Washington State to: NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS

Washington State Department of Health

Virtual Hearing on Privacy, Confidentiality and Security Considerations for Data Collection and Use during a Public Health Emergency

September 14, 2020

Presenter

Bryant Thomas Karras MD

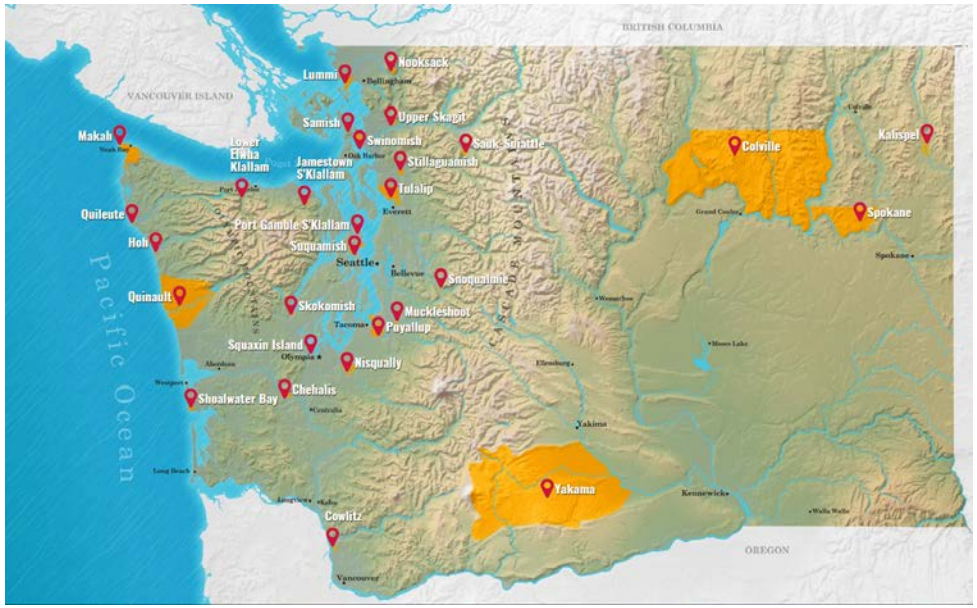
WA State Department of Health
Chief Informatics Officer

In the Office of the State Health Officer/ Chief Science Officer

Territorial Acknowledgement

Washington State public health reporting and syndromic data are gathered in the unceded territories of 29 federally recognized tribes, as well as that of the Duwamish Tribe, which is still fighting for federal recognition.

We thank our Tribal and Urban Indian health partners for their work and collaboration to support the health of Washington State.

