Oregon's Reportable Infectious Disease Data:

What data are collected? Why? And how?

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Public Health Surveillance

- The ongoing, systematic collection, analysis, and interpretation of health-related data essential to planning, implementation, and evaluation of public health practice, closely integrated with the timely dissemination of these data to those responsible for prevention and control.

Adapted from: Thacker SB, Birkhead GS. Surveillance. In: Gregg, MB, ed. Field epidemiology. Oxford, England: Oxford University Press; 2008.

Public Health Surveillance Goal

□ Provide information that can be used for health action by public health personnel, government leaders, and the public to guide public health policy and programs

Smith PF, Hadler JL, Stanbury M, et al. Blueprint version 2.0: updating public health surveillance for the 21st century. J Public Health Manag Pract 2013;19:231–9.

Uses of Public Health Surveillance

- ☐ Identify patients and their contacts for treatment and intervention
- ☐ Detect epidemics, health problems, changes in health behaviors
- ☐ Estimate magnitude and scope of health problems
- ☐ Measure trends and characterize disease
- ☐ Monitor changes in infectious and environmental agents
- ☐ Assess effectiveness of programs and control measures
- ☐ Develop hypotheses and stimulate research

Centers for Disease Control and Prevention (CDC). Introduction to Public Health. In: Public Health 101 Series. Atlanta, GA: U.S. Department of Health and Human Services, CDC; 2014. Available at: https://www.cdc.gov/training/publichealth101/surveillance.html

Oregon Communicable Disease Surveillance Systems

- Orpheus: Oregon Public Health Epidemiology User System

- DUDE: Directory of Useful Databases for Epidemiologists

Orpheus: Oregon Public Health Epidemiology User System

Orpheus holds data on reportable infectious disease cases

Orpheus

- Developed in 2008 in FileMaker to modernize public health data exchange

- Contains electronic lab reports, electronic case reports, provider reports

- Has automated functionality with:
  - ESSENCE (Syndromic surveillance system)
  - ALERTII (Immunization database)
  - MMIS (Medicaid Management Information System)

What are Reportable Diseases/Exposures?

- Immediately reportable diseases in Orpheus include:
  - Anthrax
  - Botulism
  - Diptheria
  - Ebola
  - Measles
  - Novel influenza
  - Poliomyelitis
  - Rabies
  - Rubella
  - Smallpox

What are Reportable Diseases/Exposures?

☐ <u>Reportable diseases within 24 hours in Orpheus include</u>:

- Campylobacteriosis
- Carbapenem-resistant Enterobacterales infection (CRE)
- Escherichia coli
- Gonorrhea
- Lead Poisoning
- Mumps
- Syphilis
- Tuberculosis
- And more…

What Kind of Data is Reported?

- Required notifiable data by OHA:
  - County
  - Disease
- Required notifiable data by Washington County from clinicians:
  - Patient name
  - Contact information
  - DOB
  - Sex
  - Diagnosis
  - Onset date
  - Other variables may be required from electronic lab reports such as specimen source site

What Kind of Data is Reported?

- REALD – Race, Ethnicity, Language, and Disability
  - Collected because:
    - Everyone does not receive the same level of health care or have the same access to health care
    - We have not been able to fully address and eliminate these inequities
    - We need to accurately identify health inequities and subpopulations that may benefit from focused interventions
    - We need to address disability as a demographic by identifying and addressing avoidable health inequities

What Kind of Data is Reported?

- REALD – Race, Ethnicity, Language, and Disability
  - Collected to:
    - Better understand the different populations we work with or serve
    - Identify and address social and health inequities
    - Guide the development of culturally specific and accessible services, and
    - Guide equitable allocation of resources to address inequities

What Kind of Data is Reported?

- SOGI – Sexual Orientation, Sex, and Gender Identity
  - Collected to:
    - Create safe, inclusive, and welcoming environments
    - Recognize the diversity of the populations we serve
    - Support health equity efforts and estimate the magnitude of health inequities
    - Direct people to group-specific services and distribute resources
    - Shift social norms about and broaden our understanding of who is included and accepted in the populations we serve

Why is This Information Collected?

- CDC reporting
  - Data is deidentified before sending to CDC
- Link to CDC dashboard with state level data
- Identify new exposures
- Monitor trends
- Inform cluster and outbreak investigations
- Prevent disease spread
- Public health modernization

Why are we Allowed to Collect this Sensitive Information?

