

# Interoperability 101 for Birth Defects Surveillance

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January 2022

*Funding Disclaimer: This work was supported by Cooperative Agreement number 6-NU380T000316, funded by the Centers for Disease Control and Prevention. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the Centers for Disease Control and Prevention or the Department of Health and Human Services.*

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# Informational sessions

Today's topics: Interoperability 101

Upcoming topics

- Achieving Interoperability (March 25)
- Coordination with Vital Records (May)
- Interoperability – What Standard do I Use? (July)



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


# Learning objectives

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- 1. Introduce the topic of interoperability and define key terms with relevant examples for birth defects programs**
- 2. Highlight trends, policies, and initiatives that may impact leadership buy-in and resources**



What is interoperability?



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

a coffee  
please

please, ein  
coffee

koohii  
please!







**A cup of coffee**



Q02 Microcephaly



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



## Why interoperability?

- Automates data exchange and reduces data entry errors
- Allows access to data with less effort
  - Rather than a review of health records within provider facility or remote access to health records
- Improved timeliness for action

# Benefits of interoperability

- Improves timeliness of data reporting
- Reduces resources required for abstraction
- Minimizes provider burden
- May improve data quality
  - Completeness and accuracy

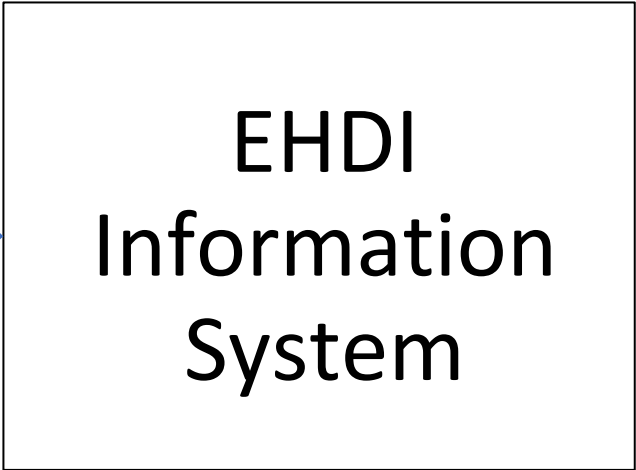


# Early Hearing Detection and Intervention



Demographics

Test Results



# Immunization Information Systems



# Interoperability and Birth Defects Surveillance

- Improved timeliness of case identification
- Balancing data timeliness with **accuracy**
- Potential to improve data sharing with other public health programs

# Interoperability myths

- Interoperability does not replace people – People are still very important for taking the data and turning it into information.
- Interoperability is not a set it and forget it system – These types of projects require monitoring and support to ensure they are up to date and functioning as expected.
- Interoperability is not a one size fits all – Each BDS program will need to make adjustments to meet the needs of your program.





Birth Defects  
Programs and  
Interoperability



## Most Recent Reviews

### Refuge Coffee Co

★★★★★ 91 reviews

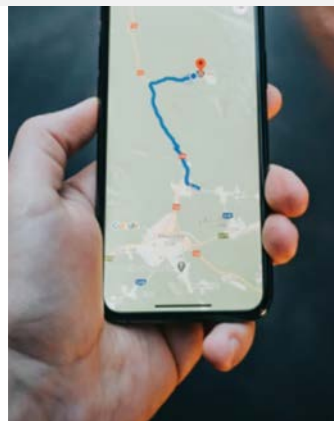
Coffee & Tea, Food Trucks





**Identify Partners**

**Establish how to get there  
(standards/transport)**



**Most Recent Reviews**

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**Policies**

**An interoperable  
system**



**Data Source (EHRs)**



**Vocabulary/Codes**



**Message standards**

# Establishing Interoperability with BDS

- Define data exchange capability
- Identify partners
- Establish data sharing relationships
- Standards adoption & implementation
- Participate in policy discussions