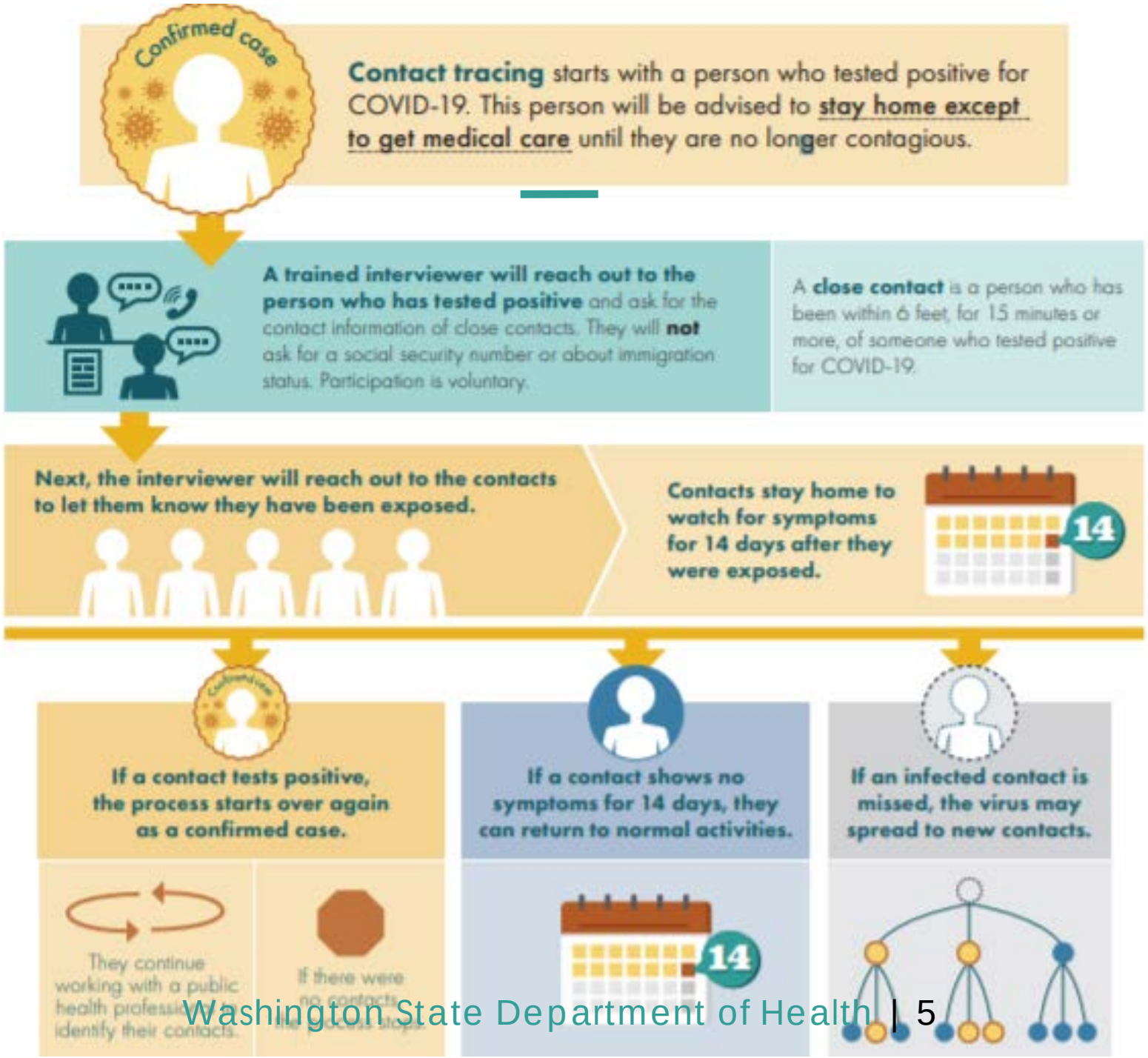


Overview

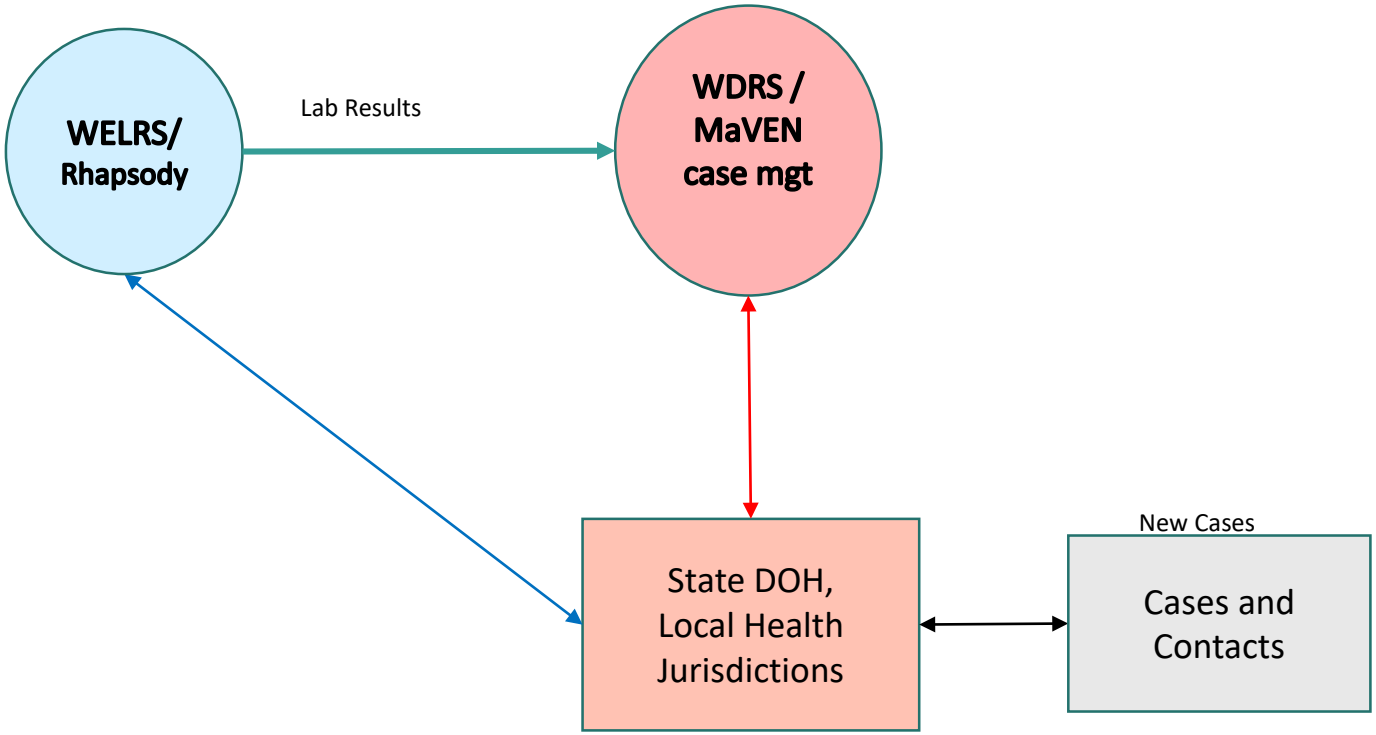
- Case investigations and contact tracing for COVID-19, complex
- Innovative COVID-19 technologies, adoption requires support
- Privacy considerations during the COVID-19 pandemic
- Data standards and coordination needs
- Workforce shortages

Time permitting:

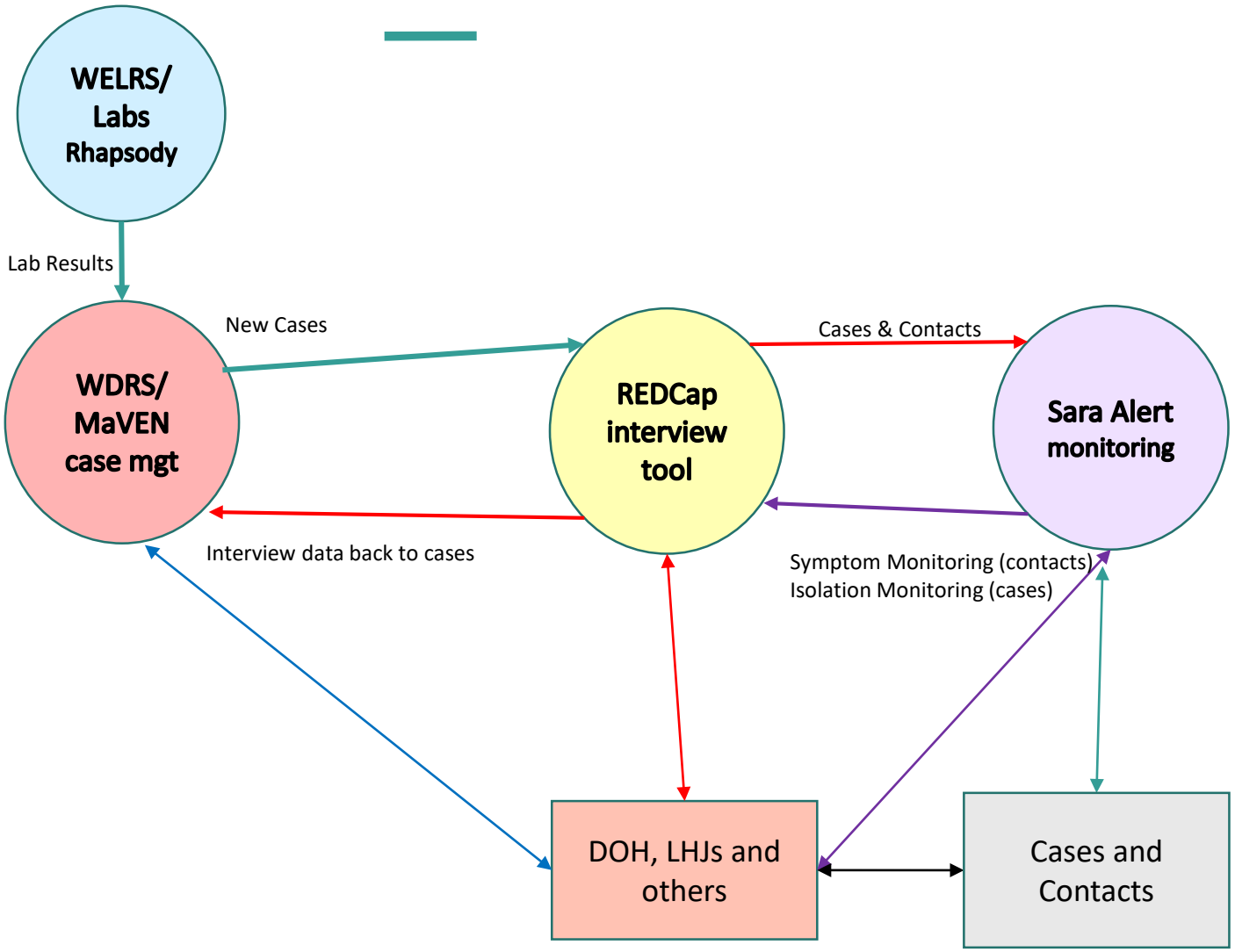
- Health IT Systems modernization and transformation


