

Achieving Interoperability: Practical Lessons Learned

Public Health Informatics Institute

March 25, 2022



A program of

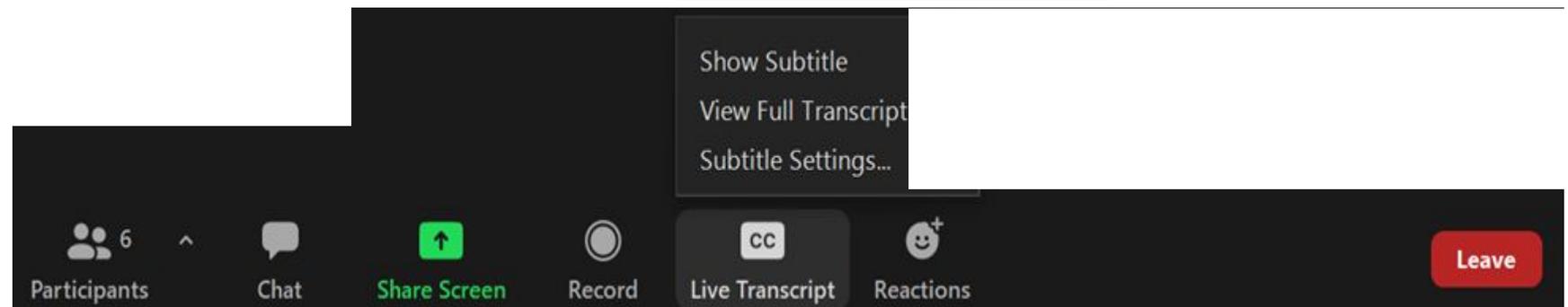
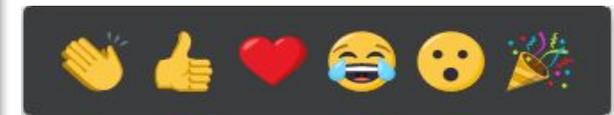
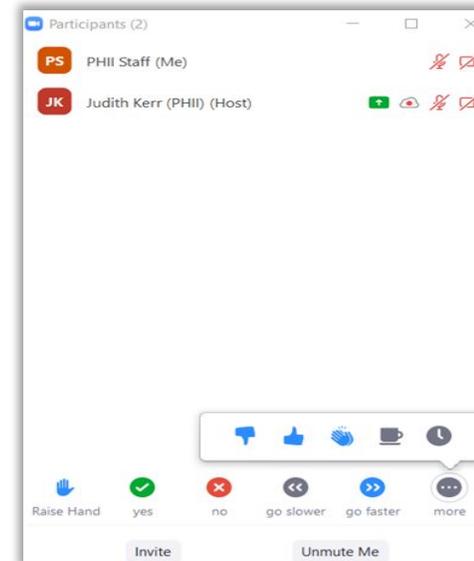


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Many images from today's presentation have been downloaded from unsplash.com and freepik.com

Finding your way around Zoom

- Rename yourself in Zoom to include your organization
- Type your questions into the chat or use reactions to communicate with presenters
- Live Transcript option





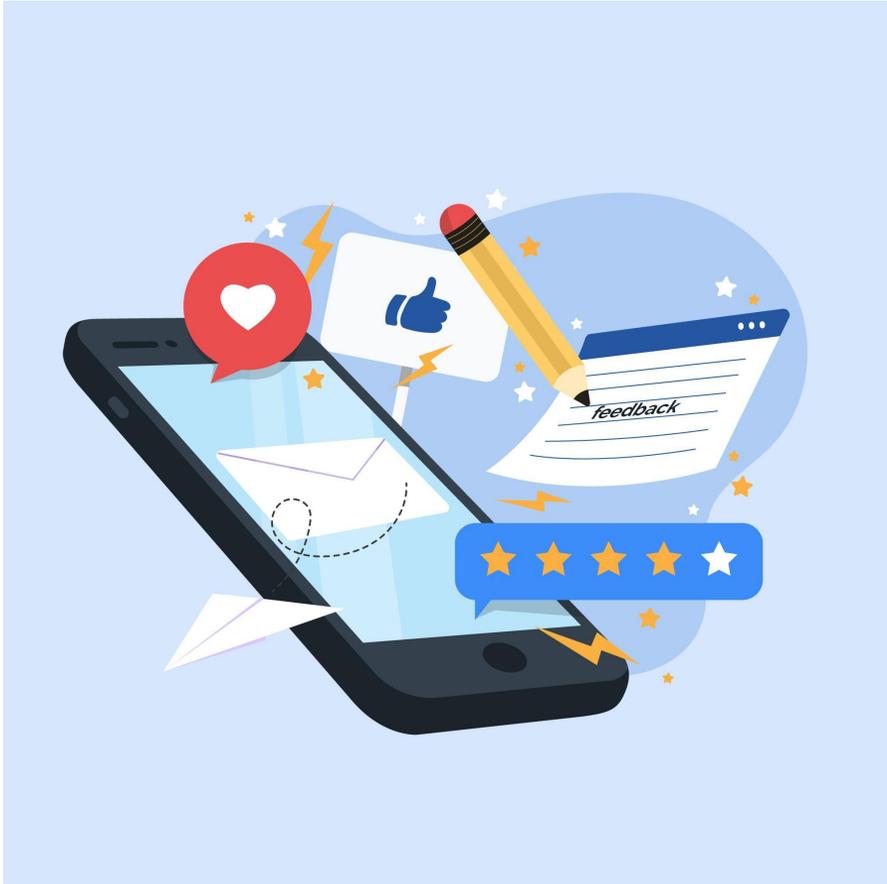
Informational sessions

Today's topics: Achieving Interoperability: Practical Lessons Learned

Upcoming topics

- Coordination with Vital Records (May 13, 2022)
- Interoperability - What Standard do I Use? (July)

