AHS
 - Act 186
 - IOM measures could also be rolled in
 - About geographic analysis and display across communities for disease outcomes and social/economic contributors for disease outcomes

Agenda
Vermont Health Data Warehousing Subcommittee Meeting #2
July 14,, 2016
Pavilion Office Building
11:00 – 12:45 PM

Meeting Goal: Reach General Agreement on Desired Outcomes; Priorities; and Use Case Approach

1. **Discuss/Accept Minutes from June**
2. **Confirm Work Group goals – do they match expectations, are they meaningful and important**
3. **Processes from Other States: Washington / Michigan-Rachel**
4. **Consensus on principles, general priorities, desired capabilities – sourced by existing state documents (draft Vermont HIT plan) and first work group discussion**
5. **Review results of homework assignment – consultation with business owners, further refinement of use cases- Group Discussion**
6. **Next steps – develop criteria to assist in prioritization; begin process of honing down to selected priority projects and scoping activities**

Minutes
Vermont Health Data Warehousing Subcommittee Meeting #2
July 14,, 2016
Pavilion Office Building
11:00 – 12:45 PM

Attendees:

Georgia Maheras, Georgia.Maheras@vermont.gov, Deputy Director for Health Care Reform-Payment and Delivery System Reform at State of Vermont

Craig Jones, Craig.Jones@vermont.gov; Director, Vermont Blueprint for Health

Casey Cleary, Casey.Cleary@vermont.gov; DII, Information Architect

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Andrew Laing, andrew.laing@vermont.gov, Agency of Human Services IT

Absent:

Richard Boes, Richard.Boes@vermont.gov; DII, Chief Information Officer

John Stern, John.Stern@vermont.gov, Health and Human Services Enterprise, Program Director

Meeting Goal: Reach General Agreement on Desired Outcomes; Priorities; and Use Case Approach

1. Discuss/Accept Minutes from June

No discussion. Minutes accepted.

2. Confirm Work Group goals – do they match expectations, are they meaningful and important

Georgia:

- The phrase “data warehouse” may not be appropriate. We want a coordinated effort around data, make data accessible to multiple people across the state, not necessarily 1 data warehouse. What is desired is one coordinated effort across the state
- 2nd goal: This work impacts all of us in some way. Overlap with HIT strategic plan, HSE, GMCB responsibilities – some overlap with each of these. No clear single place for this. In terms of accomplishments, come thru with a series of recommendations that we can vet through series of

folks who have responsibilities. This will help with transition plan since we are in a transition time.

- In light of everyone here – all sensitive to resource pressures in state budget. It would be helpful to identify places where we could be more efficient. Efficiency would be appreciated.

3. Processes from Other States: Washington / Michigan-Rachel

Georgia:

- Maybe we don't need to reinvent wheel, steal liberally from others where appropriate

Rachel:

- In order to assist workgroup, look at what other states are doing and benchmark activities that have already been done or may be done. Has talked with WA state and Michigan – these states have dealt with similar issues. Both states have SIM grants and are pursuing similar activities
- WA State's Health Care Authority Efforts focus on:
 - AIM – Analytical, Interoperability and Measurement – Tools, Interoperable systems, and standardized measurement
 - Working across state agencies
 - Have visualized Data interconnections: Healthier Washington
 - Common measurement strategy, APCD, clinical data repository feed into AIM
 - Medicaid clinical data:
 - Craig Jones: Who is leading initiative?
 - Rachel
 - The Health Care Authority – lead implementation, design, development – other State agencies are part of governance structure
 - Integrated Client Database: Administered by WA Department of Social and Health Services; VT equivalent is AHS.
 - Georgia :
 - Integrated eligibility is in a retooling phase. Not suggesting to AHS or DII that work that has been done would be thrown out
 - Rachel – this is not integrated eligibility – it is integrated database
 - One of value propositions for a broadly integrated database – develop relationships between various health components, more robust demographic databases. (Vermont example shared by Heidi re pre-K-12 database). Conceptual models for how an integrated database could be utilized. Various components of health care could be included also.
 - Many challenges described by director: Governance, trust, infrastructure has to respond constantly, staff expertise, lots of data but lacking skill expertise.
 - Heidi: Is the challenge of legal authority and ability to share data an issue in WA?

- Rachel: Governance for the WA integrated client database spends most of their time on this. MI strategy is to rigorously document each use case so they can spell things out so everyone involved is comfortable
 - Casey: What is meant by being able to “legally share”?
 - Heidi: many of data sources have records – data has been obtained with agreement from data sharer that data will not be further shared. Birth and death records have challenges with sharing electronically. There are many data use agreements in place which are designed to protect PII. Each data source has its layer of complication
- PRISM – Predictive modeling. WA database supports this and results are delivered to health plans. One of components to authorizing and authenticating users. This is an application that uses the database
- Michigan
 - Variety of data sources and data exchange opportunities – HIE facilitates the external data sharing – in this context state is focused on single point of entry to access and collect state data. HIE strategy is in center. Of all the potential data sources and data consumers – the data warehouse is just 1 component of strategy. Broader vision is to create pathways to provide this type of access to benefit consumers
 - Rigorous process to documenting use cases: this framework is being used for HIE and for exchange from state data warehouse
 - By developing technical capability, legal framework, and use case structure – able to figure out what data is needed, who is going to get it. Much broader availability and access to data
 - Heidi: We don’t have electronic solutions but have all the same data sets as MI.
 - Rachel – 2 stages: 1st is sharing, making it available, but 2nd challenge is to deliver it in a way that is an integrated view. Delivering data in context of what you are using it for. MIs HIE is supporting this.
 - Heidi: No specialized and reporting tools. Have the data but not the tools.
 - Craig: Doesn’t see the aggregation of data for exploratory work (in MI), WA has more exploratory use of data. Is there something in MI approach that will go outside use cases?
 - Rachel: MI is moving toward developing data aggregation service as next component. Not happening in state data warehouse but rather in HIE. With MI – wanted to introduce Use Case framework to look at navigating who can use data and how.
 - John Rancourt: MI universe of data is through various clients not a single database. WA example is more of a single database.
 - Rachel: MI is trying to figure out their own data access
- 4. **Consensus on principles, general priorities, desired capabilities – sourced by existing state documents (draft Vermont HIT plan) and first work group discussion.**

David:

- Rachel and Larry put together a document to summarize goals of this group, “Vermont Health Data Warehouse: Background on Vermont Health Data Warehouse Project” (Attached and will be in Committee Repository.)

Rachel:

- Document is meant to be a resource and consensus of what has been going on
 - 1st describe what are basic set of activities
 - 2nd what are the goals for the workgroup
 - everyone in this group will need to commit resources to develop this plan
 - This is being done on behalf of Vermonters, a public good resource
- Roger Tubby (in place of Susan): Data should be considered a public good – in terms of privacy, data flows should also be transparent – it should be public at every stage of how it’s touched
- Craig: Is there a good example of “Open Use” as opposed to discrete use cases and what is governance approach to these examples?
 - Casey: if you look to public service – Policing – historically transparent – health care has not embraced the open data movement. Public service (NY, Chicago, LA) put as much info as possible around civic info and let public decipher.
 - Craig: Has this been done in healthcare?
 - Rachel: WA is a pioneer – of all places identified we should look at WA more closely. Open data question is important – general movement of open data was first stage. Put all data out that is in public domain. Feds have put out thousands of databases in healthcare sphere. We are going to next step which is to take disparate datasets and create Architecture and analytical tools: how to have relational data and tools to make data accessible and used. Need to observe correct legal protections. 2 things:
 - Technical discussion to make data more accessible,
 - Continue examination of fed and state laws, evaluated and potentially changed in future. Governance models are protecting and need to make sure people are comfortable with use of data.
 - How should use cases be prioritized?
- Roger: just put an RFP out for an expert opinion on how to get VHCURES data out for public use. Looking forward to how get a model that can be adjusted over time

5. Review results of homework assignment – consultation with business owners, further refinement of use cases- Group Discussion

Georgia:

- Casey and Heidi did their homework

Heidi - What’s happening through Early Learning Challenge:

- Race to Top initiative to make sure kids are ready for school. Link and track data for children, not just school age also birth to school.

- Recognition about determinants for being ready to learn – physical health, family circumstances, etc.
- Wanted opportunity to create systems for sharing data that is highly protected data – need to go beyond standard data use agreements.
- Hired external consultant to help with this process

Casey: Data Governance

- GMCB has its own Data Governance Council
- Race to top / building bright futures: narrowest scope possible, governance around this information. Possible to use these fundamentals structures. Nancy Smith and Andrew involved on this. Agency of Education, building bright futures, AHS, DII, DCF, VDH, and DVHA – Head Start database, focused demographic and use cases.
- Heidi – is there an opportunity to build on this that may provide a template? Although for a narrow population – can create something that complements 18+ population. Can we build on this?
- Heidi; SPHINX system– a lot of Patient Identified data: create reports by patient and provider
- Casey: Governance discussion is a work in progress with goal. Many different governance discussions. Want to avoid 7 different ways of doing it. How to manage data governance across the state and deal with uniqueness of data. There are about 5
 - HR, ANR are very different from AHS
 - Need common foundation of what data governance is
 - Logistics around this, what does a roadmap look like?
 - Baseline material that specific info can be added to. Push forward same message and info to everyone.
 - Need a statewide data governance program. Not to replace agency data governance but they should collaborate. State level council would have administrative strategic members with state agencies underneath and then departments under them. Constant communication both vertical and horizontal on policies and procedures regarding data. These could be inserted into RFIs so that proposals from vendors come back with appropriate
- David: Where would data governance regarding personal identifier info get set?
 - Casey: At various levels but with agreement and commonality. Governance needs to incorporate private sector needs.
 - Andrew: Need common language to do interchange. AHS tries to use Nationals?
 - Roger question: What % of agencies have data governance in places.
 - Casey: Formally 1 – VCGI, informally – VDH has great stuff going on that is not formalized and standardized
 - Larry; directionally more energy toward this setting up data governance, pockets of energy erupting. GMCB. Time to capture energy to use it as a tool to get some of these activities done.
- Casey: Regarding the idea that maybe data warehouse is wrong label...
 - Step 1 is to create a governance structure that generates policies and practices
 - David: Are there are the resources to really do all these functions within organizations?
 - Casey: Governance project should be funded by itself, should be pushing forward at state level. Trying to get creative on how to fund.
 - Roger: More efficient to have it more centralized

- Casey: Each agency needs data analysts, specialists to handle data.
- Heidi – completely agree, trying to build analytical capacity
- Rachel: Ideally efficiency associated with these types of activities. At a minimum getting this done on a statewide basis and/or agency level should result in efficiencies
 - Casey: Department of Ed has a very sophisticated stats department – need more collaboration perhaps to make use of this
 - Casey: Data quality management effort checklist
 - For use to include in contracts

Georgia: Any other thoughts or comments on homework?

- Heidi – Programs are interested in finding whether their programs are having an impact, what are outcomes. Some help from VHCURES and hospital discharge, matching to data available from VDH and SPHINX is helpful. Many programs VDH operates need to also connect to / developing apps that would be useful to track the intervention. Have developed tool on the actual intervention, and making sure data points they are met. Similar to Blueprint and DocSite. Seeing what changes have been made over time and impact on patients. More interest in applications than data warehouse. Use case would be evaluating effectiveness of an intervention
- Craig: at a use level, as Blueprint put out practice profiles, etc., external community has been responsive. Interested in seeing associations that they haven't seen before and how they compare to others in state. As clinical data is linked to claims, one of most basic needs is a common identity layer. The ability to extract data that can be reliably linked to other sources is the biggest needs/highest priority.
- Roger: the master person index
- Craig: Identity layer in combination to governance structure would really accelerate ability to do modeling and exploratory work. Those 2 steps would be huge to accelerate work. Big technical gap not having a common identifier
- Heidi: Agree about needs. Staff have been trying to work with VITL to do this. Not as successful as they'd like to be
 - Larry: Diagram from John Rancourt to support states in building HIT infrastructure that could broadly support systems that could pull together
 - John: The Stack: Modular functions for value based payment. What are functions needed? Identity management is one of core functionalities. Could be a shared service across agencies. Also provider directories. The idea of these functions could be inside state in HIE, or housed and distributed in different systems. Data flowing through shared architecture and flowing to other agencies and entities. We do have a provider directory. Identity management could be like an NPI. Utah is exploring their topics through their SIM work.
- Georgia; helpful to get additional use cases people have developed. Beneficial for project team to reach out to private sector colleagues. We are not only users of this data. Also, other input about priorities and needs. Intent is to do coordination not takeover. Use collective resources widely.
- Craig: provider registry is critical.