Confirmed case
Contact tracing starts with a person who tested positive for COVID-19. This person will be advised to stay home except to get medical care until they are no longer contagious.
A trained interviewer will reach out to the person who has tested positive and ask for the contact information of close contacts. They will not ask for a social security number or about immigration status. Participation is voluntary.
A close contact is a person who has been within 6 feet, for 15 minutes or more, of someone who tested positive for COVID-19.
Next, the interviewer will reach out to the contacts to let them know they have been exposed.
Contacts stay home to watch for symptoms for 14 days after they were exposed.
14
If a contact tests positive, the process starts over again as a confirmed case.
If a contact shows no symptoms for 14 days, they can return to normal activities.
If an infected contact is missed, the virus may spread to new contacts.
They continue working with a public health professional to identify their contacts.
If there were no contacts, the process stops.
14

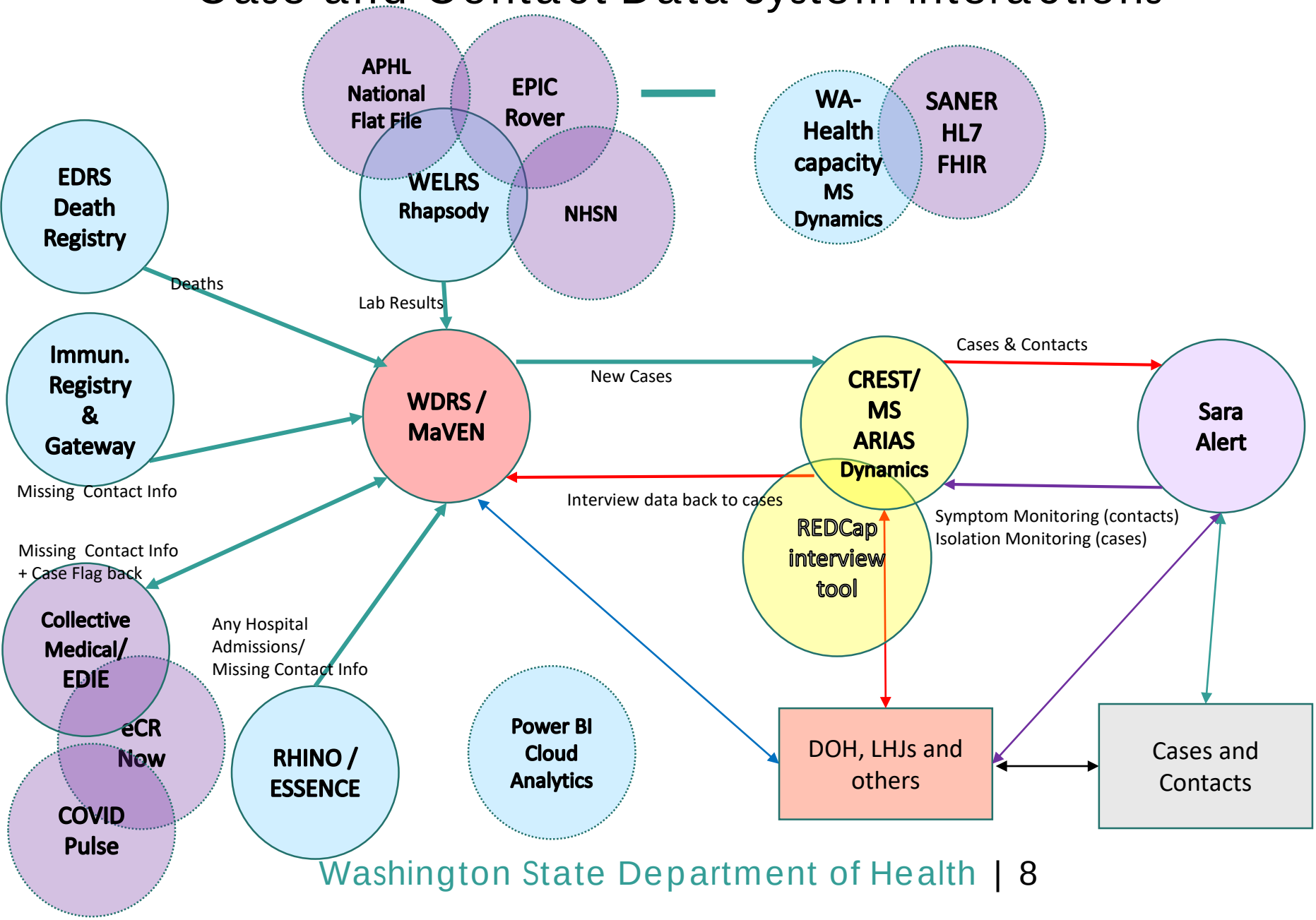
Pre COVID
Case and Contact Data System Interactions