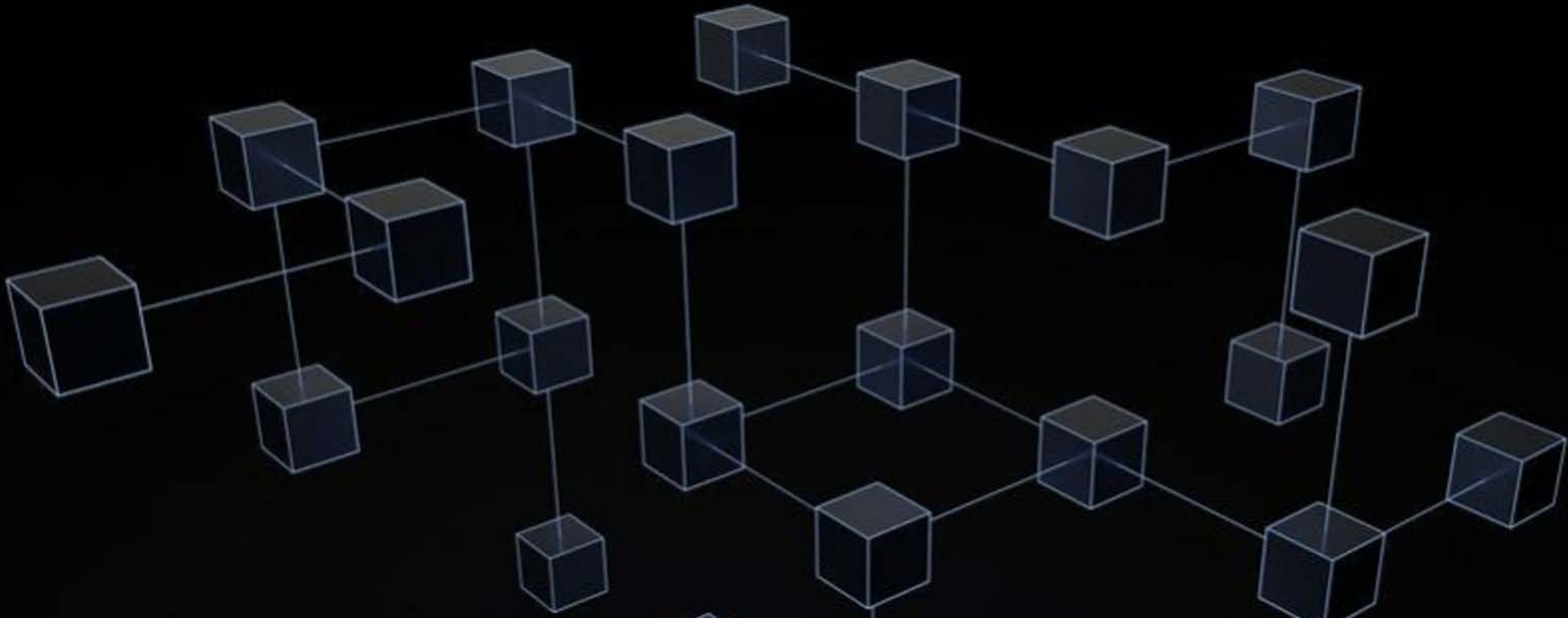
**An interoperable  
system**



# Data exchange capability

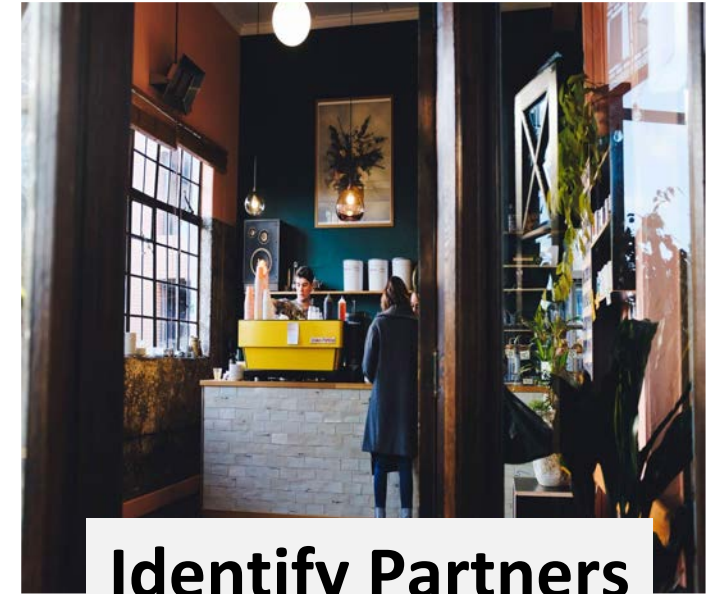


**Electronic exchange of data** – The ability to send, receive and process data that are electronically transferred from one information system to another without manual intervention.



# Interoperability with BDS

- Define data exchange capability
- Identify partners
- Establish data sharing relationships
- Standards adoption & implementation
- Participate in policy discussions



**Identify Partners**



**Data Source (EHRs)**



## Data Exchange Partners

Entities that send data to or receive data from the program in the course of conducting business or meeting reporting requirements.