Appendix C: Data Governance Materials – Department of Information and Innovation

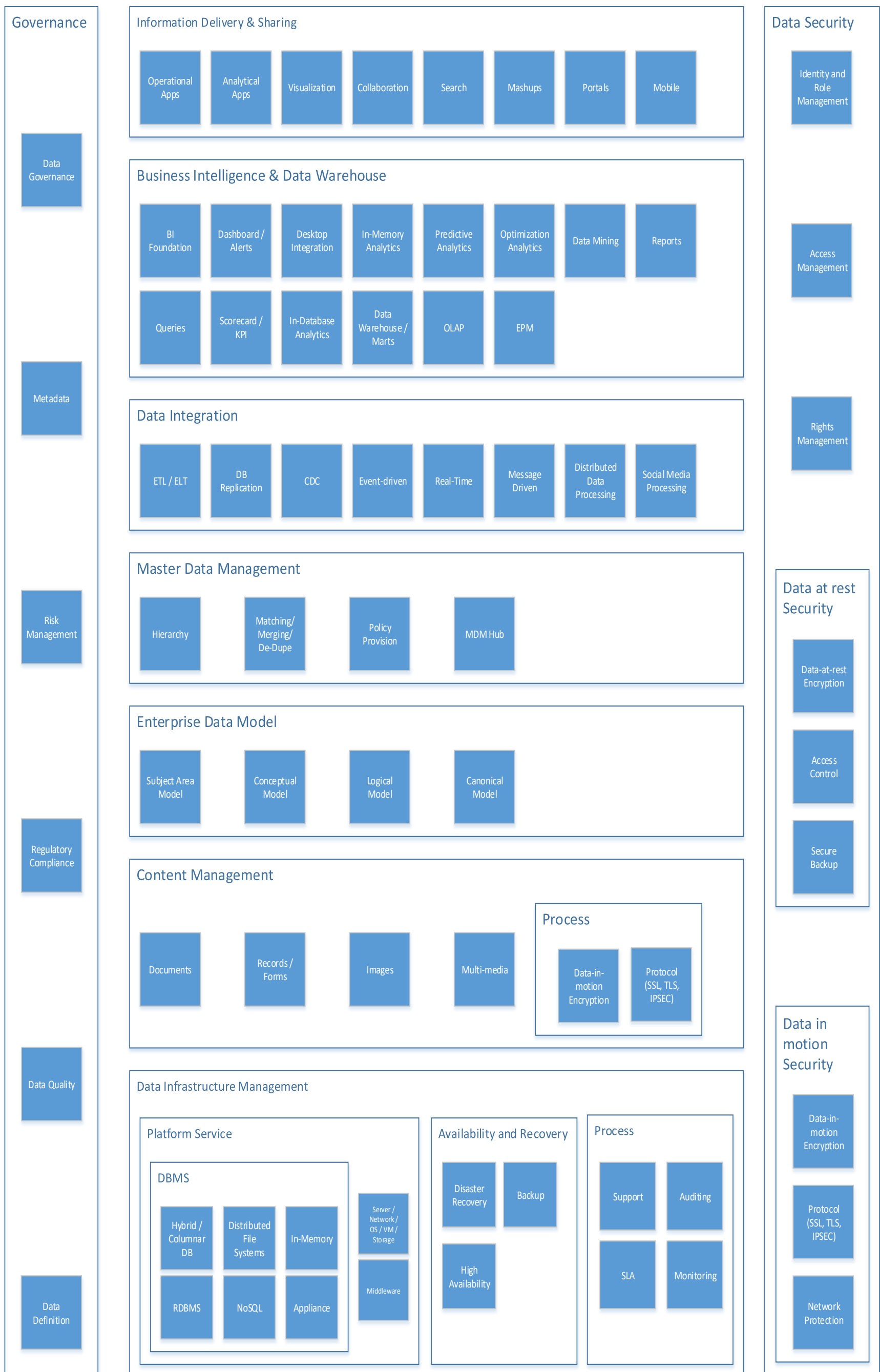
Vermont Enterprise Architecture Framework-Information Architecture, 2015-2016

Data Governance Slides

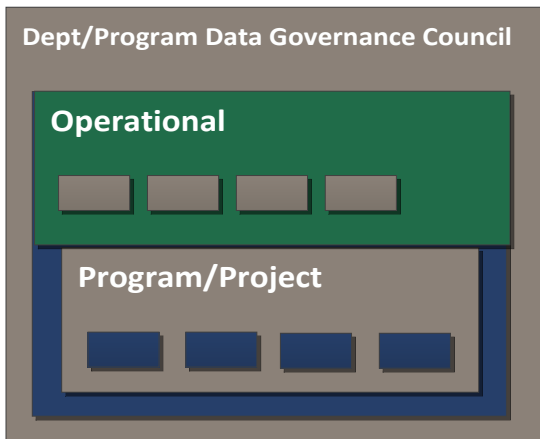
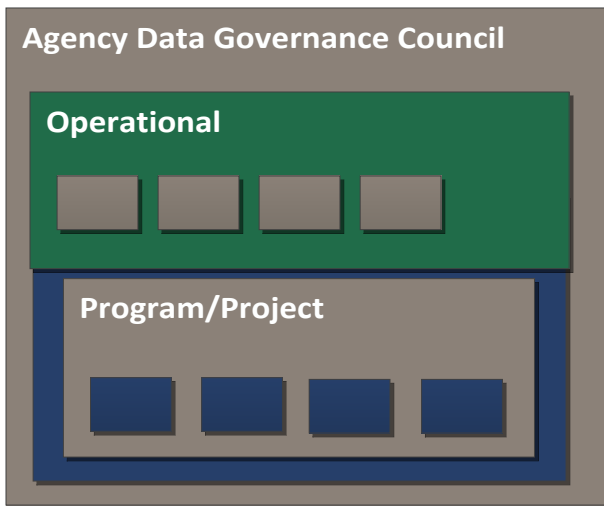
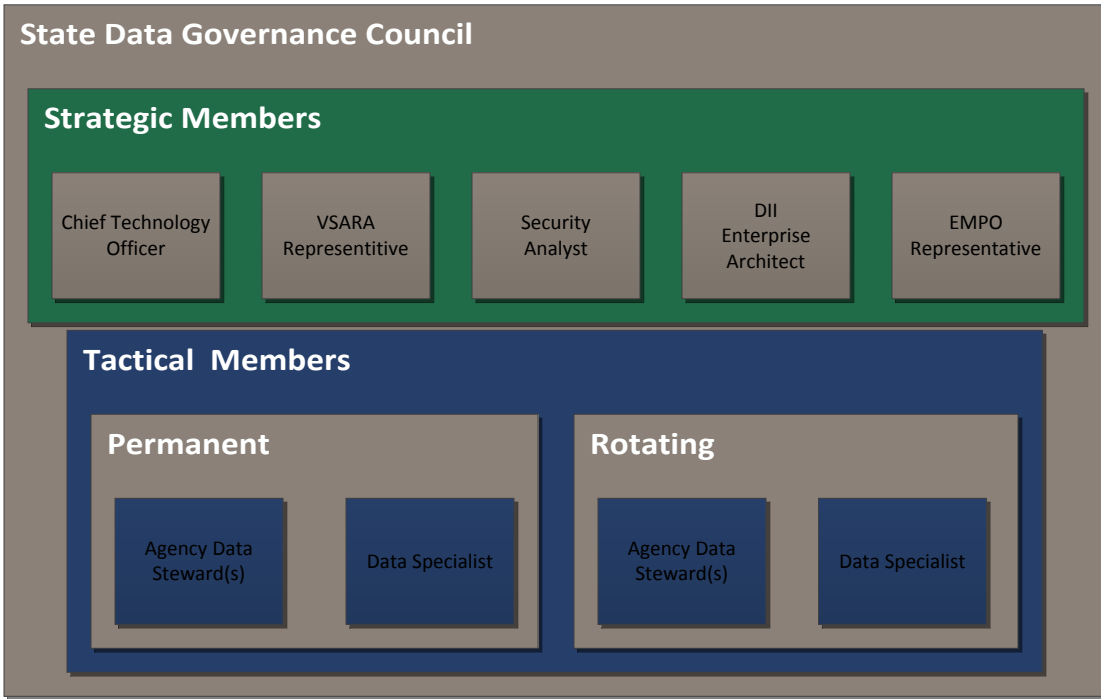
Data Quality Management Worksheets: Checklist; Dashboard; & Spreadsheet



VERMONT ENTERPRISE ARCHITECTURE FRAMEWORK - INFORMATION ARCHITECTURE 2016-2017



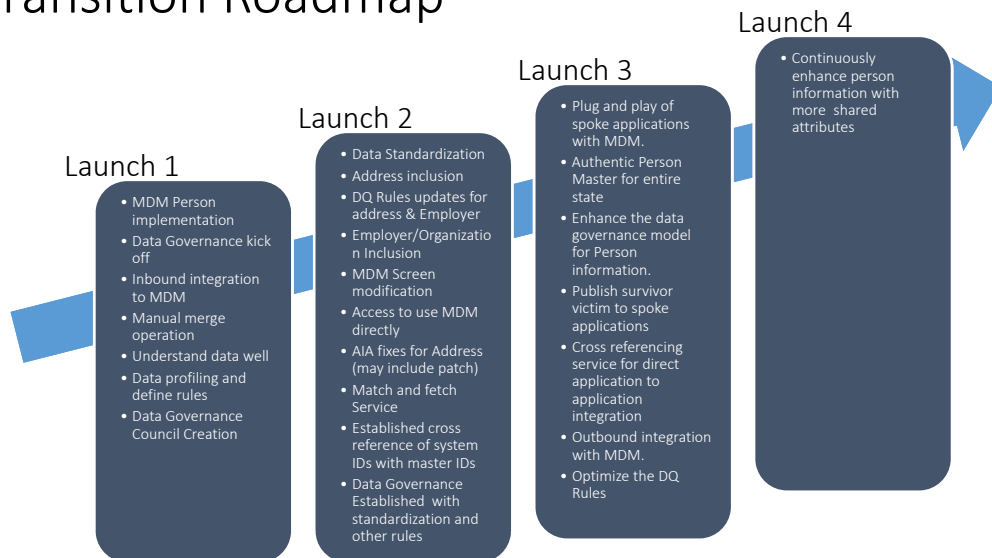
Balance Standardization versus Uniqueness



Data Governance

Maturity Model and Roadmap

Transition Roadmap



Maturity Model

	1 - Initial	2 - Developing	3 - Defined	4 - Managed	5 - Optimized
Governance	Ad Hoc – informal	Subsumed into InfoSec (and InfoSec governance structures)	IAM governance structure defined and accepted	IAM governance structure fulfilled and refined	IAM governance optimized
Organization	Informational basic roles and responsibilities decentralized	Technical projects sponsored by Bus and CISO: Informal inventory of IAM skills	IAM PMO established, IAM roles and training needs defined	IAM PMO active; RACI matrix defined, proactive skill development	Optimal integration with business; skills optimized
Vision and Strategy	Conceptual awareness at best	Certain business drivers identified: tactical priorities set	Business-aligned vision defined: strategic priorities set	IAM vision and strategy continually reviewed to track business strategy	Periodic optimization of vision and strategy
Process	Ad hoc – informal	Semiformal BU-specific and target-specific process	Formal process defined, consistent across the Bus and target systems	Formal process integrated and refined; aligned with business process	Process optimization
Architecture and Infrastructure Design	Possible use of target specific productivity	Disjointed technical projects: technology	Discrete architecture defined: rationalization	IAM Architecture refined and aligned	IAM architecture imbedded within EA;
Maturity Level	Maturity Level	Awareness	Corrective		Operational Excellence
		(maybe) effectiveness improvements: low direct value	improvements tied to GRC Imperatives	to all key business imperatives; high direct value	optimization; transformational direct value

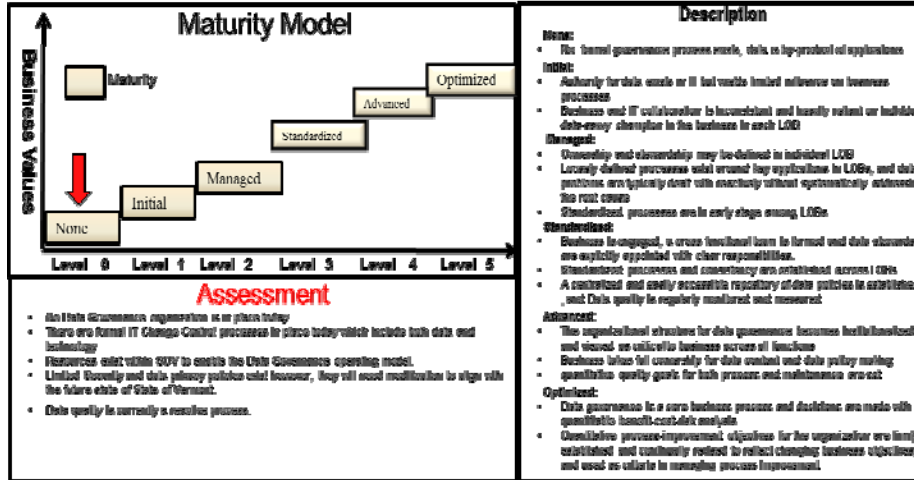
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Maturity Model

	Level 1	Level 2	Level 3	Level 4	Level 5
Maturity Level	Data Integration with minimal focus on data quality	Managing basic data quality within application or functional silos (CRM, BI/DW, finance, call center)	“Master” data within application or functional silos (typically analytical MDM)	Enterprise master data for single data domain (customer, product, etc.) and governance	Cross-enterprise master data for multiple data domains
Enabling Technology	ETL, EAI, custom code	Data profiling; niche (address verification) data quality software	Enterprise-class data quality software	Domain-specific (PIM, CDI) MDM; SOA optional	Comprehensive MDM ecosystem; service-oriented architecture (SOA) required
Usage Scenario	Enterprise resource planning (ERP) application migration/upgrade	Data mart for direct marketing campaign management (data quality focus on address verification)	De-duplicate customers in customer relationship management (CRM) app to improve call center efficiency	Improve Efficiencies for supply chain, deliver on the promise of CRM, inventory management, and provide reporting of product data	Deliver trusted and contextual information insights to any relevant stakeholder
Maturity Level	Ignorance	Awareness	Corrective		Operational Excellence

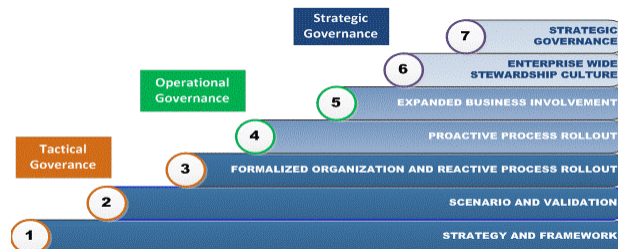
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Data Governance Specific Maturity Model



Data Governance Partners

- Enterprise / Information Architecture
- Regulatory and Compliance
- Information Security
- Project Management Office
- Audit and Legal



Checklist to Assess Data Quality Management (DQM) Efforts

Use the Data Quality Model Functions checklist below to assess overall data quality management efforts.