Early-days COVID
Case and Contact Data System Interactions



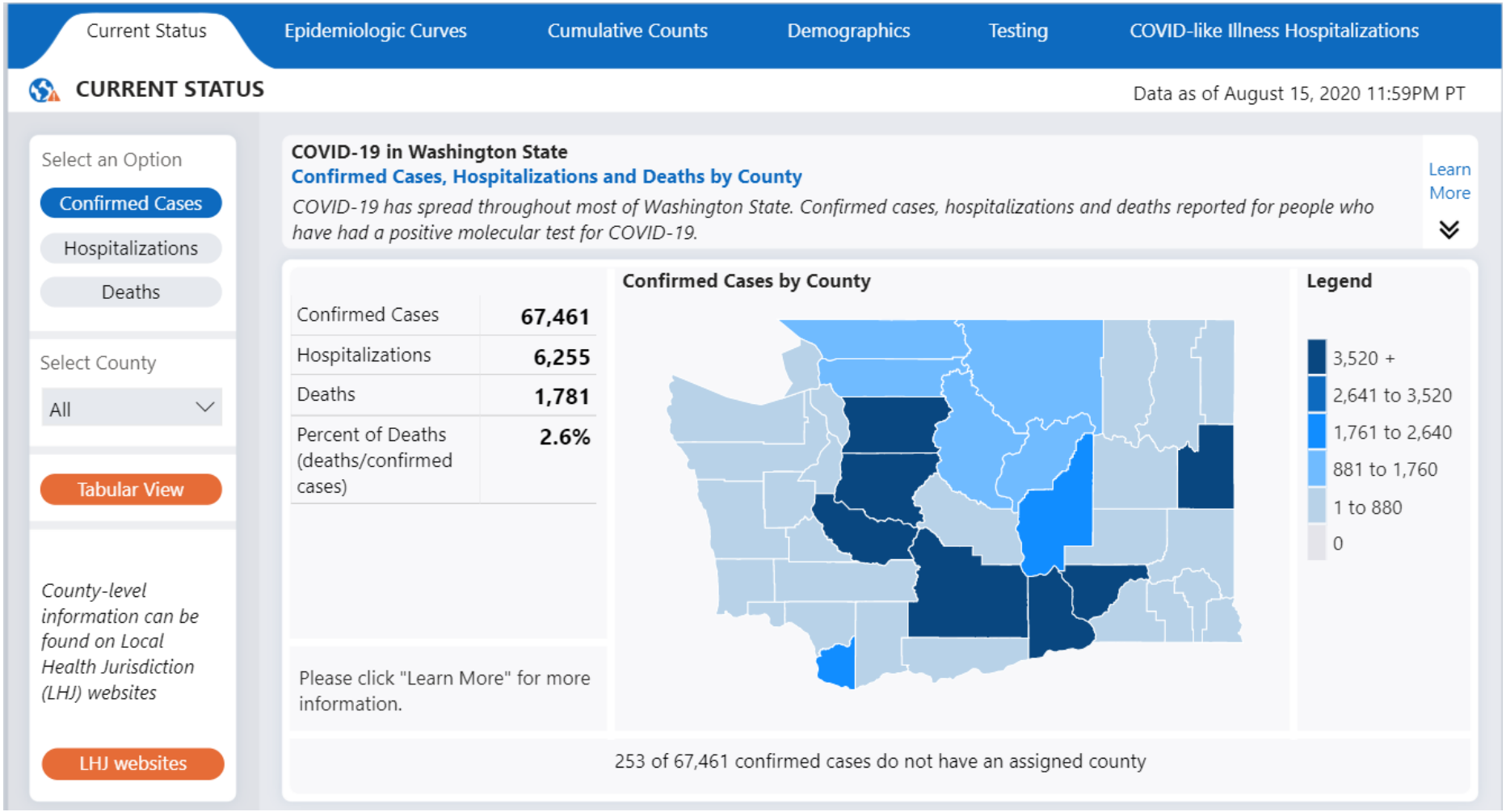
Post COVID
Case and Contact Data System Interactions



Case and Contact Data Systems--Challenges

- Increasing complexity
- Need for extensible cloud based capacity
- Integration of multiple data sources
- Need for master patient/person index on labs and cases
  - if incomplete location can not assign jurisdiction
  - inaccurate phone(s)
  - missing demographics race and ethnicity
- Need to protect privacy during public reporting and public disclosure requests

Public Dashboards



New innovations that need integration and resources

- Bluetooth Google Apple Exposure Notification
- Electronic case reporting with APHL tech assistance
- Leverage power of HIE (Health Information Exchange) for bi-directional HIPAA compliant sharing
  - COVID-PULSE
  - Collective Medical EDIE
  - Kno2 and Care**e**quality
- Master Person Index and proof of concept soon
- New Labs, well meaning test sites, not following standards
  - Overworking public health workforce to on-board
  - Flat File from non-HL7 ready labs, need APHL tech assistance…
  - Mobile data collection at mass test sites and Long-term Care

Use case: exposure notification app

Apple/Google proposal

- Bluetooth signals through Google/Apple API detect users in proximity (currently within 6 feet for 15 minutes or more).
- Their phones exchange anonymous key codes.
- If a user tests positive, they are instructed to enter a PIN to upload keys.
- Regularly phones look for matching keys and then alerts user of their potential exposure to someone who tested positive.
- User is directed to follow up with appropriate public health response (TBD).

Exposure Notification app in Washington?

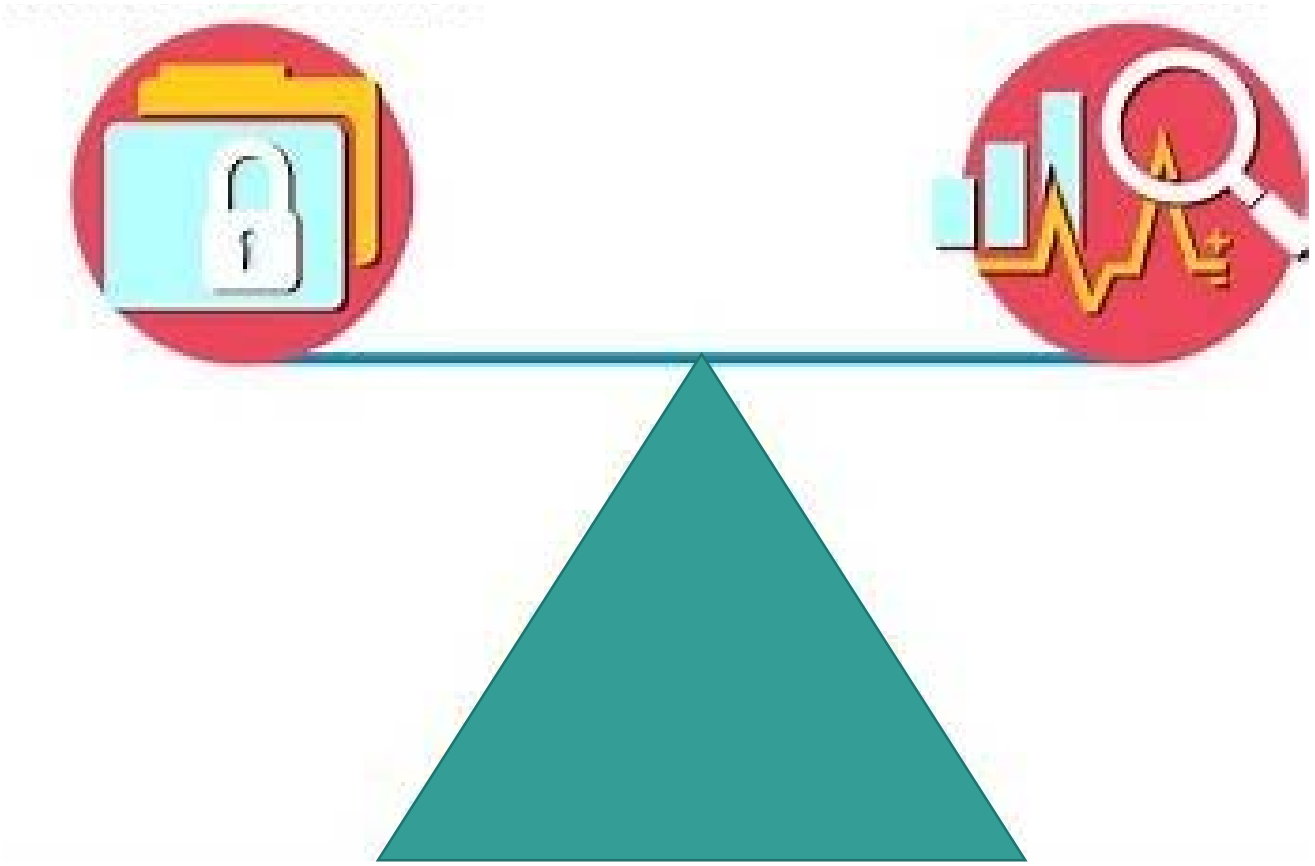
- Proximity and time based anonymous notifications
- No geolocation, privacy preserving
- Use is voluntary, anonymous keys to national server requires consent
- CommonCircle.US Washington's potential Exposure Notification app
- Being developed by UW and Microsoft volunteers Open-Source
- Uses Google/Apple API and compatible with EN-Express
- To be downloaded on smartphones, available in multiple languages