# Establish Data Sharing Relationships

- Engage partners
- Identify and communicate the value proposition
- Start small, then expand:
- Address market-based concerns
- Adapt and expand existing agreements and partnerships
- Anticipate the time and investment needed

<https://phii.org/sites/default/files/resource/files/Data%20Governance%20and%20Data%20Sharing%20Agreements.pdf>

## Data Governance

Data governance is the set of policies and procedures that determine the who, how and why of data management within the organization to support compliance and legal requirements

(Source: [AHIMA](#))

## Information Governance

An organization-wide framework for managing information throughout its lifecycle and supporting the organization's strategy, operations, and regulatory, legal and environmental requirements

(Source: [AHIMA](#))

# Electronic Health Records (EHRs)

- A digital (or electronic) version of a patient's paper chart
- EHRs allow for the electronic storage and maintenance of patients medical histories over time by a provider.
- Built to share information with providers and public health
- Automate and streamline provider workflow

# Health Information Technology

- Health IT makes it possible to better manage patient care through secure use and sharing of health information.
  - Includes the use of EHRs

# Interoperability with BDS

- Establish data exchange capability
- Establish data sharing relationships
- Standards adoption & implementation
- Participate in policy discussions

# What are standards?

- Standards define how information is packaged
- Standards support clinical practice and care delivery
- There are many different types of standards:
  - Messaging – the format the information is in
  - Vocabulary – the agreed upon terminology
  - Transport – the way the information gets from one place to another

# What is HL7?

- A standards developing organization (SDO)
- Founded in 1987
- Nonprofit
- Volunteer-based
- International
- Healthcare Interoperability Standards Developer



<http://hl7.org/>

# What are messaging standards?

- Agreed upon way to share data
- A messaging standard defines how the data should be communicated
  - The language, structure, and data types
- Messaging standards include
  - Version 2 (v2)
  - Clinical Document Architecture (CDA)
  - Fast Healthcare Interoperability Resources (FHIR)



**Message  
standards**



# Clinical Document Architecture

- Documents (XML)
- CDA contains structured and unstructured data
- Uses
  - Discharge summaries, imaging, pathology reports
  - Reporting to cancer registries
  - Birth and fetal death reporting
  - Birth defects reporting
  - Electronic Initial Case Reports (eICRs) for reportable conditions



# HL7 Version 2 (V2)

- Most widely implemented standard
- Used in exchange of clinical data between systems
  - Lab orders and results
  - Immunizations
  - Patient referrals
  - EHDI and CCHD
- Supports a central patient care system
- Used by IT vendors and healthcare providers, and now consumed by public health



# Fast Healthcare Interoperability Resources

- [FHIR](#) – Release 4
- Uses best features from existing HL7 standards
- Consists of independent building blocks called Resources
- Focuses on implementation
- Features Resource maturity
- Maintains strong foundation in web standards



HL7<sup>®</sup> FHIR<sup>®</sup>

# Patient Name

HL7 V2	HL7 CDA	HL7 FHIR
PID  0493575^^^2^ID 1 454721   <b>DOE^JOHN</b> <b>^^^^</b>  DOE^JOHN^^^^  19480203 M  B 254	<admission document> <patient> <name first = "John" last = "Doe"/> <age 23/> </patient> </admission document>	String name;  name = <b>FHIR.patient()</b>

# Patient Name Examples

**Figure 75: US Realm Patient Name (PTN.US.FIELDED) - Birth Defects IG Specific Constraints**

- CDA

```
<name use="L">  
  <given>Evelyn</given>  
  <given qualifier="CL">Eve</given>  
  <family qualifier="BR">Everywoman</family>  
  <suffix qualifier="AC">J.D.</suffix>  
  <usablePeriod>  
    <low value="20150909" />  
    <high value="20151009" />  
  </usablePeriod>  
</name>
```

- V2

```
PID|1||MRN12345||Jones^BabyGirl|James|201201300005-0600|F||2106-  
3^White^HL70005~1002-5^American Indian or Alaska  
Native^HL70005|201  
Street^^Arlington^TX^99999^USA||^PRN^PH^^011^555^555-  
5555||eng^English^ISO6392|||98766|||1234555|N^Not Hispanic or  
Latino^HL70189|HospitalABC|N|1|
```