Webinar Feedback



- Six short questions at the end of the zoom call
- Help us gauge the effectiveness of our webinar and provide additional resources to assist you in achieving interoperability

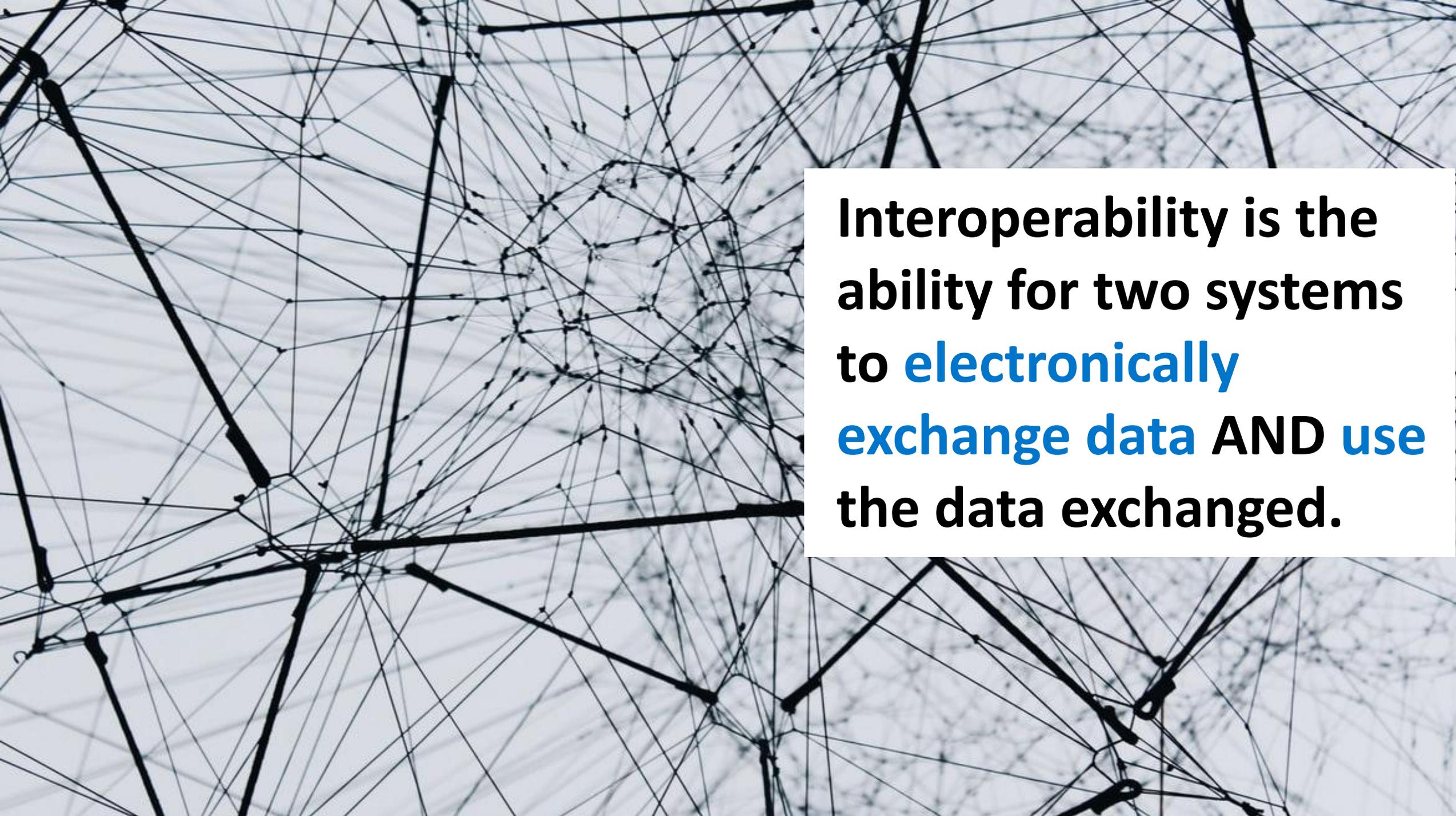


Laura Pabst, MPH
Centers for Disease Control and Prevention
National Center on Birth Defects and Developmental Disabilities



Poll Question:

What is interoperability?



Interoperability is the ability for two systems to electronically exchange data AND use the data exchanged.