- State oversight team will conduct reviews to determine feasibility and make recommendations
- Currently in pilot at UW

Privacy considerations in public health surveillance

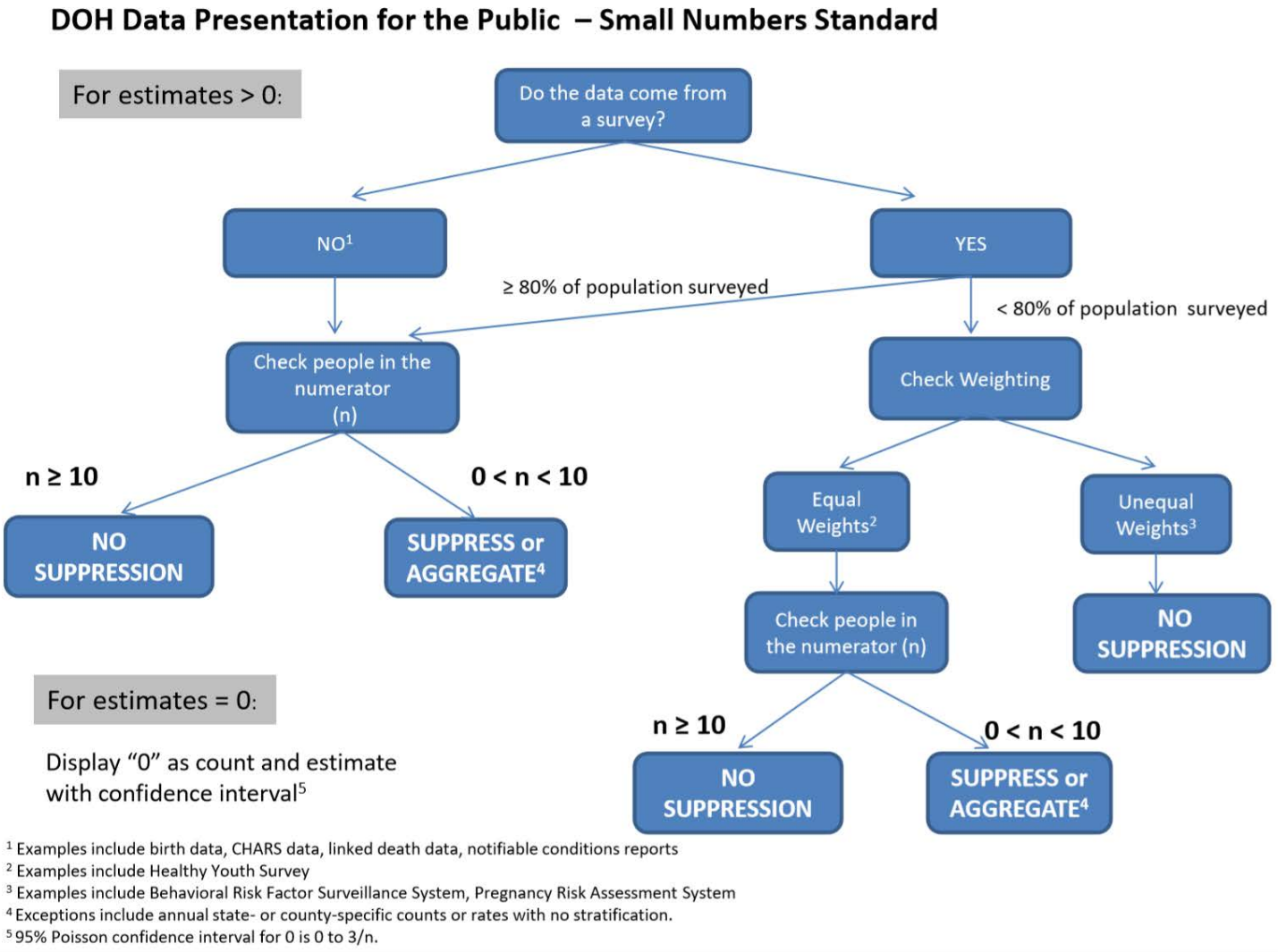
- Privacy and confidentiality are cornerstones of public health data collection. Without trust that health information will be protected, public health suffers.
- HIPAA does not limit protected health information (PHI) provided to Public Health (DOH), but the STATE Health Care Information Act rules and other laws do.
- Identifiable patient data is exempt from disclosure (under State rules and code)

Privacy Considerations for Release in public health surveillance



Ref for graphic: cen.acs.org/articles/92/i15/Secret-Science.html

Aggregate Reporting



[1] Examples include birth data, CHARS data, linked death data, notifiable conditions reports
[2] Examples include Healthy Youth Survey
[3] Examples include Behavioral Risk Factor Surveillance System, Pregnancy Risk Assessment System
[4] Exceptions include annual state- or county-specific counts or rates with no stratification.
[5] 95% Poisson confidence interval for 0 is 0 to 3/n.

