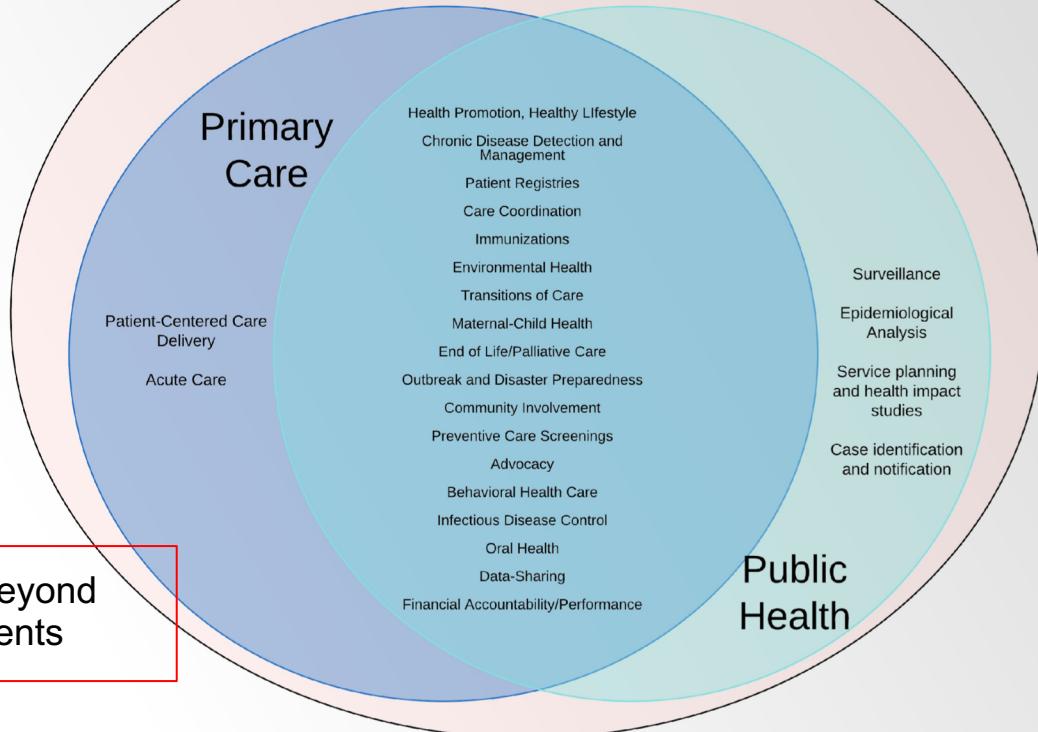# Data/Advocacy - Gift that keeps giving

Why it is important for USAPI notifiable data to be visible nationally?

- Visibility, awareness, recognition - "What gets measured, gets done."
- Participation on the same level with States
- Influence the appropriators in Congress as well as other partners
- Prioritizes interventions vs grant driven prioritization

Public Health and Primary Care Integration at CHCC

CNMI Population Health

Adapted from the American Academy of Family Physicians Integration of Primary Care and Public Health (Position Paper)

Primary Care

Patient-Centered Care Delivery

Acute Care

Health Promotion, Healthy LIfestyle
Chronic Disease Detection and Management
Patient Registries
Care Coordination
Immunizations
Environmental Health
Transitions of Care
Maternal-Child Health
End of Life/Palliative Care
Outbreak and Disaster Preparedness
Community Involvement
Preventive Care Screenings
Advocacy
Behavioral Health Care
Infectious Disease Control
Oral Health
Data-Sharing
Financial Accountability/Performance

Surveillance

Epidemiological Analysis

Service planning and health impact studies

Case identification and notification

Public Health

Data needs are beyond Federal requirements

Continuum of Care

Credit: Kaitlyn Nieses-Mocanu

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Typical Reporting Pathway - Notifiable Conditions

County	State	National

Eg. County of Honolulu, Maui, Hawaii

Eg. CA has 62 reporting sites

CNMI has potentially 3 reporting sites: Saipan, Tinian, Rota

Consolidation at the State level, aggregation.

Submission to Federal Agency

Reportable Conditions = National Center for Health Statistics at CDC

National Consolidation National Reports

** Public Use Data Sets**

Visibility
- KFF
- TFAH

cdc.gov/nchs/data_access/ftp_data.htm

CDC Centers for Disease Control and Prevention
CDC 24/7: Saving Lives, Protecting People™

All A-Z Topics

Search   All CDC ▾

National Center for Health Statistics

CDC > NCHS > Data Access

🏠 Data Access

National Death Index +

Public-Use Data Files −

  Compressed Mortality File +

  Data User Agreement

  Inter-university Consortium for Political and Social Research

  SPACE Program

  Vital Statistics Online

Related Sites

Public-Use Data Files and Documentation

The National Center for Health Statistics (NCHS) is pleased to offer downloadable public-use data files through the Centers for Disease Control and Prevention's (CDC) FTP file server. Users of this service have access to data sets, documentation, and questionnaires from NCHS surveys and data collection systems. Downloading instructions are available in "readme" files.

Public-use data files are prepared and disseminated to provide access to the full scope of the data. This allows researchers to manipulate the data in a format appropriate for their analyses. NCHS makes every effort to release data collected through its surveys and data systems in a timely manner.

Users of NCHS public-use data files must comply with data use restrictions to ensure that the information will be used solely for statistical analysis or reporting purposes.

On This Page

NHANES

National Health Care Surveys

NVSS

NSFG

NHIS

NIS

LSOA

SLAITS

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What are the challenges? And solutions? Examples?

- **Focus on Notifiable (reportable) conditions**
  - NEDSS = National Electronic Disease Surveillance System - standards driven - Jurisdiction system or CDC developed system-SaSS
  - NETSS - National Electronic Telecommunications System for Surveillance - one system, one approach, less flexibility
- Theories - challenges
  - Islands are reporting to CDC using NEDSS - data visibility
  - Islands are reporting to CDC using other than NEDSS, data is being accepted, but not published into national datasets
  - Islands are reporting to CDC using other than NEDSS, data is not being accepted.
  - Islands are not reporting

Examples?

- From the Federal perspective
    - CDC NCHHSTP ATLAS
    - CDC NCHHSTP DTBE
- From the external perspective (receive datafiles from CDC NCHS)
    - Trust for America's Health
    - Kaiser Family Foundation

https://www.tfah.org/states/

https://www.kff.org/hivaids/state-indicator/aids-diagnoses-adults-and-adolescents/?state=mp

https://www.cdc.gov/nchhstp/stateprofiles/default.htm

https://www.cdc.gov/nchhstp/atlas/index.htm

https://www.cdc.gov/tb/statistics/reports/2018/table28.htm

How can participating in NEDSS help my jurisdiction?

- Visibility, awareness, recognition
- Participation on the same level with States, **standardized data collection tools**
- **Data included in public data files to** Influence the appropriators in Congress (no lobbying by federal agencies) as well as other interested NGOs (who can lobby within reason)

How can I plan to implement NEDSS?

- Guam, CNMI - procurement, setup, implementation, incorporation
- Peer to peer technical assistance: Guam's time was influential for CNMI planning
- Discuss with NCHHSTP and ELC teams

Challenge to the PIHOA Board

1. Longer term: By Nov 2020, 4/6 USAPIs are 100% active on NEDSS; remaining 2 jurisdictions have a workplan to achieve active participation by March 2021

2. Shorter term: By March 2020, USAPIs work with NCHHSTP, NCEZID, and NCHS to resolve the inconsistencies with data accepting, reporting, publishing so as to inform a pathway to data visibility success for all USAPIs