Achieving interoperability
looks different for each
jurisdiction





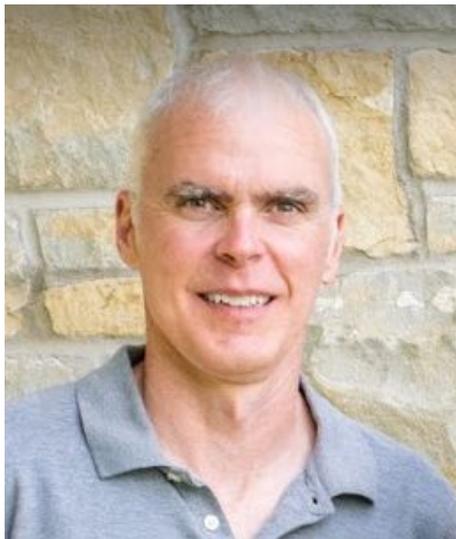
Poll Question:

What does BDS interoperability look like in your jurisdiction/State?

Learning objectives

- 1. Highlight and share experiences, best practices and challenges around achieving interoperable solutions for birth defects surveillance**
- 2. Identify potential resources and tools that birth defects surveillance programs can use to support data use and data exchange**

Webinar Speakers



Craig Newman (Altarum, Michigan Department of Health and Human Services)



SOLUTIONS TO ADVANCE HEALTH



J. Michael Bryan (Georgia Department of Public Health)



PHI.org

Michigan/MDHHS Division of Vital Records & Health Statistics

Altarum

Where is birth defect reporting interoperability?

Interoperability in Michigan

- Started with the recognized need for standardized, electronic reporting
- The existing Birth Defects system wasn't up to the job
 - Existing registry was unsupported and isolated
 - Data input was non-standardized and manual
 - Manual processes were needed for linking with other state systems and programs
- A whole new approach was needed!



What Michigan needed

- Requirements for a new system
 - Automate data input and output processing
 - Allow for maintenance of validation look-up tables
 - Automate record matching/linking process
 - Built in data validation and reporting
 - Add support for different ways of reporting data
- Leadership support
 - Birth Defects Surveillance is part of the Division for Vital Records and Health Statistics
 - Support from Michigan Medicaid Implementation Advanced Planning Document (IAPD)

C-CDA as a national standard

- Consolidated Clinical Document Architecture (C-CDA) is a document standard for the transmission of structured summary data
- 16 states participated in requirements gathering for a C-CDA standard



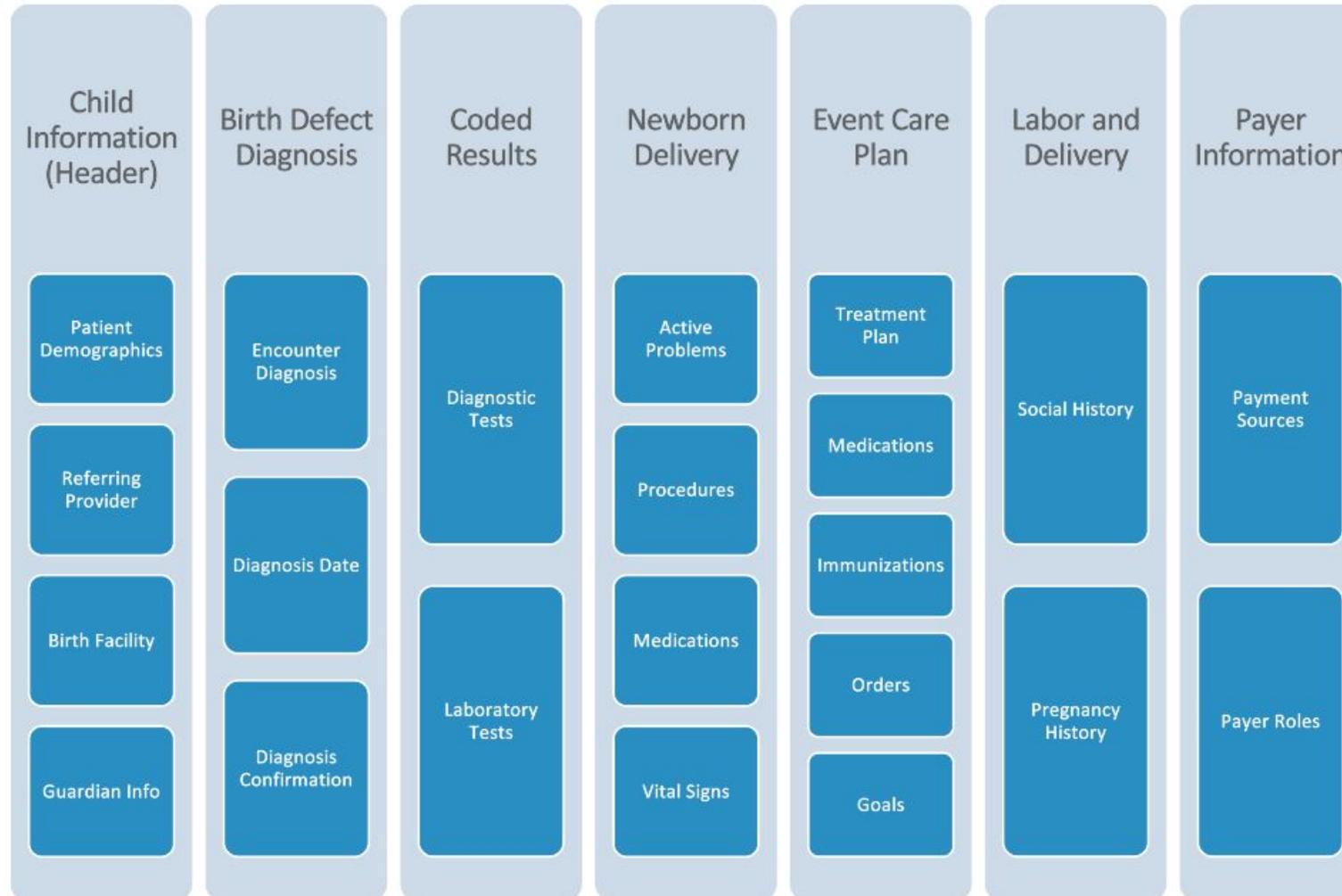
HL7 C-CDA Ambulatory
Implementation Guide
Published for Standard
Trial Use (STU)