Application	Yes	No	How
<i>The purpose for data collection</i>			
The application's purpose, the question to be answered, or the aim for collecting the data is clear			
Boundaries or limitations of data collected are known and communicated			
Complete data are collected for the application			
Value of the data is identical across applications and systems			
The application is of value and is appropriate for the intent			
Timely data are available			
Total	0	0	

Collection	Yes	No	How
<i>The process by which data elements are accumulated</i>			
Education and training is effective and timely			
Communication of data definitions is timely and appropriate			
Data source provides most accurate, most timely, and least costly data			
Data collection is standardized			
Data standards exist			
Updates and changes are communicated appropriately and on a timely basis			
Data definitions are clear and concise			
Data are collected at the appropriate level of detail or granularity			
Acceptable values or value ranges for each data element are defined; edits are determined			
The data collection instrument is validated			
Quality (i.e., accuracy) is routinely monitored			
Meaningful use is achieved via the evaluation of EHR data			
Total	0	0	

Warehousing and Interoperability	Yes	No	How
<i>Processes and systems used to archive data</i>			
Appropriate edits are in place			
Data ownership is established			
Guidelines for access to data and/or systems are in place			
Data inventory is maintained			
Relationships of data owners, data collectors, and data end users are managed			
Appropriate conversion tables are in place			
Systems, tables, and databases are updated appropriately			
Current data are available			
Data (data definitions, data ownership, policies, data sources, etc.) are appropriately archived, purged, and retained			
Data are warehoused at the appropriate level of detail or granularity			
Appropriate retention schedules are established			
Data are available on a timely basis			
Health information exchange is achieved as a result of interoperability			
Total	0	0	

Characteristic	Application	Collection	Warehousing	Analysis
<p>Data Accuracy:</p> <p>The extent to which the data are free of identifiable errors.</p>	<p>To facilitate accuracy, determine the application's purpose, the question to be answered, or the aim for collecting the data element.</p> <p>Standard acceptable values should be used where available. Where possible, value flags such as dosages, drug interactions, allergies, and constraints should be implemented.</p> <p>Use of structured data is important to enable the sharing and exchange of health information with HIEs and other organizations.</p> <p>The system of data entry for lab values, such as temperature or blood pressure, must maintain a consistent integer format. Any deviation, to free text for example, might cause the loss or misinterpretation of data.</p>	<p>Ensuring accuracy involves appropriate education and training along with timely and appropriate communication of data definitions to those who collect data. Data definitions require continuous revisions and validations to stay current. The applications should constrain entry to allowable values where possible.</p> <p>For example, data accuracy will help ensure that a patient height cannot be entered erroneously as five inches when it is in fact 50 inches. In addition to a primary data error, this would impact any calculated fields such as Body Mass Index (BMI).</p>	<p>To warehouse data, appropriate edits should be in place to ensure accuracy, such as basic field length checks.</p> <p>Also, error reports are generated related to transfers to and from the warehouse.</p> <p>All warehouses should have a correction and change management policy to track any changes.</p>	<p>To accurately analyze data, ensure that database architecture, relationships, algorithms, formulas, programming, and translation systems are correct.</p> <p>For example, ensure that the encoder assigns correct codes and that the appropriate Diagnosis Related Group DRG is assigned for the codes entered.</p> <p>Continual data validation is important to ensure that each record or entry within the database is correct.</p>
<p>Data Accessibility:</p> <p>Data items that are easily obtainable and legal to access with strong protections and controls built into the process.</p>	<p>The application and legal, financial, process, and other boundaries determine which data to collect. Ensure that collected data are legal to collect for the application and are based on well-defined privacy and content standards.</p> <p>For example, recording the date of birth and race in the EHR is appropriate and should only occur once with verification. Subsequently, the values should roll forward.</p>	<p>When developing the data collection instrument, explore methods to access needed data and ensure that the best, least costly method is selected. The amount of accessible data may be increased through system interfaces and integration of systems.</p> <p>For example, the best and easiest method to obtain demographic information may be to obtain it from an existing system. Another method may be to assign data collection by the expertise of each team member. For example, the admission staff collects demographic data, the nursing staff collects symptoms, and the HIM staff assigns codes.</p> <p>Data entry should undergo a cost-benefit analysis process to determine which method provides the best data most efficiently.</p>	<p>Technology and hardware impact accessibility. Establish data ownership and guidelines for who may access or modify data and/or systems. Inventory data to facilitate access.</p> <p>In the EHR it may be advisable to establish data ownership or governance at the data element level, especially data which are reused. For example, allergies are recorded by many different clinicians and come in many forms. Who defines what an allergy is? How does this impact the use of allergies in the EHR, especially for clinical decision support?</p>	<p>Access to complete, current data will better ensure accurate analysis and data mining. Otherwise results and conclusions may be inaccurate or inappropriate.</p> <p>For example, use of the Medicare case mix index (CMI) alone does not accurately reflect total hospital CMI. Consequently, strategic planning based solely on Medicare CMI may not be appropriate.</p>

Characteristic	Application	Collection	Warehousing	Analysis
<p>Data Comprehensiveness: All required data items are included. Ensures that the entire scope of the data is collected with intentional limitations documented.</p>	<p>Clarify how the data will be used and identify end users to ensure complete data are collected for the application. Include a problem statement and cost-benefit or impact study when collected data are increased.</p> <p>For example, in addition to outcome it may be important to gather data that impact outcomes.</p>	<p>Cost-effective comprehensive data collection may be achieved via interface to or download from other automated systems.</p> <p>Data definition and data precision impact comprehensive data collection (see these characteristics below).</p>	<p>Warehousing includes managing relationships of data owners, data collectors, and data end-users to ensure that all are aware of the available data in the inventory and accessible systems. This also helps to reduce redundant data collection.</p>	<p>Ensure that all pertinent data impacting the application are analyzed in concert.</p> <p>This is especially important when EHR clinical decision support is utilized. Incomplete data can result in underreporting a numerator or denominator.</p>
<p>Data Consistency: The extent to which the healthcare data are reliable and the same across applications.</p>	<p>Data consistency adds to the integrity of data.</p> <p>Data are consistent when the value of the data is the same across applications and systems, such as the patient's medical record number. In addition, related data items should agree.</p> <p>For example, drug dosing.</p>	<p>The use of data definitions, extensive training, standardized data collection (procedures, rules, edits, and process) and integrated/interfaced systems facilitate consistency.</p> <p>Static data should be moved between users. For example, once date of birth has been definitively established, age at the time of treatment should be calculated, not entered by a user who might make an error.</p>	<p>Warehousing employs edits or conversion tables to ensure consistency. Coordinate edits and tables with data definition changes or data definition differences across systems. Document edits data relationships and linkages.</p>	<p>Analyze data under reproducible circumstances by using standard formulas, scientific equations, programming, variance calculations, and other methods. Compare "apples to apples."</p> <p>Any manipulation of data, aggregating or otherwise, should be documented thoroughly to identify data sources, types, codes, and calculations. For example, how is BMI calculated and has the formula been checked?</p>
<p>Data Currency: The extent to which data are up-to-date; a datum value is up-to-date if it is current for a specific point in time. It is outdated if it was current at a preceding time yet incorrect at a later time.</p>	<p>The appropriateness or parameters or value within an application changes over time. Currency preservation is essential.</p> <p>Within an EHR, it is imperative that guidelines and algorithms are consistent and up-to-date. For example, acceptable blood pressure ranges have lowered, as have target HbA1C levels.</p>	<p>Data definitions change or are modified over time. These should be documented so that current and future users know what the data mean. These changes should be made in accordance with information and data governance policies and practices. Further, they must be communicated in a timely manner to those collecting data and to the end users.</p>	<p>To ensure current data are available, warehousing involves continually validating systems, tables, and databases. The dates of warehousing events should be documented as well as challenges with memory and storage limitations.</p>	<p>The lack of availability of current data impacts the data quality.</p> <p>Clinically, issues such as the lack of a patient's most current lab values, medications or a new diagnoses can impact another application which may be abstracting such data necessary in tracking disease outbreak or for biosurveillance purposes.</p> <p>Validating data from various fiscal and calendar years should also be considered.</p>

Characteristic	Application	Collection	Warehousing	Analysis
<p>Data Definition:</p> <p>The specific meaning of a healthcare related data element.</p>	<p>The application's purpose, the question to be answered, or the aim for collecting the data element must be clarified to ensure appropriate and complete data definitions.</p> <p>For example, the distinction between ethnicity and race should be understood and consistently applied during the registration process. Selection options for these fields should be limited to choices that are in adherence with the data dictionary</p>	<p>Clear, concise and consistent data definitions facilitate accurate data collection.</p> <p>Inconsistent data definitions are problematic and affect patient care such as not being able to correctly identify a patient.</p> <p>A data dictionary provides a descriptive list of names, definitions, and attributes of data elements to be captured in an information system or database and offers a base for data not to be misinterpreted.</p>	<p>Warehousing includes archiving documentation and data. Consequently, data ownership documentation and definitions should be maintained over time and clearly communicate to staff.</p> <p>Inventory maintenance activities (purging, updates, and others), purpose for collecting data, collection policies, information management policies, and data sources should be maintained over time also.</p>	<p>For appropriate analysis, display data needs to reflect the purpose for which the data were collected.</p> <p>Appropriate comparisons, relationships, and linkages need to be shown visually.</p>
<p>Data Granularity:</p> <p>The level of detail at which the attributes and values of healthcare data are defined.</p>	<p>A single application may require varying levels of detail or granularity.</p> <p>For example, census statistics may be utilized daily, weekly, or monthly depending upon the application. Census is needed daily to ensure adequate staffing and food service. However, the monthly trend is needed for long-range planning.</p> <p>Similarly, lab test results may be trended at various levels of detail.</p>	<p>Collect data at the appropriate level of detail or granularity.</p> <p>For example, the temperature of 100° may be recorded. The granularity for recording outdoor temperatures is different from recording patient temperatures. If patient Jane Doe's temperature is 100°, does that mean 99.6° or 100.4°?</p> <p>Appropriate granularity for this application dictates that the data need to be recorded to the first decimal point while appropriate granularity for recording outdoor temperatures may not require it.</p>	<p>Warehouse data at the appropriate level of detail or granularity.</p> <p>For example, exception or error reports reflect granularity based on the application. A spike (exception) in the daily census may show little or no impact on the month-to-date or monthly reports.</p>	<p>Appropriate analysis reflects the level of detail or granularity of the data collected.</p> <p>For example, a spike (exception) in the daily census resulting in immediate action to ensure adequate food service and staffing may have had no impact on analysis of the census for long-range planning. Of particular note for analysis is the impact of any rounding which might be done for numerical data.</p>
<p>Data Precision:</p> <p>Data values should be strictly stated to support the purpose.</p>	<p>The application's purpose, the question to be answered, or the aim for collecting the data element must be clarified to ensure data precision.</p> <p>What level of detail is needed for the data collection purpose? Are age ranges or four U.S. regions sufficient?</p>	<p>To collect data precise enough for the application, define acceptable values or value ranges for each data item.</p> <p>For example, limit values for gender to male, female, and unknown; or collect information by age ranges or allow more detailed collection to fully meet the needs.</p>	<p>Are warehouses receiving and storing all data elements being transferred from the source system?</p>	<p>If the precision of the data has been altered in the analysis, is the process understood and well documented?</p> <p>For example, analyzing a blood pressure value before and after the initiation of anti-hypertensive medication will not be precise unless the purpose is clearly stated and data values are clearly defined as the before anti-hypertensive and after anti-hypertensive blood pressure values.</p>