Freedom of Information Act
CDC planned release public use dataset

WA comments on Centers for Disease Control and Prevention (CDC) is plan to release a public use dataset of COVID-19 individual case records with approximately 100 variables.

- Public trust is required for effective case investigation and contact tracing.
- We are already finding that cases are wary of providing contact information.
- Release of this level of granularity and identifiability may further erode trust the public has with state, local and tribal health, and may jeopardize disease investigations.
- Exact specimen collection, symptom onset, symptom resolution and CDC notification dates to be extremely problematic.
- Provision of exact dates will facilitate linkage to other data sources.

Plausible scenario:

- A user may identify social media posts from Washington State residents mentioning getting tested on specific dates, mentioning that the result was positive and including one other piece of information available in the non-confidential fields (such as being hospitalized)
- A user may then combine the above information with publically available data to identify and obtain demographic data for a subset of these individuals. This would result in a set of individuals with known identity for whom both test date, demographic information and one piece of additional information are known
- The user would then look for matches to this information in the COVID-19 public use dataset (PUD). If a unique match is found then that individual is identified in the PUD data (note that the L-diversity does not guarantee protection due to the additional piece of information)
- This would then reveal information these individuals have chosen not to make public, such as ICU ventilation, specific symptoms etc.

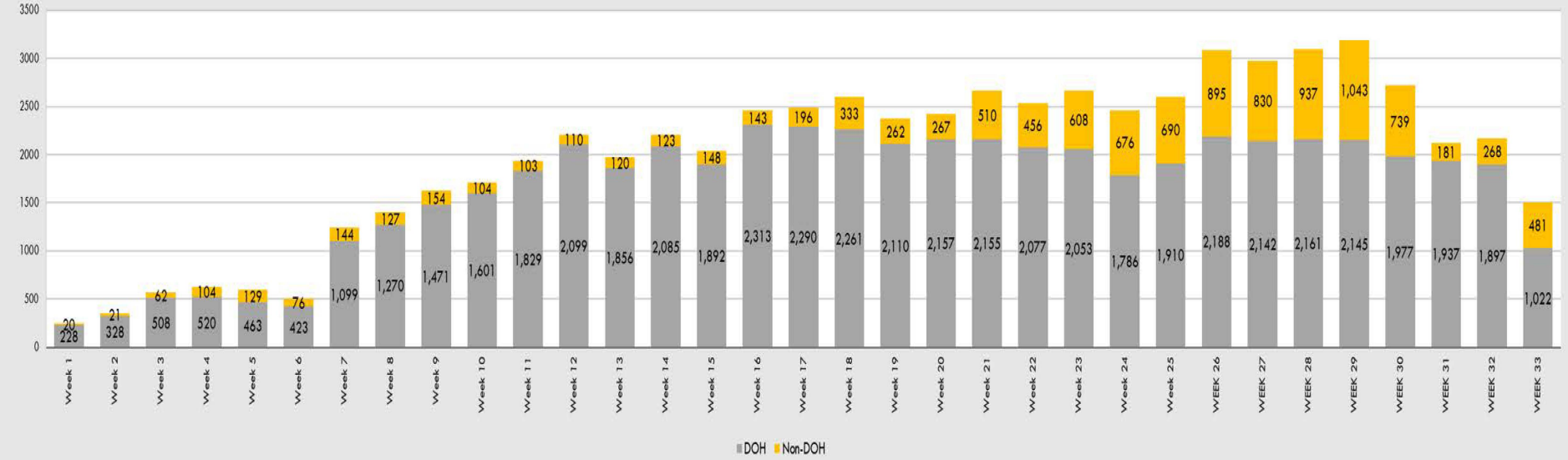
Standards and coordination lacking

- Centralizing to CDC or HHS does not allow states to ensure privacy and confidentiality. Even de-identified record level reports of line level data are of concern
- PH Case Reporting and Management Systems (MaVEN, NEDSS Base System (NBS)) are not well funded to modernize to new standards
- Case investigation and contact tracing systems (MS Dynamics, RedCAP, Salesforce, and dimagi CommCare) no standards or interoperable plan between states
- Sara Alert does use standards, but interoperability can't work as a one-way street
- Bluetooth Exposure Notification has potential if it can be coordinated and marketed well
- Care Coordination systems for support and wrap around services is an open question

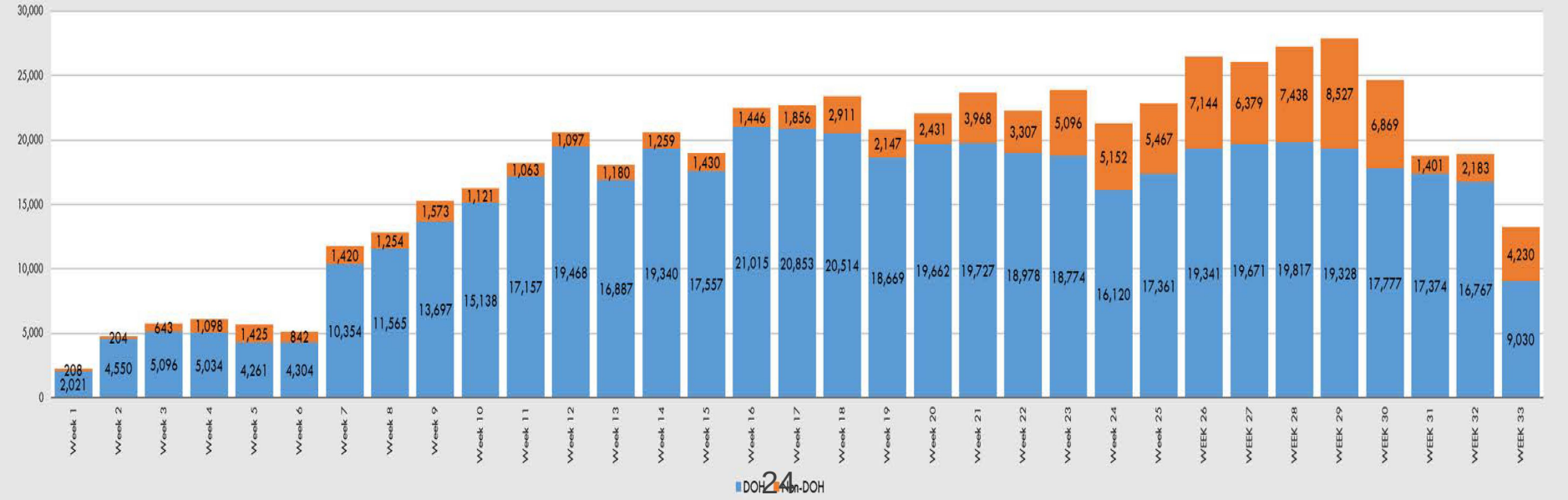
Critical workforce and research gaps

- Our most valued pandemic responders related to informatics are graduates of the CDC Applied Public Health Informatics Fellowship program
- CDC ceased funding for this program, which leaves a critical gap - we have no way to replace this expertise and no pipeline for new graduates
- People in these key roles in Washington have resigned due to an overwhelming workload
- Universities are no longer training this subject area due to lack of research funding (Public Health Informatics Centers of Excellence are no longer funded)