- Updated the implementation guide to include hospital settings
- Balloted the updated implementation guide

- Complete ballot reconciliation updates
- Prepare states for C-CDA processing
- September-request to publish the guide

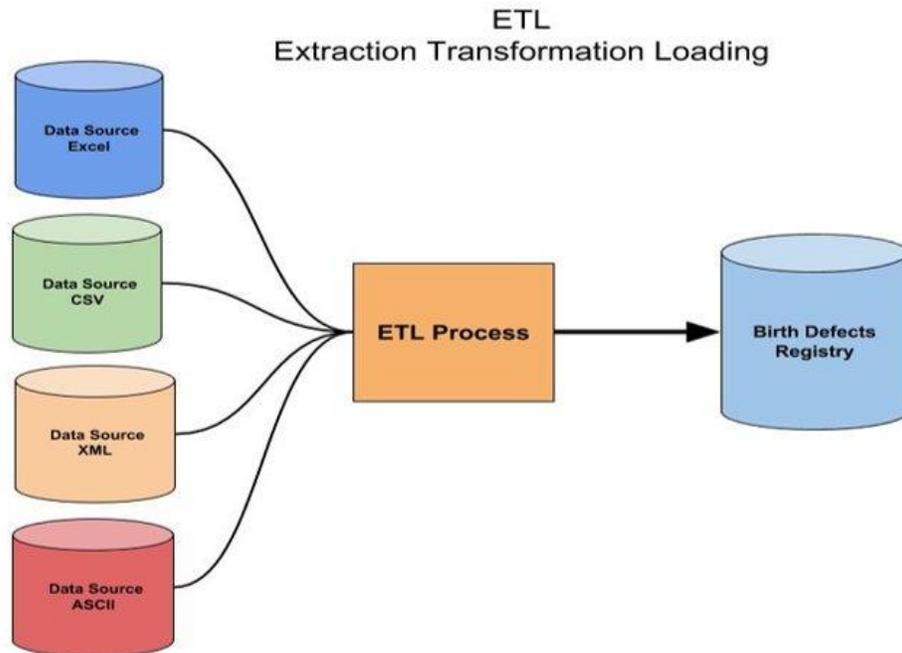
- Recruit EHR vendors/sites for piloting
- Develop an IHE or FHIR form

A comprehensive document



Data are flowing today...

- Via Birth Certification (online web portal)
- Paper forms
- Flat files



Lesson Learned:

Standardize your file format (and enforce it) - if you don't, someone else will make one up and it will not conform to your specification!

But not as a C-CDA

- CDA was not the answer in the real-world
- EHR vendors didn't support it despite engagement with them
 - EHRs didn't have all the data
 - The “push” model has a dependency on EHR vendor support
 - Having either a stick or a carrot is helpful

Lesson Learned:

Having a standard is not enough, there has to be a motivating force for implementation.

But how will it flow tomorrow?

- Will FHIR be the answer?
- FHIR provides many more options to share data
 - Query
 - Questionnaires
 - Document
 - Messages
- FHIR is not a silver bullet
 - Authorization to access data is not a minor issue
 - Not all data will be available
 - It needs to be adopted by vendors and submitters



But how will it flow tomorrow?(cont'd)

- Public Health and FHIR is a very active field with lots of ways to contribute – get involved!
 - Helios Accelerator
 - Public Health FHIR Implementation Collaborative
 - Bulk FHIR
 - FHIR At Scale Taskforce (FAST)
 - United States Core Data for Interoperability USCDI/USCDI+/US Core
- The foundation for FHIR exists
 - Draft Birth Defects FHIR IG
 - Birth Defects Reporting Domain Analysis Model (DAM)



But how do we get from here to there?



Be realistic

- We are not going to reach nirvana in one step
- Some of the data you need may be unavailable' Not everything is captured in the EHR
 - Not everything captured is stored discretely
 - Not all discrete data is easily accessible
- But some of it is – start there!