Characteristic	Application	Collection	Warehousing	Analysis
<p>Data Relevancy:</p> <p>The extent to which healthcare-related data are useful for the purposes for which they were collected.</p>	<p>The application's purpose and the rationale for collecting the data element must be clarified to ensure data relevancy.</p>	<p>To better ensure relevancy, complete a pilot of the data collection instrument to validate its use. A "parallel" test may also be appropriate, completing the new or revised instrument and the current process simultaneously. Communicate results to those collecting data and to the end users. Facilitate or negotiate changes as needed across disciplines or users.</p>	<p>Establish appropriate retention schedules to ensure availability of relevant data. Relevancy is defined by the application.</p> <p>It may be appropriate for warehouses to subset data related to its relevancy for certain uses.</p>	<p>For appropriate analysis, display data to reflect the purpose for which the data were collected as defined by the application.</p> <p>Demonstrate appropriate comparisons, relationships, and linkages to establish relevancy.</p>
<p>Data Timeliness:</p> <p>Concept of data quality that involves whether the data is up-to-date and available within a useful time frame. Timeliness is determined by how the data are being used and their context.</p>	<p>Timeliness is defined by the application.</p> <p>For example, patient census is needed daily to provide sufficient day-to-day operations staffing, such as nursing and food service. However, annual or monthly patient census data are needed for the organization's strategic planning.</p> <p>In the EHR, vitals may be taken once per visit for ambulatory care patients, but every 15 minutes or more often for critically ill patients.</p>	<p>Timely data collection is a function of the process and collection instrument.</p> <p>In the EHR, system performance plays an important role in data timeliness. Data display should be sub-second and data entry should occur instantaneously.</p>	<p>Warehousing ensures that data are available per information management policy and retention schedules.</p> <p>For EHR or clinical data warehouses, is the data updated concurrently or does it occur in a batch process?</p>	<p>Timely data analysis allows for the initiation of action to avoid adverse impacts. For some applications, such as allergy-drug or drug-drug interactions, timely may be seconds. For others, such as the prevalence of a disease over time, it may be years.</p>

Data Element/Data Quality Requirement	<i>Accuracy</i>	<i>Completeness</i>	<i>Consistency</i>	<i>Currency</i>	<i>Precision</i>
Patient Demographics					
Patient Events					
Laboratory Results					
Care Summaries					
Pathology Reports					
Radiology Reports					
Other Transcribed Reports					
Immunizations					

Data Element/Data Quality Business Rules	<i>Definitional Conformance</i>	<i>Range Conformance</i>	<i>Format Conformance</i>	<i>Mapping Conformance</i>	<i>Value Presence and Record Completeness</i>
Patient Demographics					
Patient Events					
Laboratory Results					
Care Summaries					
Pathology Reports					
Radiology Reports					
Other Transcribed Reports					
Immunizations					

Data Quality Stakeholders/Reporting Capabilities	<i>Group</i>	<i>Filter</i>	<i>Query</i>	<i>Extract</i>	<i>Dashboard</i>
Patients					
Organizations					
Healthcare Service Areas					
Payers					
Locations					
Primary Care Physicians					
DVHA					
GMCB					
CMS					

Data Element/Data Quality Metrics	<i>Measureability</i>	<i>Business Relevance</i>	<i>Accountability/Stewardship</i>	<i>Controllability</i>	<i>Acceptability</i>
Patient Demographics					
Patient Events					
Laboratory Results					
Care Summaries					
Pathology Reports					
Radiology Reports					
Other Transcribed Reports					
Immunizations					

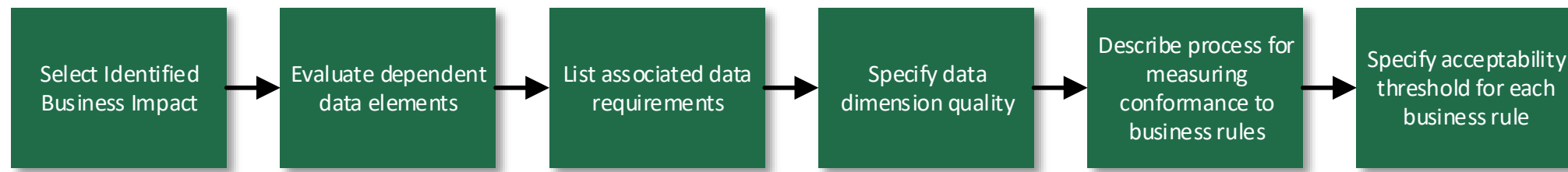
Data Element/Data Quality Requirement	<i>Privacy</i>	<i>Timeliness</i>	<i>Uniqueness</i>	<i>Validity</i>	<i>Referential Integrity</i>
Patient Demographics					
Patient Events					
Laboratory Results					
Care Summaries					
Pathology Reports					
Radiology Reports					
Other Transcribed Reports					
Immunizations					

Data Element/Data Quality Business Rules	<i>Consistency Rules</i>	<i>Accuracy Verification</i>	<i>Timeliness Validation</i>
Patient Demographics			
Patient Events			
Laboratory Results			
Care Summaries			
Pathology Reports			
Radiology Reports			
Other Transcribed Reports			
Immunizations			

Data Quality Stakeholders/Reporting Capabilities	<i>Service Level Thresholds</i>
Patients	
Organizations	
Healthcare Service Areas	
Payers	
Locations	
Primary Care Physicians	
DVHA	
GMCB	
CMS	

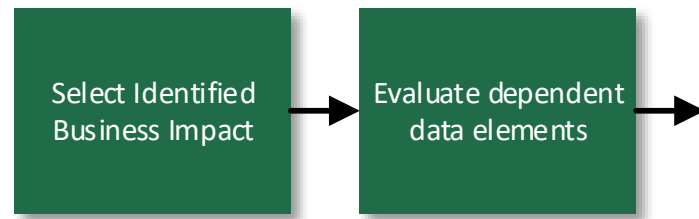
Data Element/Data Quality Metrics	<i>Trackability</i>
Patient Demographics	
Patient Events	
Laboratory Results	
Care Summaries	
Pathology Reports	
Radiology Reports	
Other Transcribed Reports	
Immunizations	

The Process for defining Data Quality Metrics



1. Select one of the identified critical business impacts.
2. Evaluate the dependent data elements, and data create and update processes associated with that business impact.
3. For each data element, list any associated data requirements.
4. For each data expectation, specify the associated dimension of data quality and one or more business rules to use to determine conformance of the data expectations.
5. For each selected business rule, describe the process for measuring conformance.
6. For each business rule, specify an acceptability threshold.

The Process for defining Data Quality Metrics



1. Select one of the identified critical business impacts.
2. Evaluate the dependent data elements, and data cre
3. For each data element, list any associated data requi
4. For each data expectation, specify the associated din
5. For each selected business rule, describe the process
6. For each business rule, specify an acceptability thresl

Analysis	Yes	No	How
<i>The process of translating data into meaningful information</i>			
Algorithms, formulas, and translation systems are valid and accurate			
Complete and current data is available			
Data impacting the application are analyzed in context			
Data are analyzed under reproducible circumstances			
Appropriate data comparisons, relationships, and linkages are displayed			
Data are analyzed at the appropriate level of detail or granularity			
Total	0	0	

Appendix 8: Data Governance Materials: Vermont Department of Health

Prenatal – Grade 12 Data Governance Mission, Purpose and Scope Statements

Vermont: Prenatal—Grade 12 Data Governance: Governance Manual - Draft

Best Practices in Implementation of Public Health Information Systems Initiatives to Improve Public Health Performance: The Vermont Experience



Prenatal – Grade 12 Data Governance Mission, Purpose and Scope Statements

- Data Governance Program Mission Statement

The mission of the Vermont Prenatal-Grade 12 Data Governance Program is to establish a federated data sharing system with key participating agencies in education, health and human services in order to inform policies and practices that support better outcomes for children and families. (adopted at April 28th meeting)

- Data Governance Program Purpose Statement

The purpose of the Vermont Prenatal-Grade 12 Data Governance Program is to ensure coordinated and effective governance for all aspects of cross-agency, cross-program data planning, sharing, maintenance, protection, access and use. (adopted at April 28th meeting)

- Data Governance Program Scope of Work

The scope of the Vermont Prenatal-Grade 12 Data Governance Program is to:

1. Establish sustained, productive cross-agency and cross-program partnerships; (adopted at April 28th meeting)
2. Establish standard operating principles and program scope; (adopted at April 28th meeting)
3. Establish the infrastructure, policies and processes for cross-sector, cross-program data sharing, analyses and reporting; (adopted at April 28th meeting)
4. Vet and prioritize guiding policy, research and data questions that align with program scope and research agenda; (adopted at April 28th meeting)
5. Engage the Data Governance Program Advisory Councils (i.e., the BBF State Advisory Council; BBF's Data & Evaluation Committee and the Agency of Education Statewide Longitudinal Data System Advisory Council) to receive their input and insight into priorities, analyses and reporting; (adopted at May 26 meeting)
6. Engage public and private subject matter experts and groups in data governance workgroups and/or individually in order to gather insight and feedback into proposed policies and processes prior to submitting recommendations to ECICT and senior agency leadership; (adopted at May 26 meeting with the caveat of either defining the ECICT or adding supplemental Org Chart)
7. Establish short- and/or long-term Data Stewards Workgroups, which may be comprised of both state agency and non-state agency subject matter experts as needed (e.g., database administrators, security and privacy experts, and researchers and analysts) to analyze tactical issues that arise, advise the Data Governance Council of concerns and recommended solutions, resolve issues within their domain, and implement policies and plans approved by senior leadership; (adopted at May 26 meeting)
8. Ensure transparent privacy, confidentiality and security standards and practices with regard to data storage, access, use and dissemination in accordance with all applicable state and federal laws and regulations; (adopted at April 28th meeting)
9. Identify sets of data elements to be gathered and shared from each data-sharing partner organization; (adopted at April 28th meeting)

10. Develop a mapping process to align data from multiple sources to a common data dictionary; (adopted at April 28th meeting)
11. Promote, coordinate and implement data sharing, storage, analysis, access and use protocols and processes that maximize efficiency and the security of each partners' data and resources based on the recommendations of the Data Stewards Workgroup and the Data Governance Council's review; (adopted at May 26 meeting)
12. Establish an end-user services model such as analytics portals as well as role-based and public reporting via linkages with public facing data portals, including Vermont's early childhood data reporting system, Vermont Insights, and agency websites; (adopted at May 26 meeting)
13. Develop an annual prioritized research agenda (adopted at May 26 meeting)
14. Develop processes for receiving, reviewing and responding to data requests; (adopted at May 26 meeting)
15. Establish annual review processes to evaluate and refine program scope, processes, and data and technology infrastructure to assure the program continuously meets stakeholder needs; (adopted at May 26 meeting)
16. Create mechanism for consideration and review of possible expansion of the Data Governance Program to include additional data sources (e.g., postsecondary, workforce, and Adult Health Outcomes) to facilitate analyses of long-term outcomes related to early childhood services; (adopted at May 26 meeting)
17. Establish program and committee charters that describe expected roles and responsibilities for Data Governance Program partner organizations and representatives, and that establish a review and enforcement process to address non-compliance with expectations. (adopted at May 26 meeting)
18. Identify and advocate for the necessary resources (e.g., staff, technology, funding) to support the work of the Data Governance Program, activities and products.
19. Attend to other items as requested. (adopted at May 26 meeting).

Vermont

Prenatal – Grade 12 Data Governance Governance Manual

Version 1.0

insert date when finalized

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REVISION HISTORY

Date	Name	Description
		Initial draft version 1.0

PRENATAL-GRADE 12 GOVERNANCE PROGRAM

Mission Statement

The mission of the Vermont Prenatal-Grade 12 Data Governance Program is to establish a federated data-sharing system with key participating agencies in education, health and human services in order to inform policies and practices that support better outcomes for children and families.

Purpose Statement

The purpose of the Vermont Prenatal-Grade 12 Data Governance Program is to ensure coordinated and effective governance for all aspects of cross-agency, cross-program data planning, sharing, maintenance, protection, access and use.