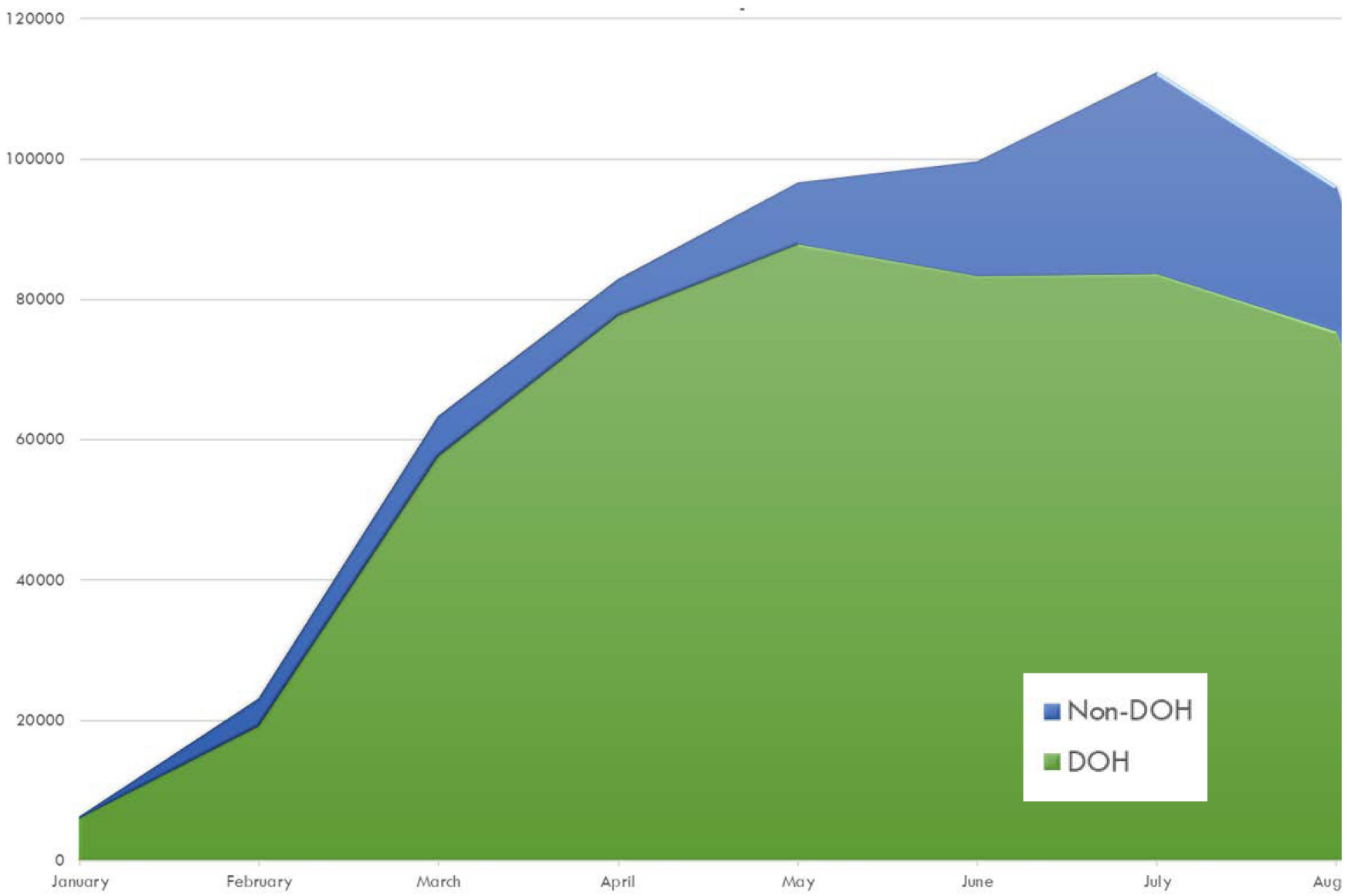
Staff Working Per Week/Day



Hours Worked Per Week/Day



Hours per Month on COVID19



Washington State Department of Health

Contact Information:

Bryant Thomas Karras, MD

Chief Informatics Officer

www.doh.wa.gov/healthit

Bryant.Karras@doh.wa.gov

Acknowledge the large number of people behind this work in multiple agencies!