Lesson Learned:

There are no quick fixes – be wary of anyone who says that they have “the” solution.

Be prepared

- Know where you are
- [PHII Readiness Assessment and Toolkits](#)
- Learn the interoperability basics
 - Free training and resources
 - [INBSI resources](#)
- Develop (and document) a clear process for onboarding submitters

Lesson Learned:

Completing a Readiness Assessment and developing a Roadmap is critical.

You are not alone

- Some of the data you need may already be nearby
 - Vital Records (Births and Deaths), Newborn Screening, Case Reports
- Work together and build a common foundation
 - Data
 - Terminology
 - Technology
 - Outreach



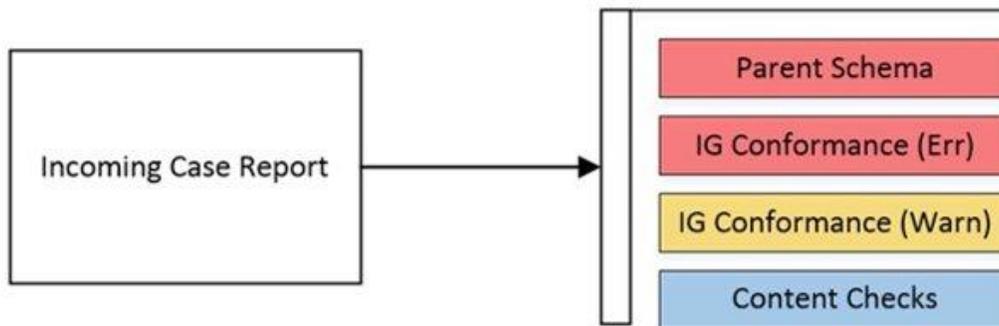
Lesson Learned:

We don't want to burden submitters with reporting the same data multiple ways. Sharing data within the jurisdiction is critical.

Just because it's electronic, doesn't mean it's good

- Electronic interoperability can help with validation and identifying trends in data

Implementation Guide (IG) Conformance



Lesson Learned:

Finding issues doesn't help if you don't communicate them back to your submitters.

Interoperability is not “one-and-done”

- It is critical to monitor the accuracy, completeness, and timeliness of data submissions from sites after go live
 - Reporting frequency
 - Case report counts
 - Duplicate reports
 - Data quality
- Monitoring and training is a continuous process and must be part of the plan

Lesson Learned:

Interoperability doesn't remove the need for staff, but rather it helps your people work up to their ceiling.



Poll Question:

Do you have the support you need internally and externally to achieve interoperability in your jurisdiction/State?

Georgia



J. Michael Bryan, Ph.D., M.P.H. (Georgia Department of Public Health)

Outline

1. Interoperability for state surveillance
2. Data – drowning in it
3. Keeping track of facilities
4. So much free text
5. A call made does not equal a record given
6. A case by any other name
7. Resources

Why Interoperability?

1. Validity

- External or Generalizability
- Internal or construct, reporting, non-response biases

2. Utility

- Data given better context through different lenses
- Cost reduction (*potentially*)
- Play to employee strengths
 - Epidemiologists are highly skilled labor, but often spend time doing medical record requests, faxing, and scanning

3. Necessity

- Seemingly inevitable
- Limitations of isolated data source modes (e.g., notifiable case reports)