Scope of Work statement

The scope of the Vermont Prenatal-Grade 12 Data Governance Program is to:

1. Establish sustained, productive cross-agency and cross-program partnerships;
2. Establish standard operating principles and program scope;
3. Establish the infrastructure, policies and processes for cross-sector, cross-program data sharing, analyses and reporting;
4. Vet and prioritize guiding policy, research and data questions that align with program scope and research agenda;
5. Engage the Data Governance Program Advisory Councils (i.e., the Building Bright Futures (BBF) State Advisory Council; BBF's Data & Evaluation Committee and the Agency of Education Statewide Longitudinal Data System Advisory Council) to receive their input and insight into priorities, analyses and reporting;
6. Engage public and private subject matter experts and groups in data governance workgroups and/or individually in order to gather insight and feedback into proposed policies and processes prior to submitting recommendations to the Early Childhood Interagency Coordinating Team (ECICT) and senior agency leadership;
7. Establish short- and/or long-term Data Stewards Workgroups, which may be comprised of both state agency and non-state agency subject matter experts as needed (e.g., database administrators, security and privacy experts, and researchers and analysts) to analyze tactical issues that arise, advise the Data Governance Council of concerns and recommended solutions, resolve issues within their domain, and implement policies and plans approved by senior leadership;
8. Ensure transparent privacy, confidentiality and security standards and practices with regard to data storage, access, use and dissemination in accordance with all applicable state and federal laws and regulations;
9. Identify sets of data elements to be gathered and shared from each data-sharing partner organization;

10. Develop a mapping process to align data from multiple sources to a common data dictionary;
11. Promote, coordinate and implement data sharing, storage, analysis, access and use protocols and processes that maximize efficiency and the security of each partners' data and resources based on the recommendations of the Data Stewards Workgroups and the Data Governance Council's review;
12. Establish an end-user services model such as analytics portals as well as role-based and public reporting via linkages with public facing data portals, including Vermont's early childhood data reporting system, Vermont Insights, and agency websites;
13. Develop an annual prioritized research agenda;
14. Develop processes for receiving, reviewing and responding to data requests;
15. Establish annual review processes to evaluate and refine program scope, processes, and data and technology infrastructure to assure the program continuously meets stakeholder needs;
16. Create a mechanism for consideration and review of possible expansion of the Data Governance Program to include additional data sources (e.g., postsecondary, workforce, and Adult Health Outcomes) to facilitate analyses of long-term outcomes related to early childhood services;
17. Establish program and committee charters that describe expected roles and responsibilities for participating Data Governance Program partner organizations and representatives, and that establish a review and enforcement process to address non-compliance with expectations;
18. Identify and advocate for the necessary resources (e.g., staff, technology, funding) to support the work of the Data Governance Program, activities and products; and
19. Attend to other items as requested.

PURPOSE OF A DATA GOVERNANCE PROGRAM

According to the Project Management Institute (PMI) Standard for Program Management: “governance is defined as the process of developing, communicating, implementing, monitoring, and assuring the policies, procedures, organization structures, and practices associated with a given program. Governance is oversight and control.” The mission of a governance program is to establish management and accountability protocols and clarify the operational chain of command. Additionally, the governance program sets out accountability processes for identifying and addressing issues relating to noncompliance with those protocols or the chain of command.

A strong *data* governance program is specifically designed to provide oversight that ensures confidentiality, integrity, and availability of the data by reducing data security risks due to unauthorized access or misuse of the data.

Vermont’s Prenatal-Grade 12 data governance program provides the overarching management structure within which all participating partners and staff operate to make sound decisions about the program’s services, products, policies and processes. Governance protocols are designed to equip executive decision-makers with information essential to effective strategic decision-making relating to operating the Prenatal-Grade 12 data-sharing program in the best interests of Vermont’s children and families.

Multiple Layers of Data Governance

Data governance programs apply to programs, projects and/or data management. A successful data governance program demands the vision, leadership and cooperation of people at all levels of implementation: leadership, project managers, program staff, and agency subject matter experts. The commitment of the leadership team is essential for the success of a data governance program. The scope and goals of governance activities differs for programs, projects and data management, as outlined below:

Program Governance provides a structure and framework for goal setting, strategic planning and decision-making. The overarching governance plan identifies key roles and responsibilities for each organization and the people involved in the program. It identifies the key stakeholders involved in program management and who is authorized to approve program activities and priorities.

Project Governance provides a framework for decision-making around specific projects, usually within a larger program or organization. Projects have specific start and end dates and are typically focused on specific content, outcomes and deliverables to be completed on time and on budget. Project governance decisions are often focused on scope, schedules, resources and technical tasks.

Data Governance addresses issues such as data management and policies, data quality, business process management, and risk management surrounding the handling of a data system. Data governance sets and enforces enterprise-wide data standards, common vocabulary, and reports. It enables management to more easily integrate, synchronize and

consolidate data from different programs or sectors and across organizations. Data governance ensures that data are:

- Reliable
- Consistent
- Valid
- Complete
- Available to those with a legitimate need for, and authority to access, the data
- Unavailable to those without a legitimate need or authorization for it

Data governance is *NOT* data cleansing or extract, transform and load data activities; data warehousing; database design; or project management. While each of these is affected by or related to the data governance program, data governance addresses more than these disciplines and each of these areas has facets beyond data governance, such as technological and architectural solutions.

Change Management

Governance programs for long-term programs and data management also typically develop processes to standardize the methods and procedures to accommodate future changes. For example, governance committees typically make decisions about changes to services, system functionality, and data definitions. Change management procedures introduce standard and methodical policies and procedures for requesting, documenting, testing, approving and implementing system changes and dealing with emergency changes.

PRENATAL-GRADE 12 DATA GOVERNANCE

In Vermont there is no single organization that has been designated to centralize and coordinate data to be shared between education, health and human services for the purposes of evaluating the relationships between early childhood programs and long-term educational outcomes. The Race to the Top Early Learning Challenge grant, received in 2014, has enabled state agencies, early childhood programs and other stakeholders to come together to form the Prenatal-Grade12 Data Governance Program to build a cross-agency, cross-program data sharing and analysis partnership to address early childhood and K-12 policies, programs and outcomes. This data governance program will oversee sophisticated data sharing and technology solutions, multiple regulations guiding data privacy and security, and detailed data sharing agreements between a state agencies and early childhood programs.

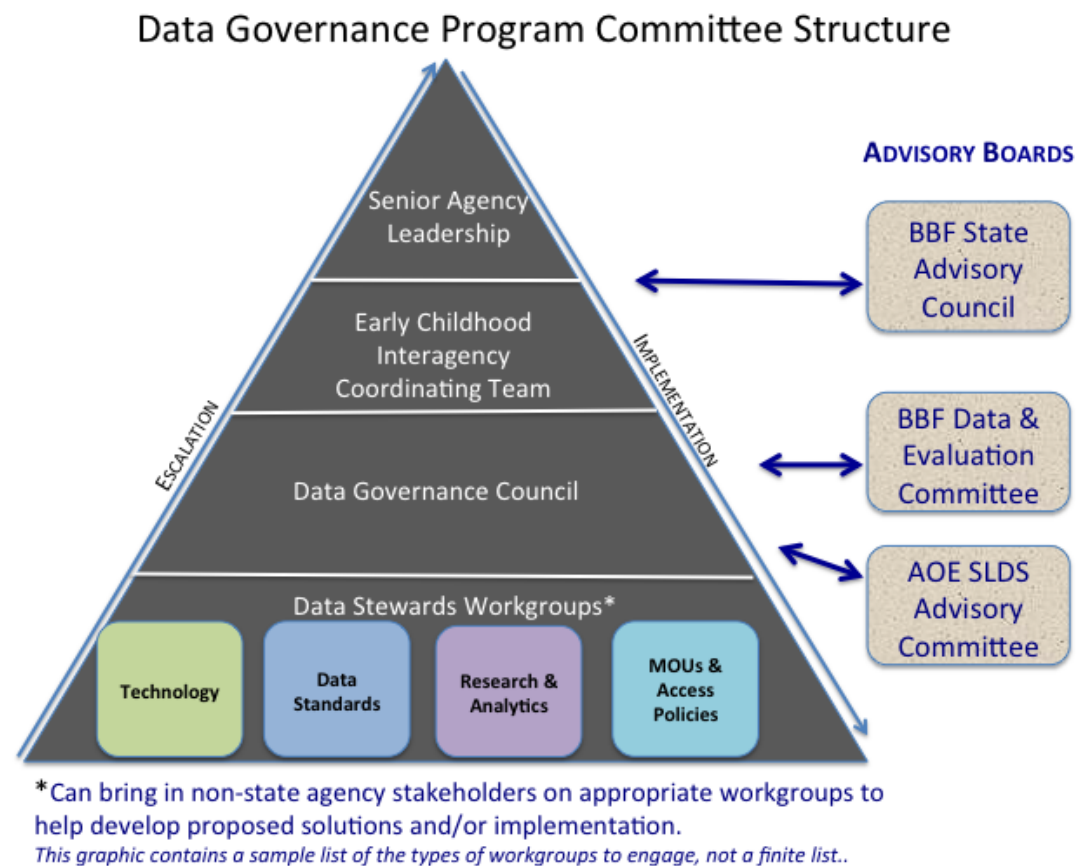
The goal of the Prenatal-Grade 12 Data Governance Program is to establish coordinated cross-agency, cross-program data-sharing and analysis processes as a long-term sustainable program that coordinates data storage, access, use and dissemination activities that will be used to provide actionable information to policymakers, state agencies, families and program providers. The effectiveness of cross-agency, cross-program analyses that span early childhood and K-12 data depends on the effective and efficient merging and analyzing data from multiple distinct and disparate source systems.

Governance Committee Structure and Responsibilities

The Prenatal-Grade 12 Data Governance Program benefits from planning and oversight via a hierarchy of governance and advisory committees, as displayed in Figure 1. This structure was vetted with multiple stakeholders from August to October 2015 and was approved by the ECICT in November of 2015.

The **Executive Team** is comprised of senior agency leadership from each partner agency. Ultimate authority for the Vermont Prenatal-Grade12 Data Governance Program rests with the senior official at each participating partner organization. Ongoing strategic planning and policy guidance is provided via the Early Childhood Interagency Coordinating Team (ECICT), which is comprised of senior agency staff from partner organizations. ECICT receives direction from senior agency leadership and provides direction to the Data Governance Council. ECICT is responsible for ensuring that data governance efforts address all relevant and mission-critical needs of the Prenatal-Grade 12 data coordination and sharing program. The executive team, including both senior officials and ECICT, manages cross-program/cross-agency data governance as a united effort to help children and families in Vermont rather than as a set of unconnected agency-specific projects. It also obtains needed funding and resources and maintains final authority and responsibility for the program.

Figure 1. Prenatal-Grade 12 Data Governance Program Committee Structure

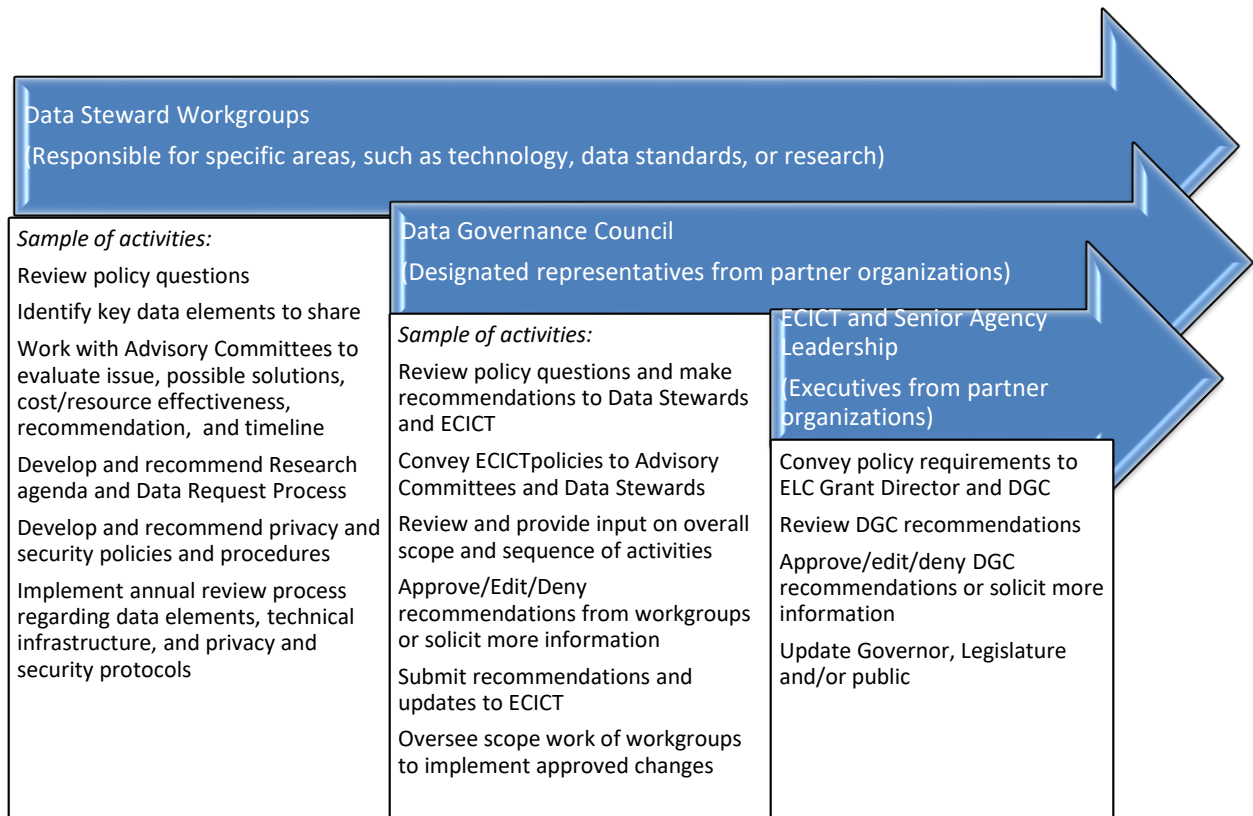


The **Data Governance Council (DGC)** is comprised of 1-3 designated representatives from each participating partner organization, with the ELC Grant Director serving as the facilitator. The DGC has a representative from Building Bright Futures (BBF)'s Vermont Insights, the Governor's Office, and the Department of Information and Innovation as ex officio members to help with coordination and collaboration. The state agency members represent data collection owners, research staff and/or Information Technology (IT) staff who have the ability, authority and responsibility to represent their agency data concerns. They may be referred to as data owners as they represent the department or program that owns particular data collections and reporting requirements. The DGC will implement the policies of the executive leadership team. It reviews, approves, and oversees the scope of work and data governance program activities, along with processes and procedures developed through the governance process. The DGC, following guidance from the executive team, also prioritizes data governance efforts and communicates with internal and external stakeholders. It identifies staff (data stewards) to participate on topic-specific workgroups that are tasked with developing processes and procedures related to cross-agency data storage, access, use and dissemination.