Washington State Department of Social & Health Services

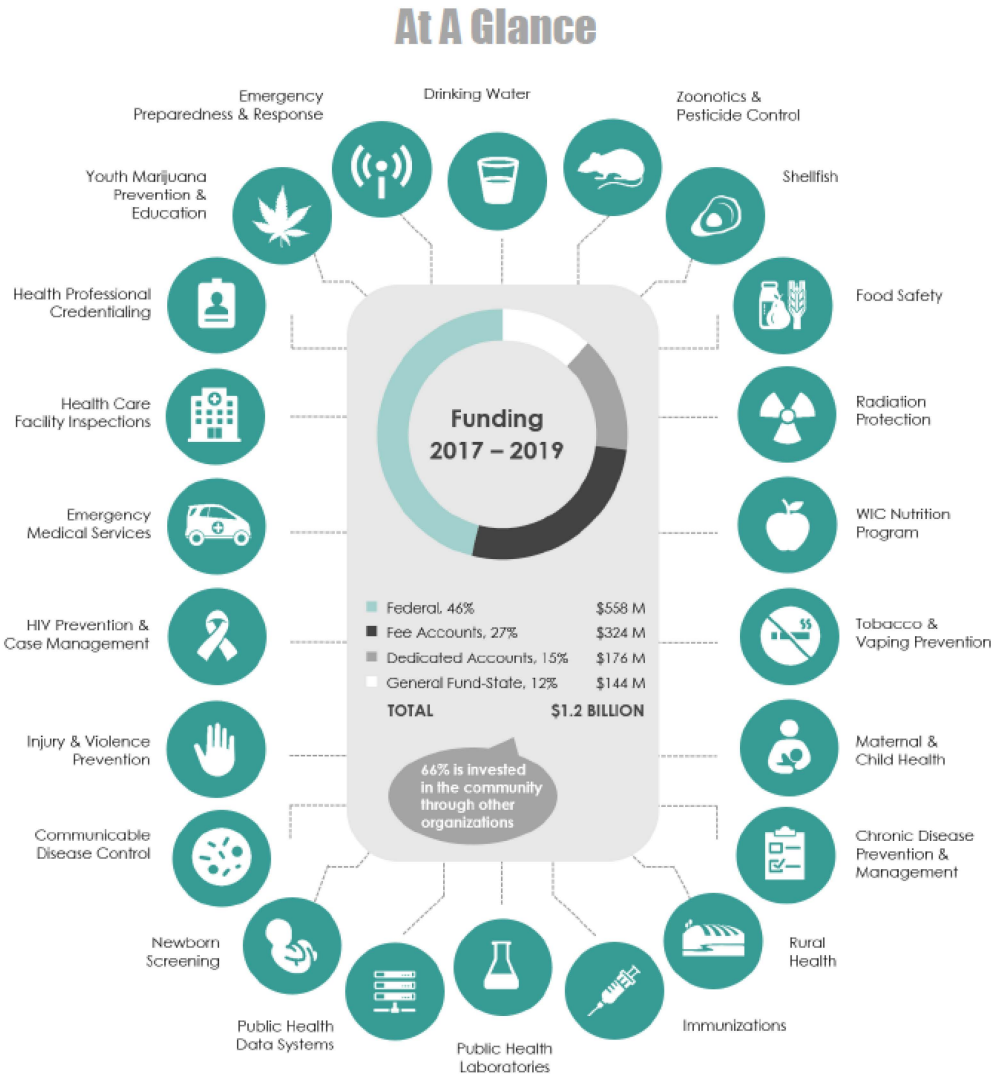
Transforming lives

Washington State Health Care Authority

Washington State Department of CHILDREN, YOUTH & FAMILIES

Washington State Department of Health is committed to providing customers with forms and publications in appropriate alternate formats. Requests can be made by calling 800-525-0127 or by email at civil.rights@doh.wa.gov. TTY users dial 711.

Washington State Department of Health Contributions to Healthcare

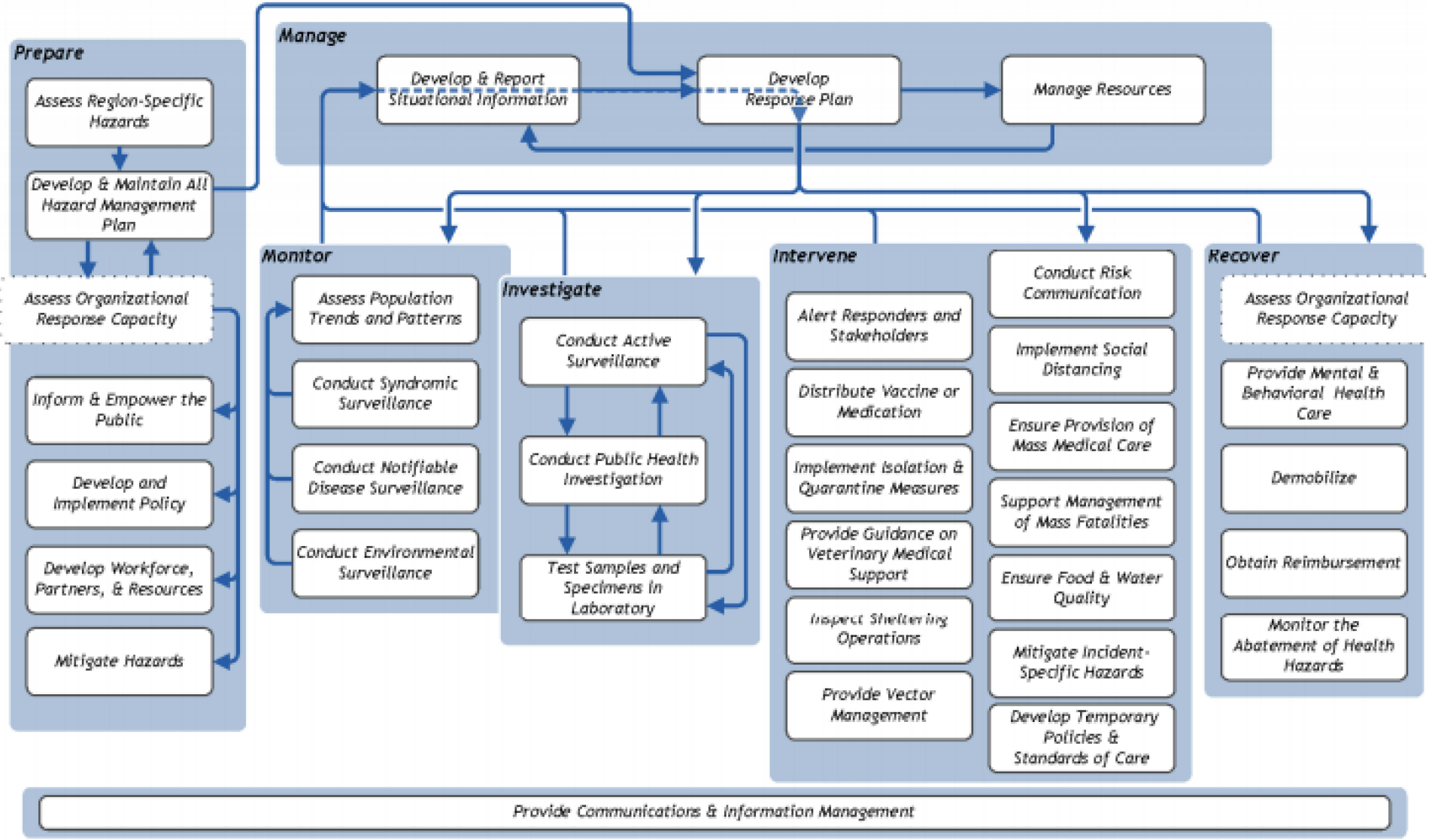


Common Ground: Public Health Preparedness Business Process Interdependencies

Common Ground Preparedness

Preparedness

Pre-Incident | Incident | Post-Incident



Legend: Business Process Group | Process | Business Process | Input Arrow | Short Circuit (the NIMS- & ICS-oriented "Manage" processes are often skipped or abbreviated during small incidents)

DOH HITECH Interoperability Diagram