# FHIR Implementation Guide – Patient Name

- Structure
- UML
- XML
- JSON
- Turtle
- R3 Diff
- All

## Structure

Name	Flags	Card.	Type	Description & Constraints
HumanName	Σ <b>N</b>		Element	Name of a human - parts and usage Elements defined in Ancestors: <a href="#">id</a> , <a href="#">extension</a>
use	?! Σ	0..1	code	usual   official   temp   nickname   anonymous   old   maiden <a href="#">NameUse (Required)</a>
text	Σ	0..1	string	Text representation of the full name
family	Σ	0..1	string	Family name (often called 'Surname')
given	Σ	0..*	string	Given names (not always 'first'). Includes middle names This repeating element order: Given Names appear in the correct order for presenting the name
prefix	Σ	0..*	string	Parts that come before the name This repeating element order: Prefixes appear in the correct order for presenting the name
suffix	Σ	0..*	string	Parts that come after the name This repeating element order: Suffixes appear in the correct order for presenting the name
period	Σ	0..1	Period	Time period when name was/is in use

```

<HumanName xmlns="http://hl7.org/fhir">
  <!-- from Element: extension -->
  <use value="[code]"/><!-- 0..1 usual | official | temp
  | nickname | anonymous | old | maiden -->
  <text value="[string]"/><!-- 0..1 Text representation
  of the full name -->
  <family value="[string]"/><!-- 0..1 Family name (often
  called 'Surname') -->
  <given value="[string]"/><!-- 0..* Given names (not
  always 'first'). Includes middle names -->
  <prefix value="[string]"/><!-- 0..* Parts that come
  before the name -->
  <suffix value="[string]"/><!-- 0..* Parts that come
  after the name -->
  <period><!-- 0..1 Period Time period when name was/is
  in use --></period>
</HumanName>
  
```

# Vocabulary Standards

- A common language for communication
- Removes ambiguity
- LOINC Code for Medical Record Number: 46106-1
  - Local codes could be
    - Medical record number
    - Hospital record number
    - Patient ID
    - MRN
    - MR
    - ID



## Vocabulary/Codes

<https://loinc.org/>

**Establish how to get there  
(standards/transport)**



# Transport Standard

- How the data is going to be delivered
  - Examples include
    - HTTPS/REST
    - SOAP
    - SFTP
    - SMTP+S/MIME



# Trigger events

- A real world event that initiates the sharing of information
- Used when a patient's information changes
  - Admission
  - Discharge
  - Transfer
  - New diagnosis code
  - Surgery

# Case trigger codes

- Without standards, EHRs will make these decisions on their own, leading to variable reporting
- Best developed with all user types represented (e.g. EHR vendors, providers, registries)
- Trigger Codes help identify cases correctly
- Health IT products generate case reports when activated by trigger codes

# Birth Defects Surveillance Trigger Codes

- Case definition for surveillance includes ICD9-CM and ICD-10 CM codes.
  - Example from [Washington State](#)

Table. List of Currently Reportable Birth Defects and the Corresponding ICD-10-CM Codes

Birth Defect	ICD-9-CM	ICD-10-CM
<b>1. Anencephaly and similar anomalies</b>	<b>740.0-740.2</b>	<b>Q00</b>
<i>Acrania</i>	740.0	Q00.0
<i>Amyelencephalus</i>	740.0	Q00.0
<i>Hemianencephaly</i>	740.0	Q00.0
<i>Hemicephaly</i>	740.0	Q00.0
<i>Craniorachischisis</i>	740.1	Q00.1
<i>Iniencephaly</i>	740.2	Q00.2
<b>2. Spina Bifida</b>	<b>741.0, 741.9</b>	<b>Q05, Q07</b>
<i>With Hydrocephalus</i>	741.0	Q05.4
<i>Arnold-Chiari syndrome, type II</i>	741.0	Q07.0
<i>Without mention of Hydrocephalus</i>	741.9	<i>Must select region of defect</i>
<i>Hydromeningocele</i>	741.9	Q05.9
<i>Hydromyelocele</i>	741.9	Q05.9
<i>Meningocele (spinal)</i>	741.9	Q05.9

# Public Health Reporting Registries

- Collects, organizes, and displays healthcare information



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**Policies**

# Policies

- National policies
  - Promoting Interoperability
  - [21st Century Cures Act](#)
  - [Trusted Exchange Framework Common Agreement \(TEFCA\)](#)
  - [United States Core Data for Interoperability \(USCDI\)](#)
  - Other federal reporting policies
- State/local regulatory and program policies
  - Data reporting
  - Data protection/security
  - IT requirements

# Interoperability considerations

- The importance of partnerships
- Scalability within a jurisdiction
- Scalability across jurisdictions



# Questions





# Questions

- What are your biggest barriers on how to begin?
  - What are your primary concerns about how to move this forward?
- Any tips on how to engage with other public health programs?
- How can you leverage other programs?
- Are there places to make other connections or natural alignment?

# Resources

- [Birth Defects Readiness Assessment](#)
- [Data Modernization Toolkit](#)
- [Data Governance and Data Sharing Agreements](#)
- [Change Management Tools](#)
- [Project Management Tools](#)
- [EHR Toolkit](#)
- [Legal Considerations for Data Sharing](#)
- [Filling in the blanks: communicating public health informatics](#)

# Glossary

Terms referenced in today's presentation can be found in Birth Defects Readiness Assessment at <https://phii.org/resources/birth-defects-surveillance-readiness-assessment/>

and in the IIS hub: <https://phii.org/what-we-do/iis-hub/>