Data stewards are the program or division representatives who are responsible for managing specific agency data collections, research activities or facets of IT (e.g., database administrator, security and privacy technology, business intelligence tools). The data stewards workgroups analyze any tactical issues that arise, advise the DGC of recommended solutions, resolve technical issues within their domains accordingly, and implement the policies and plans approved by the DGC and executive team. Data Stewards workgroups may be convened on a short- or long-term basis, as necessary, and they may include subject matter experts from outside state agencies as they analyze solutions and develop recommendations.

Figure 2 displays the primary responsibilities for the three key data governance committees. Once the DGC creates a Data Steward Workgroup to address a specific activity (e.g., identify key variables to share and map to a central data standard), the workgroup develops a proposal for how to implement a solution and submits that proposal to the DGC. Once the DGC has reviewed the proposal, it will request changes from the Data Steward Workgroup or approve the proposal as is. Once approved, the DGC will send to the ECICT for review and approval. The ECICT may request changes or approve the proposal. Once approved by the ECICT, ECICT members will inform their respective Senior Agency Leadership of the proposal or request their review and final approval.

Figure 2. Governance Committee Responsibilities



Data Governance Program **Advisory Committees** (i.e., the BBF State Advisory Council, BBF Data & Evaluation Committee and AOE State Longitudinal Data System Committee) will bring representation

from local providers, regional councils, non-profits and philanthropy. The advisory committees will provide ongoing review, feedback and input on legislative, programmatic or data-related issues and support the public information efforts of the Prenatal-Grade 12 data governance program. The advisory committees will also advise on the prioritization of reporting and research activities that meet the information needs of policymakers and practitioners. Additional ad hoc advisory committees may be established as needed on a short- or long-term basis with a variety of external subject matter experts to address particular issues.

Example of Prenatal-Grade 12 Committee Process

For example, a stakeholder wants to know how students who participated in Head Start perform on the Kindergarten Readiness Survey and on Grade 3 Reading and Mathematics tests. The answer to this question requires data from multiple sources, including Head Start program data and data from the Agency of Education Statewide Longitudinal Data System. To answer the question, the DGC needs to engage staff and resources to review the data elements needed from each data source, and the programs must also have an executed Memorandum of Understanding (MOU) that addresses the elements to be shared, the uses of those elements, who can access and analyze the data, and how and with whom the information will be shared. The DGC will need to find ways to engage different types of subject matter experts; either through ad hoc or formal data steward workgroups to develop the data sharing and analyses plans and ensures a workable MOU that meets each agency's needs and concerns. Once the plans are approved, the DGC can take them to advisory committees for review and discussion and to the ECICT for review and approval.

Policy questions that require cross-agency, cross program analyses can come from any stakeholder in Vermont, including but not limited to state agencies, legislators, or program providers. Policy questions that will be addressed by the Prenatal-Grade 12 Data Governance Program are vetted and prioritized through the review and discussion by the governance program DGC and ECICT committees, as well as the program's Advisory Committees to ensure input from external stakeholders.

Participating Partner Organizations

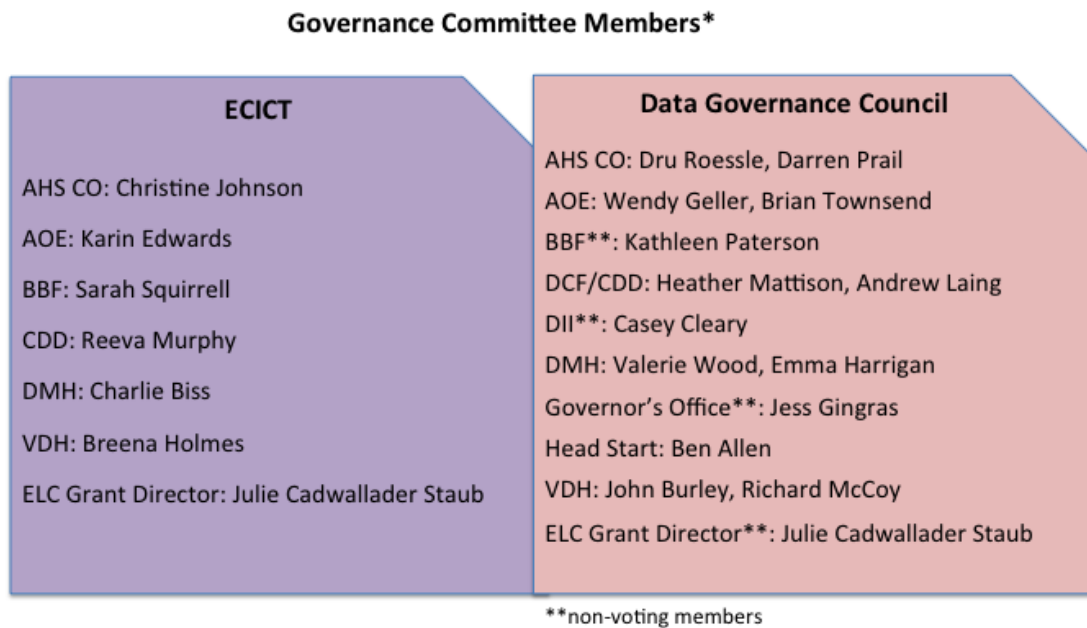
State agency representatives, advisory group members and subject matter experts from the field will be efficiently and effectively engaged in governance program activities over the life of the program. Figure 3 identifies the state agencies involved in the Prenatal-Grade 12 Governance Program and lists, and which personnel participate in each governance committee.

Data Governance Program Coordination

The ELC Grant Director provides functional and organizational infrastructure support to the Prenatal-Grade 12 Data Governance Program and will serve initially as the Data Governance Coordinator. The Data Governance Coordinator makes decisions as necessary to fulfill the data program's mission and

serves as the liaison to the ECICT. When the program is fully operational, a Data Governance Coordinator may need to be hired to be responsible for the day-to-day operation of the program and provide support to data governance council and committee meetings, including agenda development and dissemination of meeting minutes. The Data Governance Coordinator will work hand-in-hand with all governance committees to execute the policies and activities as directed by the executive team.

Figure 3. Prenatal-Grade 12 Governance Program Committee Members



* One vote per organization, not per person

Data Governance Policy

Prenatal-Grade 12 Data Governance Program policies require each participating partner organization to:

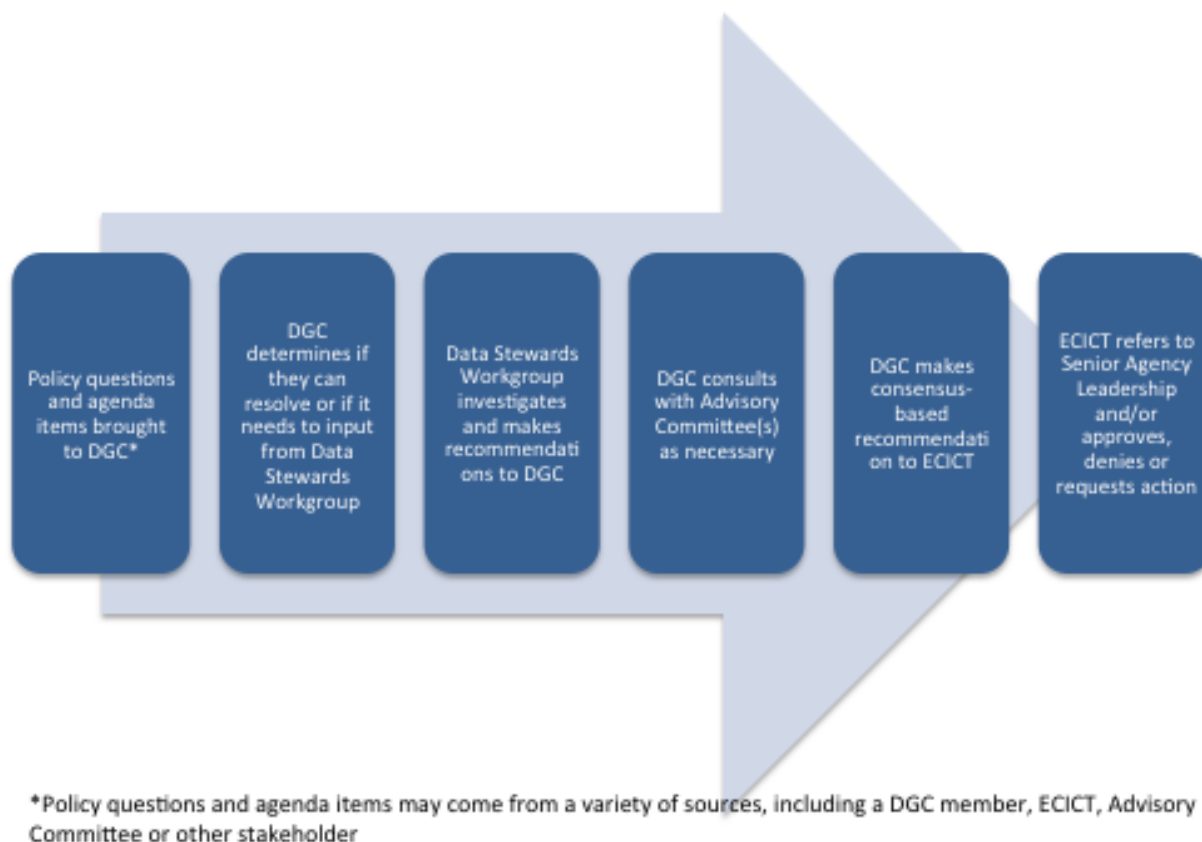
- **Participate in the statewide Prenatal-Grade 12 data governance program:** Representatives from partner organizations will participate in the governance program by serving on committees and/or providing input when asked. Committee members will represent their organization and have the authority and responsibility to make decisions on behalf of their organization for the benefit of the Prenatal-Grade 12 data governance program statewide.
- **Assign Subject Matter Experts (SMEs) to participate in Governance Committee meetings:** Partner organizations will designate SMEs from their respective organizations with sufficient expertise and give them the authority and responsibility to make recommendations to the governance committees and Governance Coordinator on preferred solutions, processes or procedures.

PRENATAL-GRADE 12 DATA GOVERNANCE PROCESS

The governance program requires established processes with regard to decision-making, organizational responsibilities and documentation support. The governance program will need to establish review and escalation processes for addressing policies and processes. These processes will determine who reviews what and how issues will be dealt with when consensus is not achieved in workgroups or committees. It is also important that the governance program has a plan to engage subject matter experts through workgroups and Advisory Committees to ensure robust review and sound decision-making.

Figure 4 summarizes the general workflow through the data governance program.

Figure 4. Workflow Process for Addressing Agenda Items



Over time, questions about early childhood or education data systems or program effectiveness may be sent to participating partner organizations or the Data Governance Coordinator for referral to the DGC. The questions may be accepted as critical policy or research questions for which cross-program analyses and reports are produced, or the DGC may decide to refer the question elsewhere if deemed out of scope of the Prenatal-Grade 12 data governance program. If accepted for review and discussion by the DGC, the council will determine the best process for addressing the issue.

To build on the previous example (see page 11), a stakeholder wants to know how students who participated in Head Start perform on the Kindergarten Readiness Survey and on Grade 3 Reading and

Mathematics tests. The answer to this question requires data from multiple sources, including Head Start program data and data from the Agency of Education Statewide Longitudinal Data System, so the DGC adds this question to its list of reports to produce. A question about the number of children participating in Head Start programs over the last three years would not be accepted by the DGC, since the answer does not require data from multiple state agencies or programs. To answer the first question, the DGC needs to engage staff and resources to review the data elements needed from each data source, including their availability, whether or not data elements from different sources can be matched and used in cross-program analyses. The programs must also have an executed Memorandum of Understanding (MOU) that addresses the elements to be shared, the uses of those elements, who can access and analyze the data, and how and with whom the information will be shared. Consequently, the DGC will need to find ways to engage different types of subject matter experts; either through ad hoc or formal data steward workgroups to develop the data sharing and analyses plans and ensures a viable MOU that supports the data sharing, analyses and dissemination. Once the plans are approved by the DGC for addressing data sharing, analysis and reporting, the DGC can take them to advisory committees for review and discussion and to the ECICT for review and approval.