Components of Interoperability

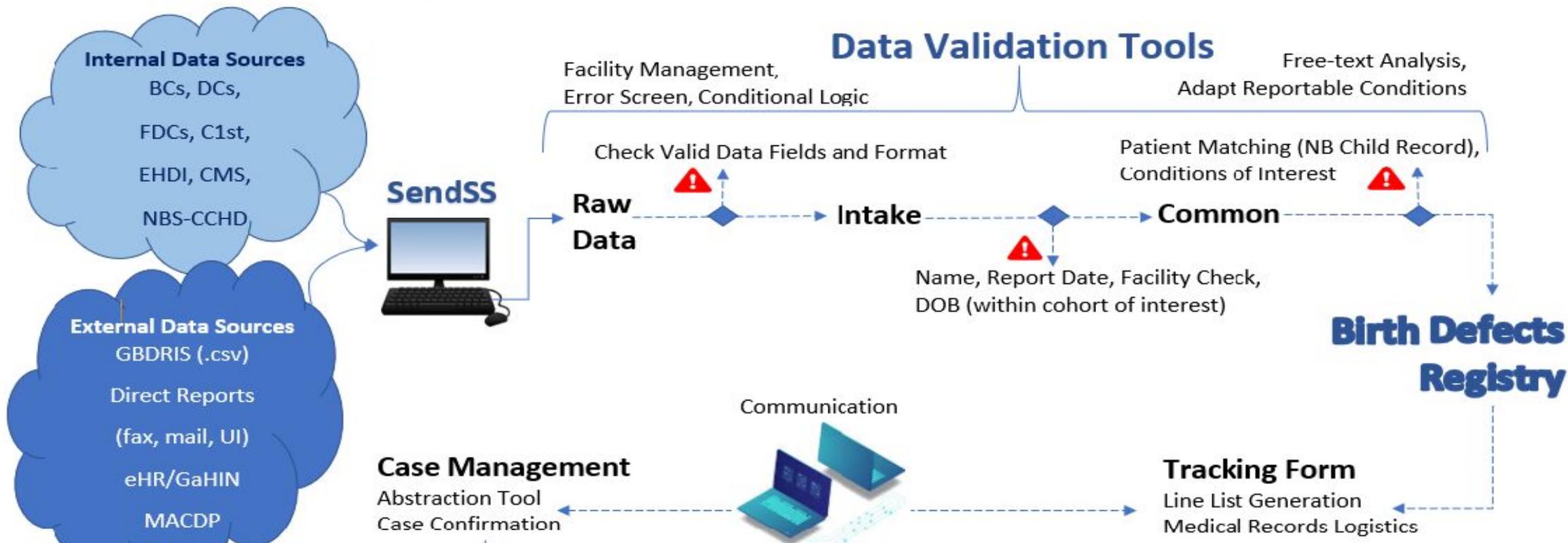
Data

1. Existing data you can access
2. Existing data you want to access
3. New data you will collect
4. System-related data you use

Processes

1. Unique Entities
 - Person
 - Facility
2. Free-Text Management
3. Case Tracking
4. Case Confirmation

Georgia Birth Defects Registry Data Flow



Internal Data Sources

BCs, DCs,
FDCs, C1st,
EHDI, CMS,
NBS-CCHD

External Data Sources

GBDRIS (.csv)
Direct Reports
(fax, mail, UI)
eHR/GaHIN
MACDP

SendSS

Raw
Data

Intake

Common

Birth Defects
Registry

Case Management

Abstraction Tool
Case Confirmation

Communication

Tracking Form

Line List Generation
Medical Records Logistics

Output

Descriptive Analyses
Data Visualization
MACDP Data Sharing
Annual Progress Reports for Facilities
Referral to Early Intervention Services



Acronyms

- BCs: Birth Certificates
- DCs: Death Certificates
- FDCs: Fetal Death Certificates
- C1st: Children First
- CMS: Children's Medical Services
- eHR: Electronic Health Record
- EHDI: Early Hearing Detection and Intervention
- NBS-CCHD: Newborn Screening Critical Congenital Heart Defects
- GaHIN: Georgia Health Information Network
- GBDRIS: Georgia Birth Defects Reporting and Information System
- MACDP: Metropolitan Atlanta Congenital Defects Program
- SendSS: State Electronic Notifiable Disease Surveillance System
- UI: User Interface Case Reporting Form

BDR Reporting Sources

Existing

Vital Records

- Birth certificates (BCs)
- Death Certificates (DCs)
- Fetal Death Certificates (FDCs)

Facility-reported

- GBDRIS: electronic line lists
- UI: paper reports entered
- Direct reports (labs, HCP)