- Federal Requirements
  - 45 CFR 164.512(b)(1)(i)
- State Requirements
  - OARs Chapter 333, Divisions 17, 18, 19, 22, & 24
    - DIVISION 17: Disease Control
    - DIVISION 18: Disease Reporting
    - DIVISION 19: Investigation and Control of Diseases
    - DIVISION 22: Human Immunodeficiency Virus (HIV) Testing and Confidentiality
    - DIVISION 24: Rules for Clinical Laboratories
- HIPAA does not apply to public health reporting

What is Public Health Modernization?

- Public Health Modernization refers to the foundation of an equity-centered public health system, reflecting Oregon's commitment to support strong vibrant communities with the goal of strengthening the public health system

- Modernization objectives began in 2017

What is Public Health Modernization?

- Modernization involves partnerships that work for everyone
  - State, local, and tribal public health authorities
  - Community based organizations
  - Regional health equity coalitions
  - Health care providers
  - Faith-based institutions
  - Schools
  - Environmental agencies
- Communicable disease has always been a priority area

Public Health Modernization Objectives

- Long term improvement of Oregon's public health system
  - Regionally focused and culturally specific public health responses
  - Statewide planning to achieve health equity
  - Statewide planning to build a sustainable workforce
  - Local communicable disease initiatives
  - Sustainable local and emerging communicable disease expertise
  - Strengthened cross-cultural relationships and partnerships

DUDE: Directory of Useful Databases for Epidemiologists

DUDE holds data on reportable infectious disease outbreaks, training tools, and infectious disease trackers

Outbreak Data in DUDE and Orpheus

- Orpheus contains person level data

- DUDE Outbreaks contains outbreak level data and is linked to Orpheus

- Summarizes person-level data of members of outbreaks

- Allows the tracking of outbreak trends

How is This Data Kept Safe?

- ☐ Kept on a secure server
- ☐ Uses Citrix access gateway, to assure that it complies with the highest level of security and confidentiality
- ☐ Curated list of who can access ORPHEUS
- ☐ Must apply for access
- ☐ Must complete security training and sign annual security oath
- ☐ Multifactor Authentication (MFA) to log in

What is the County's Role in Orpheus?

- Stewards of the county data
  - Data Analysts
    - Analysis of data from simple counts to complicated modeling
  - Epidemiologists
    - Outbreak investigations
    - Investigating novel exposures and concerning trends
  - Nurses
    - Case management and tracking

Strengths of Orpheus

- ☐ Centralized state system

- ☐ Standardizes case information

- ☐ Link multiple disease records to same person record

- ☐ Informs cluster and outbreak investigations

Limitations of Orpheus

- Database was intended for case and outbreak management
- Limited equity indicators are collected
  - Income
  - Insurance status
  - Education status
  - Immigration status
  - Place of birth (rarely collected)
  - Language fluency (rarely collected)

Where Can I See Information from Orpheus?

- [Oregon's Respiratory Virus Data | Tableau Public](#)
- [End HIV Oregon | Tableau Public](#)
- [HIV/STI Prevention Testing | Tableau Public](#)
- [Syphilis | Tableau Public](#)
- [Gonorrhea | Tableau Public](#)
- [Chlamydia | Tableau Public](#)
- [Tuberculosis Annual Profile | Tableau Public](#)
- [Monthly Communicable Disease Surveillance Report | Tableau Public](#)
- [Weekly Communicable Disease Report | Tableau Public](#)
- [Hospital Healthcare-Associated Infections Data Dashboard | Tableau Public](#)

How Can I Request Information?

- ☐ If the data you are looking for are not in a public dashboard, you can email us

- ☐ We do not have a formal request system in place, but requests are welcome

- ☐ Responses may take up to 10 business days

Summary

- Reporting of communicable diseases is required
- Orpheus holds patient level data on reportable infections
- DUDE holds outbreak data and summarizes patient level data of outbreak members
- Data is securely stored
- Data collection and modernization goals aim to reduce health inequities in the community
- Deidentified data is available in state dashboards or by request

Questions?

☐ What would you like to know more about?

☐ What parts of these data are of interest to you?

☐ How can we make this more accessible for you?

☐ How can we make this more useful to you?

Contact

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