Data Governance Program Decision-Making Process

Decisions are made by consensus (unanimity):

- If consensus is not reached, the matter at hand is addressed through negotiation, formal vote or escalated to the next level of governance.
- Lack of consensus is determined when a member or their designate objects to a proposed action or decision. In the event of non-consensus, each partner organization has one vote to be cast by its respective representatives or designates.
- Each Governance committee member is required to send a delegate to vote on their behalf if they are not able to attend a meeting. In the event of the absence of a governance committee member authorized to participate in consensus or vote, and if a delegate was not sent to represent that agency, the partner organization agrees to adhere to the decision made by the group, unless there were extenuating circumstances for the absences. In that case, the partner organization may be given an opportunity to request reconsideration of the decision reached in their absence.
- At all levels of the decision-making process, negotiation and modifications to the proposed decision will occur in an effort to reach consensus.
- If consensus is not reached in ECICT or by senior agency leadership, no action on the matter will be taken and a new proposal may be developed by the DGC.
- Ex officio members—those members who do not own data--shall provide input to committees or partners but do not have a vote.

Decisions are documented as made and distributed to partner agencies:

- An agenda detailing decisions to be made at a meeting, and any supporting documentation, is distributed to partners at least three days in advance of a meeting.
- Items for action at a meeting must be distributed at least seven calendar days in advance.

- Meeting notes summarize decisions made, votes or abstentions of each partner.

Each governance committee member is responsible for understanding the level of authority delegated to him or her by the agency executive and communicating in a timely fashion to their committee and/or the governance coordinator when a decision is to be made outside the scope of his or her authority. For example, DGC members would likely refer legal discussions to agency general counsel or create a workgroup consisting of agency legal counsel.

Data Governance Operating Procedures:

- Each governance committee will include at least one representative from key partner organizations, but there is only one vote per organization.
- DGC members will consist of designated representatives from participating partner organizations, and the chair and vice-chair are elected.
- DGC decisions and recommendations are submitted to the ECICT for final approval.
- Issues that cannot be resolved in the DGC meetings will be escalated to the ECICT.
- Issues that cannot be resolved in the Data Steward Workgroups will be escalated to the DGC.
- Governance committees may solicit input from other committees, Advisory Committees or other external stakeholders not already participating in the Governance Program.
- Data Steward Workgroups make recommendations to the DGC, but do not have the authority to make binding decisions on behalf of the Prenatal-Grade 12 Governance Program.
- Advisory Committees make recommendations in response to requests from any governance committee, and the Governance Coordinator takes those recommendations to the DGC for consideration and decision-making, as needed.
- Members of each committee are required to attend regularly scheduled meetings or send a designee in member's place, and to respond to all action items in a timely manner.
- Consistently inactive members will be identified and asked to resign, so that another representative from the same agency or organization can participate.
- Members of all committees are responsible for reviewing all materials prior to meetings and participating in all data governance discussions with an enterprise-wide focus for the governance program, not just as a representative of a participating partner organization.
- Members will serve at the pleasure of the ECICT and Senior Agency leadership.

Documentation Support by the Data Governance Coordinator

To the extent possible:

- Agendas will be distributed five days in advance of meetings and clearly identify items for action, discussion, or for information only.
- Ensure that meeting notes are taken and distributed to group members and interested others within one week of the meeting.
- Action items listing responsible parties will be documented in the meeting notes.

- All documents slated for review will be delivered electronically to group members five days in advance of the meeting.

APPENDIX A: GOVERNANCE PROGRAM OPERATING PRINCIPLES

Insert operating principles here once developed



July 2012

Best Practices in Implementation of Public Health Information Systems Initiatives to Improve Public Health Performance: The Vermont Experience

In collaboration with the National Association of County and City Health Officials and the Centers for Disease Control and Prevention, NORC at the University of Chicago is compiling a series of best practice reports highlighting successful practices in public health information systems and health IT on the state and local levels. The findings and conclusions in this document are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention. This case study was supported by funds made available from the Centers for Disease Control and Prevention, Office for State, Tribal, Local and Territorial Support, under Grant #3U38HM000449-04S2, CFDA # 93.283.

BACKGROUND

The Vermont Department of Health (VDH) serves 626,000 Vermont residents, many of whom live in rural areas. The state-wide public health system in Vermont is centralized; all local public health professionals in Vermont are employed by the state. VDH is housed within the superagency, the Agency of Human Services (AHS), which includes, among others, the Department for Children and Families, Department of Corrections, and the Department of Vermont Health Access, which administers Medicaid. Services provided by VDH include child and family services such as Women, Infants, and Children (WIC), epidemiology, vital records, chronic and communicable disease services, emergency response, environmental health, mental health, and substance abuse. A dedicated IT department handles VDH's full suite of software development and maintenance needs.

The state and VDH have worked to align their priorities, which are informed by national initiatives such as the Patient Protection and Affordable Care Act (ACA). Vermont's health initiatives have supported and emphasized prevention and performance improvement. For example, in May of 2011, Governor Peter Shumlin signed a bill creating a single-payer insurance plan. The bill includes opportunities for supporting public health, such as potentially increasing access to preventive services and contains language urging the necessity of seeking public health accreditation for the state health department. At the same time, VDH is prioritizing efforts to

support other state initiatives, particularly initiatives related to health information technology (HIT) such as Meaningful Use and health information exchange (HIE).

VERMONT'S APPROACH TO HEALTH IT

While the role of public health in Vermont's health reform initiatives is still being defined, state and VDH leadership feel strongly that HIT will be necessary to support multiple state initiatives. Two of VDH's major HIT initiatives are designed to support Meaningful Use and HIE. Additionally, in keeping with the aims of the ACA, VDH is developing a dashboard to improve performance management within the Department.

VDH has approached these initiatives as it approaches all of its initiatives – in a spirit of collaboration. In addition to collaborating with state partners, including other members of the HIE initiative, VDH works to coordinate between its different agencies. For example, representatives from multiple programs including vital statistics, immunization, childhood metabolic screening, and others met to discuss their respective and collective IT system needs. VDH also collaborates with external state and national partners including Performance Improvement Managers (PIMs) throughout New England. One of the factors facilitating collaboration is the small size of both the Vermont population and the governmental workforce.

HEALTH IT STRATEGIES

Dashboard for Performance Management

As part of their involvement in the National Public Health Improvement Initiative (NPHII), VDH is in the process of developing a dashboard to aid performance management. Healthy Vermonters 2020 – the foundation of the state health assessment – was the jumping off point for Vermont's dashboard, which will allow users to visualize population health changes and use the information to plan or adjust health programs accordingly. The process has been facilitated by the relatively new AHS superagency leadership, which, along with the recent activity around the prioritization of preventive and public health initiatives including the single-payer insurance plan, has encouraged and supported the dashboard project.

VDH is also collaborating with other New England performance improvement managers in order to share best practices, problem solve, and identify economies of scale. VDH staff members report that performance managers throughout the country are interested in creating nationally compatible systems to compare health outcomes and performance across departments. As such, it would also be optimal to design and implement systems that are technologically interoperable. Currently, VDH staff members have completed the procurement process for a dashboard product and plan to begin implementation in the fall of 2012.

Health Information Exchange and Meaningful Use

As part of their participation in the state HIE and Meaningful Use initiatives, VDH is working towards implementing Health Level 7 (HL7) interoperability in the immunization registry to facilitate data exchange, specifically with providers, and establishing an electronic laboratory exchange system between the state lab and Vermont's hospitals. Both initiatives also support the state's goal of improving health care, enumerated in the single-payer plan, in addition to improving public health performance.

Immunization Registry HL7 Compatibility

To be eligible for Meaningful Use compliance incentives, providers must choose from one of three public health activities. One of these activities requires submitting immunization information to the state health department.¹ To facilitate this exchange, VDH is upgrading their registry to use Health Level 7 (HL7) standard 2.5.1 required by Meaningful Use.² The immunization registry is part of the department's integrated data system that includes the child hearing screening registry, childhood metabolic screening, birth registry, and child lead registry.

In addition to Meaningful Use requirements, the new data exchange system is expected to decrease provider administrative burden and improve the quality of clinical care. The current IT systems necessitate health providers entering health data twice – once into their EHR systems and once into the state system. The upgraded registry will be interoperable with clinical systems, thereby decreasing administrative burden. This information exchange will also allow physicians to visualize a broader dataset which will provide them with a richer understanding of their patients, and may therefore improve clinical outcomes.

Laboratory Exchange

VDH's laboratory exchange supports the state's HIE initiative to build a comprehensive, interoperable health IT infrastructure. The laboratory exchange initiative will allow hospitals to order laboratory testing from the state Public Health Laboratory and receive the results electronically, neither of which can currently be conducted by hospitals. Like the immunization registry initiative, laboratory exchange will decrease administrative burden for providers and public health personnel. Additionally, it will decrease the length of time between submission of a request and the availability of results.

WHAT HAS BEEN ACCOMPLISHED?

Successes

Regardless of funding source, all health IT positions within VDH are housed in the departmental IT office. Implementing this approach has increased capacity in the IT department and provided departments and programs access to the resources of an entire IT team rather than the single skill set that a sole IT staff member would be able to provide. This collaborative approach to health IT will help VDH staff develop more effective and informed IT systems while also helping align the Department of Health with the state agency's overarching strategies and initiatives. VDH's emphasis on participation from stakeholders has helped staff plan effective solutions that will benefit initiatives across VDH and the state, as well as other performance improvement managers across the nation.

VDH has taken advantage of the funding sources that have been available for health IT initiatives. Vermont is currently funding the aforementioned dashboard with NPHII funding and the immunization registry initiatives with Immunization funding from the CDC. These funding sources have enabled the state to work towards electronic information exchange between state registries and provider EHR systems. VDH's investment in health IT strategies has not only decrease administrative burden but has also provide physicians with an increasingly comprehensive understanding of their patients' health. VDH is also leveraging existing resources, such as Healthy Vermonters 2020, to help inform their dashboard system and encourage alignment with the state's priorities.

¹ "Medicaid and Medicare EHR Incentive Program: Meaningful Use Stage 1 Requirements Overview." *EHR Incentive Program Overview*. Centers for Medicare and Medicaid Services, n.d. Web. 12 Dec. 2011. Available at: www.cms.gov/EHRIncentivePrograms/.

² "Vermont Implementation Guide for HL7 Immunization Messaging, Version 1.7." Vermont Department of Health. 15 May 2012. Available at: <http://www.vitl.net/sites/default/files/documents/support/VermontHL7ImmunizationImplementationGuide.pdf>.

Additionally, VDH has benefitted from a widespread support for public health as a result of Vermont's health reform legislation, which has helped facilitate planning for health IT strategies in concert with other VDH staff and departments. VDH's commissioner has also made it a priority to bring public health to the table.

Challenges and Barriers

As a centralized governmental public health system, VDH receives all of its funding from federal sources and general state dollars, which leaves VDH particularly vulnerable to cuts in federal funding. Most public health IT positions are supported through CDC funding, which tend to be categorical and narrowly targeted to immediate programmatic needs. This poses challenges in developing and maintaining IT infrastructure. Few sources have been designated expressly to building IT infrastructure.

In addition to perennial funding challenges, there have been cuts in the Public Health Emergency Preparedness grant that have the potential to impact the six grant-funded IT positions at VDH. Additionally, Vermont's NPHII funding was decreased by nearly \$500,000 between FY2010 and FY2011.³ Because supplementary state funding is unlikely, VDH staff members are wary of the possibility of additional budget cuts and expressed concern about their ability to maintain IT staff should VDH funding further diminish.

While VDH's current public health IT staff works effectively with VDH directors and program managers, recruiting additional qualified IT staff and informaticists remains challenging. For instance, VDH was unable to fill five IT vacancies for a period of time. Several of those positions have since been filled as a result of reclassifying the position to a lower pay grade and hiring individuals with little or no experience. A significant part of the recruiting challenge is the dual skill set necessary for public health IT professionals; these individuals need both public health and technological expertise to provide effective technology interfaces for public health programs. Staff explained how relatively few applicants possess expertise in both areas.

In addition to the challenges the VDH might ordinarily face in finding qualified individuals, Vermont has the added barrier of recruiting from a small population, coupled with a lack of graduate public health "feeder" programs. As a result, VDH must either recruit from out-of-state or send staff out-of-state to study public health as well as informatics. Currently, VDH is working to reduce recruitment difficulties by identifying compelling messages to encourage students to pursue careers in public health. VDH staff members also noted that being able to determine the correct size of a public health IT department may be helpful in recruiting efforts because there is no established public health IT staffing metric.