NBS and Referrals

- EHDI
- CCHD
- Children 1st

MACDP: CDC surveillance

CMS: Children's Medical Services

GaHIN: GA Health Info Network

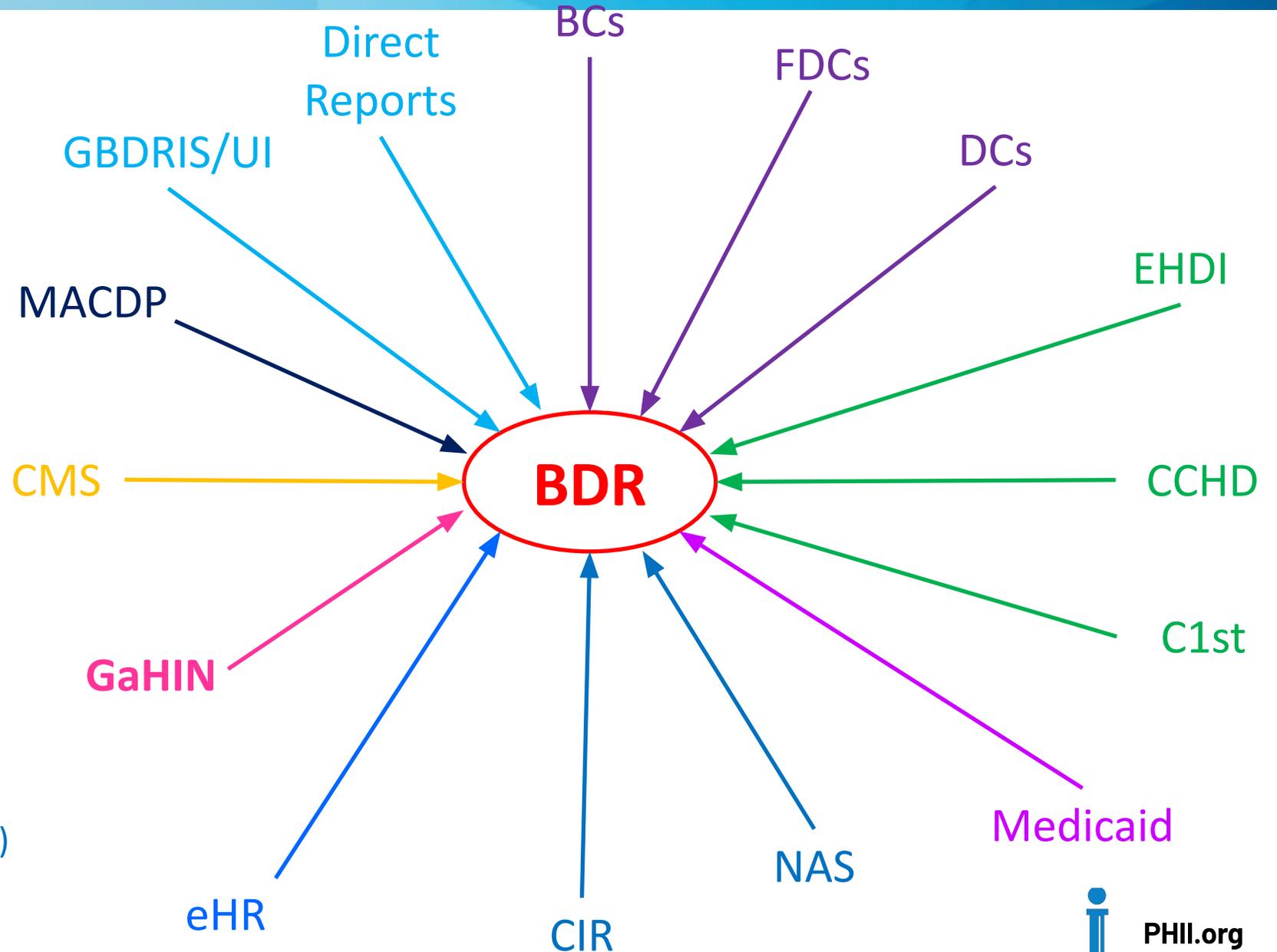
Planned

SendSS-based surveillance systems

- Neonatal abstinence syndrome (NAS)
- Congenital Infections Registry (CIR)

Medicaid claims

Electronic health records (eHR)



Unique Birthing Facilities

- Goal: ensure capacity to track facilities to better monitor birth defect reporting and burden
- Facility Master Table
 - Spelling variations, abbreviations, name changes, acquisitions
- Ongoing effort to maintain
- Method to identify facility differs by modes of reporting

Facility	Current?	Historic?	New?
AUGUSTA UNIVERISTY MEDICAL CENTER	Y		
GEORGIA REGENTS MEDICAL CENTER	N		
GEORGIA REGENTS UNIVERSITY	N		
AUGUSTA UNIVERSITY MEDICAL CENTER -	Y		
Georgia Health Sciences Medical Center	N		
AU	N		
AU MEDICAL CENTER	N		

Free-Text Management

- Goal: increase value of data provided by optimizing use of free-text fields
- Convert text to ICD Code
- Enhanced case identification and management
- Complicated – time investment
- Ongoing maintenance

This reports shows the way regular expressions include and exclude freetext. Is using updated free-text mapping definitions from bdr_ft_regexp_core.

Please supply any parameters you wish for this report.

String:

ICD:

Regular Expressions In Use

String:
ICD::Q90

NUM	REID	POSITIVERE	NEGATIVERE	ACTIVE	ICD CODE	VERBATIM	USAGE TYPE
1	2600	((TRISOMY 21).*(NONMOSAICISM))(Q90\0)		Y	Q90.0	Trisomy 21, nonmosaicism (meiotic nondisjunction)	BIRTH
2	2610	((DOWN TRISOMY ?21).*(MOS(AI A)C))(((MOS(AI A)C).*(DOWN TRISOMY ?21)))(Q90\1)	(TRI).*(18 13 9 8)	Y	Q90.1	Trisomy 21, mosaicism (mitotic nondisjunction)	BIRTH
3	2620	(TRISOMY ?21).*(TRANSLOCATION))(Q90\2)		Y	Q90.2	Trisomy 21, translocation	BIRTH
4	2630	((TR Y)(ST?[EO](NO)?MY?))(CHROMOSOME).*(21))(DOWNS?))(Q90\9)	(HX).*(DOWNS?))(DOWNWARD))(FAMILY HISTORY)	Y	Q90.9	Down syndrome, unspecified	BIRTH

Tracking Form

- Goal: expedite case disposition through better case tracking
- New Data... or maybe more like case metadata
- Manage surveillance logistics
- Status of correspondence with facility
- Communication with colleagues

1

Ascertainment Source: Ebc ▼
BDR Status: Suspected Bd ▼

2

Birthing Facility: Wellstar West Georgia Medical Center ▼
Birthing Facility Phone: []-[]-[] Birthing Facility Fax: []-[]-[]
Reporting Facility: Wellstar West Georgia Medical Center ▼
Reporting Facility Phone: []-[]-[] Reporting Facility Fax: []-[]-[]

3

Mailed: Choose One ▼
Date Last Requested: []/[]/[]

4

[Add New Correspondence](#)

5

[Add New Comment](#)

[Add New HCP](#)