Outside of funding and workforce challenges, VDH is facing challenges associated with identifying individuals in various registry systems. Currently, only the registries associated with the Vermont Shared Public Health Information Exchange (SPHINX) system – consisting of the immunization registry, electronic birth and death registries, blood lead results, newborn hearing screening, metabolic screening, and WIC⁴ — attribute a unique identifier to an individual. Because Social Security numbers are unavailable to VDH registries, individuals must be identified by a combination of personal information fields including gender and date of birth. Without a unique identifier, the chances of having duplicate or mismatched entries in a dataset increases. Such errors have the potential to impact the performance of VDH as well as external partners who rely on registry data, such as health care providers. In order to address this challenge, VDH periodically cleans the data and conducts training for all staff members who enter vital records data to improve data quality.

³ "National Public Health Improvement Initiative: Vermont Department of Health." *Centers for Disease Control and Prevention*. N.p., 2 Sept. 2011. Web. 12 Dec. 2011. Available at: <http://www.cdc.gov/ostlts/nphii/vermont>.

⁴ Hooley, Cindy, and Richard McCoy. *Applying the CDC NEDSS Model to Vital Records*. San Diego, CA: Vermont Department of Health, 2006. Available at: <http://www.naphsis.org/index.asp?bid=944>.

Looking Forward

In the immediate term, obtaining and retaining a full IT support staff will remain a significant challenge for VDH to overcome. In the long-term, VDH will look to ensure that their work continues to meet the needs of their target populations and that their health IT systems are able to assist them in illustrating that those needs are being met. Through efforts to eliminate siloed systems, as well as increasing interoperability among systems that must remain independent, VDH looks to streamline their public health IT efforts while continuing to ensure that they are able to access the data they need.

ADVICE FOR HEALTH DEPARTMENTS

- House public health IT positions in a departmental IT office to allow programs access to a broader range of IT skills.
- Establish metrics for the optimal size and configuration of a public health IT department to help identify gaps in IT personnel size and to better target the IT recruiting process.
- Collaborate with other health departments on initiatives of national importance to provide a valuable opportunity to share best practices and lessons learned, as well as identify potential economies of scale.

FOR MORE INFORMATION

Vermont Department of Health:

- <http://healthvermont.gov/>

Vermont Immunization Registry:

- <http://healthvermont.gov/hc/IMR/index.aspx>

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For additional information about this project, please contact Alana Knudson, PhD, at NORC at the University of Chicago (knudson-alana@norc.org) or Michelle Chuk Zamperetti at NACCHO (mzamperetti@naccho.org).

Appendix 9: Health Data Approaches: Washington and Michigan



Presentation of Health Data Approaches in Washington and Michigan

Prepared for the
Data Warehousing Subcommittee
Health Data Infrastructure Work Group
Vermont Health Care Innovation Project

Rachel Block, HIT Consultant
July 14, 2016

1

STONE ENVIRONMENTAL

AIM

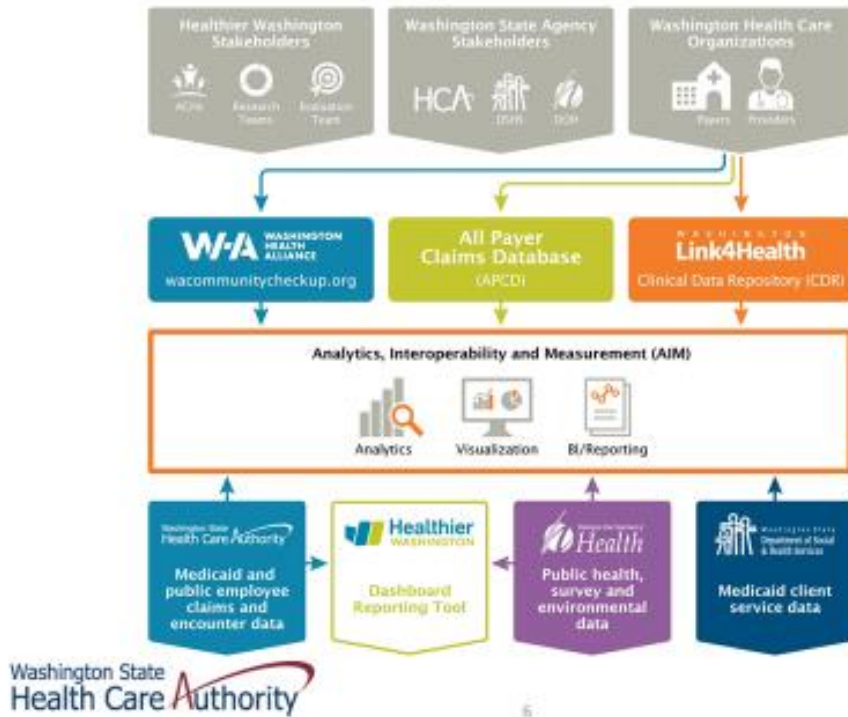


- Analytics, Interoperability and Measurement
 - Analytic tools (data → information)
 - Interoperable systems, and
 - Standardized measurement strategies
- Supports payment redesign models
- Works across state agencies – breaking down silos
- Is a key support mechanism to achieving better health, better care and lower costs

Washington State
Health Care Authority

4

AIM Strategy: Interconnections



AIM Governance and Stakeholding

- **HCA:**
 - Clinical Data Repository (CDR)
 - HCA Decision Support
 - Heathier Washington (ACHs, payment redesign models, operations)
 - ProviderOne data team (Medicaid data)
 - Public Employee Benefits data team
 - Healthcare Information Technology (HIT)

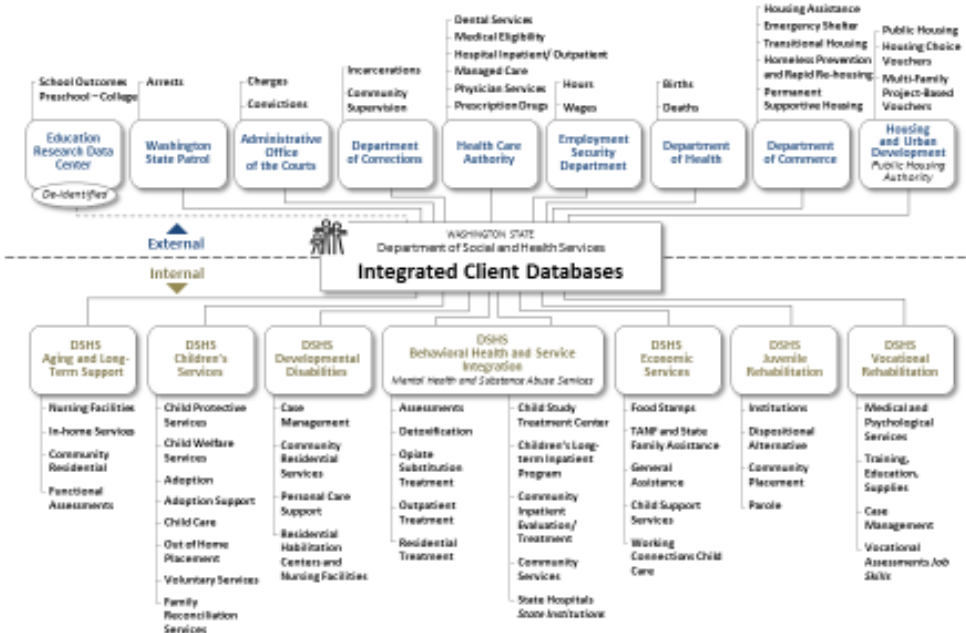
- **State government partners:**
 - Department of Health (DOH)
 - Department of Social and Human Services (DSHS)
 - Office of Financial Management (OFM)
 - Office of the Chief Information Officer (OCIO)

Tools bring value-added dimensions

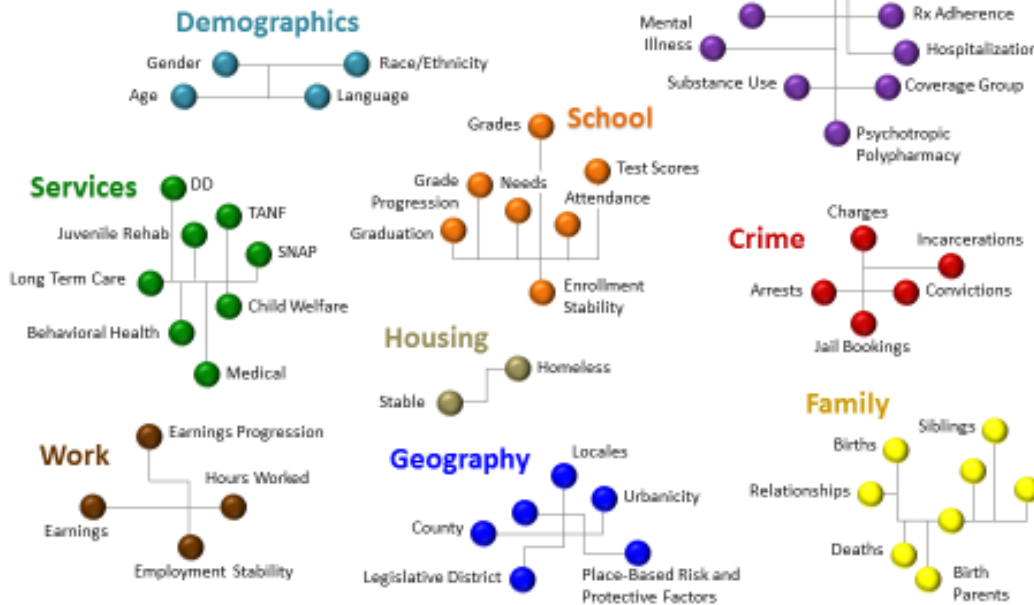


Washington State Health Care Authority

RDA's Integrated Social Client Databases



Creating Analytically Meaningful Measurement Concepts



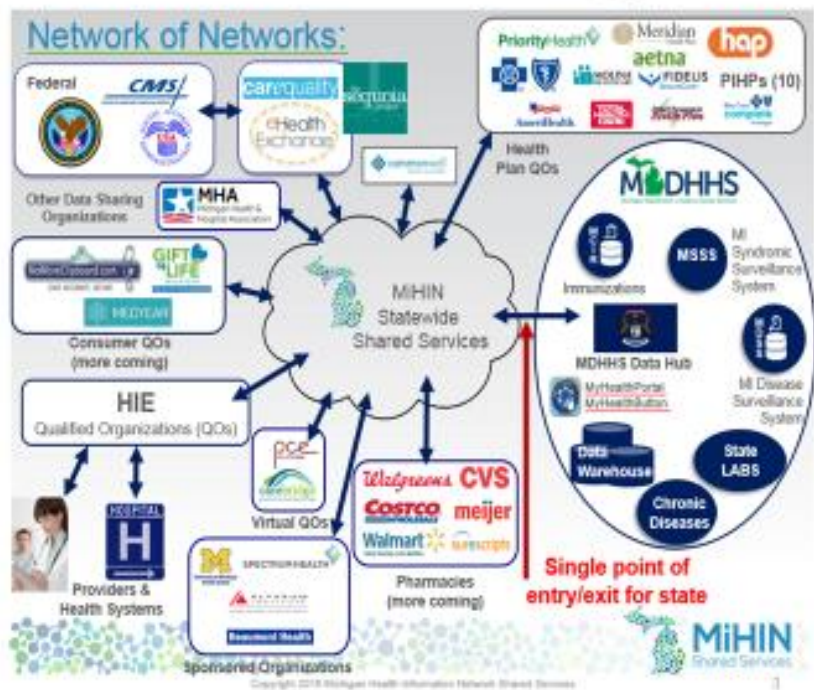
Data Integration Challenges

- ▶ Building and maintaining trust among data owners
- ▶ Establishing effective governance structures
- ▶ Maintaining an analytical data infrastructure in a constantly evolving policy, program and IT system environment
- ▶ Recruiting and retaining state agency staff with analytical expertise
- ▶ Finding contractors with program/policy subject matter expertise and familiarity with state agency data systems
- ▶ Data are plentiful – analytical skills informed by policy and program expertise are scarce

PRISM: Rapid-Cycle Predictive Modeling and Data Integration in a Clinical Decision Support Web Application

- ▶ **Data sources:**
 - Medical, mental health and LTSS services from multiple IT systems
 - Medicare Parts A/B/D data integration for dual eligibles
 - LTSS functional assessments
 - Housing status (including some local jail stay data) from living arrangement data gathered through the eligibility determinations
- ▶ **Data refreshed on a weekly basis for the entire Medicaid population**
- ▶ **Dynamic alignment of patients to health plans and care coordination organizations, with global patient look-up capability for providers**
- ▶ **Rigorous user authorization and access control processes**
- ▶ **1,100 currently authorized users and 700,000 page views in past 12 months**

MI HIT and HIE Strategy



10

Use Case Components



Use Case Summary (UCS)- explains purpose and value proposition/business case for sharing data



Use Case Exhibit (UCE)- short legal amendment to Master Use Case Agreement covering specific rules and message content for one Use Case that may have multiple data sharing scenarios



Use Case Implementation Guide (UCIG) - technical specification that outlines standard format details for data transmission & content

MiHIN Statewide Use Case and Scenario Status