Case Confirmation

- Goal: expedite surveillance through standard data collection
- Existing plus New Data
- Adherent to guidelines
 - Definitions matter
- Dependent on
 - Starting point
 - Jurisdiction needs
 - Grant requirements
 - Funding
- Communication with colleagues

BD Reported and Confirmed

1 BD Reported: Q21.0-Ventricular septal defect :: Q21.2-Atrioventricular septal defect (AVSD)

ICD(s) reported	Verbatim	Certainty	Confirmation Date
<input type="checkbox"/> Q21.0 - Ventricular septal defect			
Report Date:			
Diagnosis date:			
Defect Abstraction			
ICD Code: Q21.0 - Ventricular septal defect			
Verbatim:			
Certainty: Choose One ▾			
Confirmation Date: <input type="text"/> / <input type="text"/> / <input type="text"/>			
Report Date: <input type="text"/> / <input type="text"/> / <input type="text"/>			
Diagnosis Date: <input type="text"/> / <input type="text"/> / <input type="text"/>			
<input type="button" value="Update"/>			
<input type="checkbox"/> Q21.2 - Atrioventricular septal defect (AVSD)			
Report Date:			
Diagnosis date:			

2

3

ICD(s) added	Verbatim	Certainty	Confirmation Date
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Conclusions

Interoperability is **critical**

Interoperability is **difficult** (no magic involved)

Interoperability is **worthwhile**

Resources

1. NBDPN Surveillance Guidelines
 - Reportable conditions
 - Data elements
 - Data management
2. External: (<https://dph.georgia.gov/birth-defects-reporting>)
 - Reportable conditions, Data elements, Codebook, CSV template for facility line lists
3. Internal: (Microsoft Teams)
 - One-Stop Shop: All reference materials and TD tasks in one place
 - Data source status, reprocessing checklist, **TD requests**, case definition and logic, reportable conditions, Auto-dx conditions, free-text notes, data dictionaries and codebook, and much more

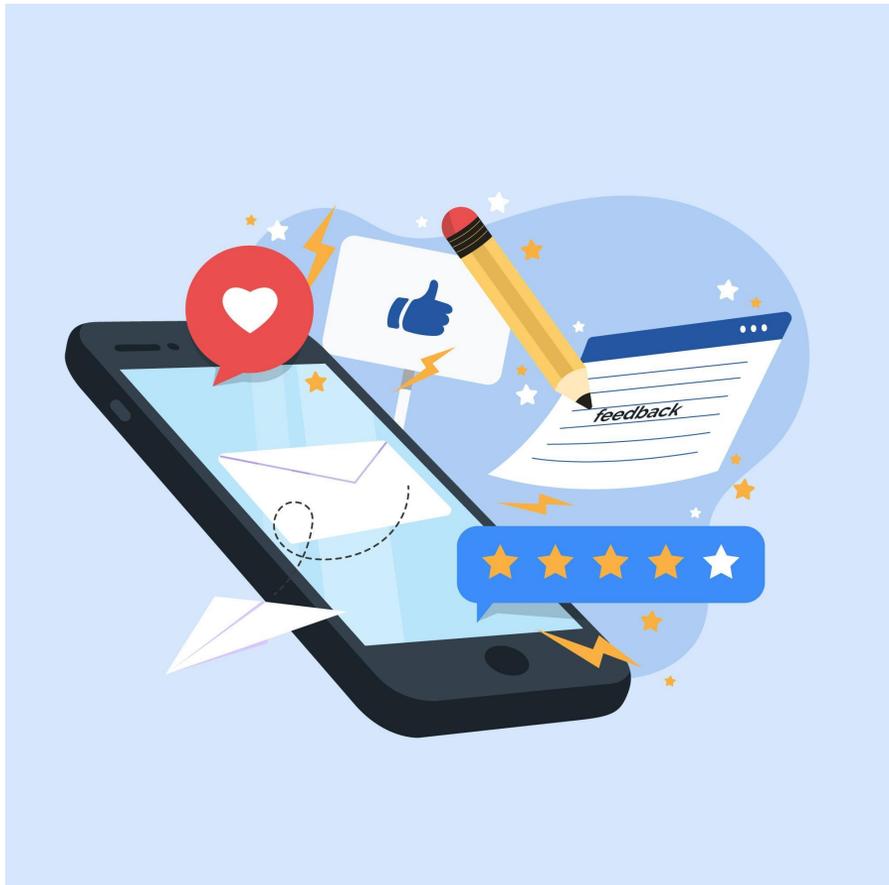
Thank you for your time!
Please feel free to contact us:

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Jerusha Barton
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Questions





Don't forget to give us your feedback in the post call survey!

Resources

- To help birth defects programs determine readiness for automated electronic data exchange using health information standards review the BDS readiness assessment
<https://phii.org/resources/birth-defects-surveillance-readiness-assessment/>
- Additional resources
 - [Innovations in Newborn Screening Interoperability](#)
 - [Birth Defects Surveillance Guidelines](#)
 - [Informatics-savvy Health Department Toolkit](#)
 - [Office of the National Coordinator for Health IT \(ONC\)](#)
 - [United States Core Data for Interoperability \(USCDI\)](#)