From Data Share to Client Care: Four Tailored Jurisdictional Approaches to Data Exchanges

Georgetown University Center for Global Health Practice and Impact

Alabama Department of Public Health

District of Columbia Department of Health

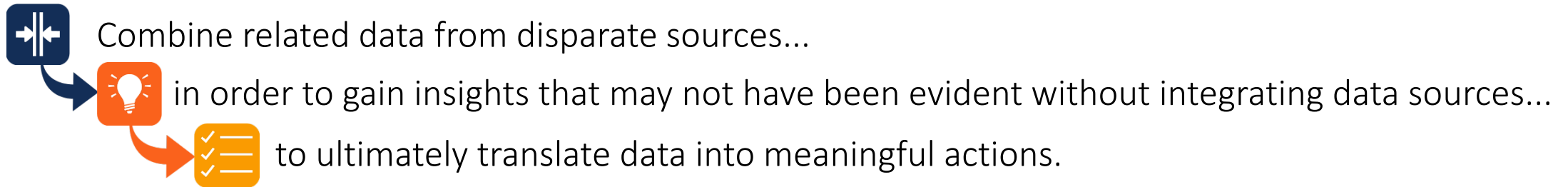Florida Department of Health

Louisiana Department of Health

2022

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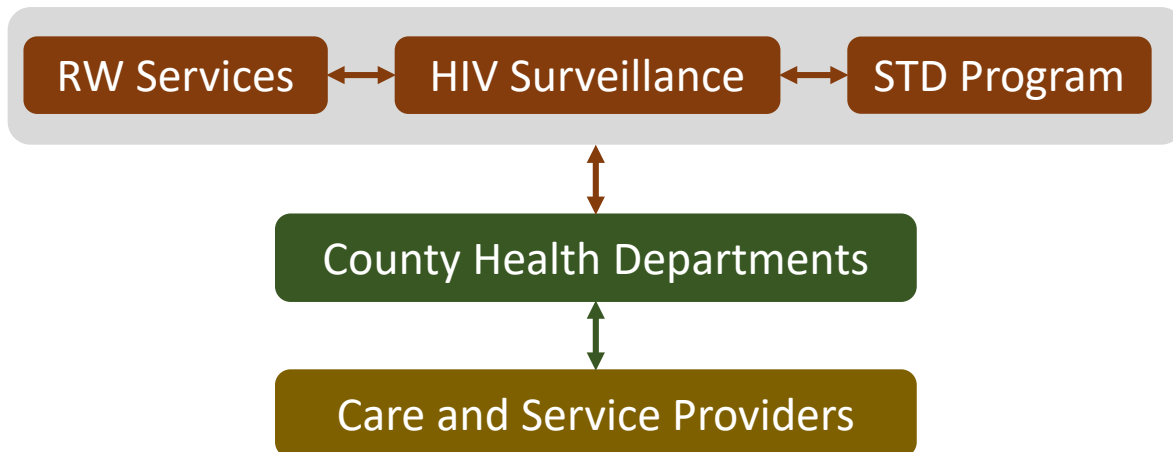
GU CGHPI Introduction

- The Center for Global Health Practice and Impact is within the Georgetown University Medical School

- We are a global, multi-disciplinary team of committed faculty experts, practitioners, staff, partners, and affiliates, serving throughout the world.

- Our Mission: CGHPI serves countries to sustainably improve their population's health and wellbeing and safeguard against health-related threats by advancing use of evidence through human-centered enterprise architecture for achievement of equity and social justice

- The vision of CGHPI is that our work will result in a world in which all countries assure conditions for achieving health equity.

HRSA 19-039 Initiative: *Improving Ryan White Outcomes Using a Tiered Technical System Approach to HIV-STI Data Linkages*

HIV-STI data linkages...

Combine related data from disparate sources...

in order to gain insights that may not have been evident without integrating data sources...

to ultimately translate data into meaningful actions.

...via a tiered technical systems approach...

RW Services ↔ HIV Surveillance ↔ STD Program

County Health Departments

Care and Service Providers

...to improve Ryan White client outcomes.

Utilize data to optimize client engagement processes ...

... to ultimately further PWH progression among the care cascade to achieve viral suppression

Background

GU provides technical assistance to the four jurisdictions involved in the project

- Alabama
- District of Columbia
- Florida
- Louisiana

Each jurisdiction is engaged in some form of data sharing that is intended to help improve client care outcomes and created continued successful progression across the HIV Care Continuum

Purpose

Review different jurisdictional approaches to conducting HIV out of care list data matching processes in order to identify persons that are truly out of care and prioritize re-engagement efforts. This presentation outlines the similarities and differences of the four jurisdictions in their processes, successes and challenges.

1. There are multiple approaches that can be taken to data matching; utilize an approach that meets the needs of all collaborators as well as their current capacity capability.

2. Emphasize the need for more coordination and collaboration among RWHAP and HIV surveillance programs.

3. Keep it simple, overcomplicating the process can be a barrier as well as a burden for participation – be cognizant of the limitations.

Alabama Department of Public Health

Tiffany Wilson, MPH

Senior Epidemiologist

HIV Data Management Division

Alabama

- The Alabama Department of Public Health (ADPH) utilizes the National Electronic Disease Surveillance System (NEDSS) Base System (AL-NBS) to gather, store, review, and update diagnosis, care, and investigation data for all persons in AL living with or diagnosed with HIV and/or notifiable STDs.

- Jefferson County Department of Health (JCDH) transitioned away from the epi system preceding ALNBS to a system made in house. Jefferson county has one of the highest burdens of HIV and STDs in the state, and therefore it was critical to JCHD that they be able to access and utilize data regarding their population on a real-time basis.
  - Homegrown data system, TIGER
  - The TIGER data system has been very successful within the county
  - The downside to this new system is that it is not directly compatible with AL-NBS

- Georgetown University met with JCHD and the University of Alabama-Birmingham (UAB) in July of 2020 to discuss gaps in data sharing between local and state systems.
  - Building and data sharing enhancement

Alabama 2

Goal

ADPH wanted to establish a DSA with UAB - one of the largest HIV providers in the state. This DSA would allow for data matching and collaborative Data to Care (D2C) activities.

Alabama 3

Process

GU facilitated multiple meetings between ADPH and UAB to discuss:

- Purpose, data needs, data use, outcomes, benefits, etc.

ADPH identified the variables that they need from UAB, as well as what variables they would provide back – UAB reviewed and agreed that the information was sufficient

GU worked with ADPH to craft a DSA for their legal team for review

ADPH DSA is still currently pending legal approval

Alabama 4

Successes

o Increased collaboration

o Drafted and submitted DSA

Challenges

- Staffing constraints

- Long legal approval process

- Heavy workload/competing priorities

Florida Department of Health

Karalee Poschman, MPH

CDC Assignee/ Epidemiologist

Bureau of Communicable Diseases

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Florida

- The Department of Health is centralized in Florida and all 67 county health departments are part of the Florida Department of Health (FDOH)

- FDOH uses the Enhanced HIV/AIDS Reporting System to collect and manage data for all persons living or diagnosed with HIV in Florida

- The HIV Data Warehouse (HIVDW) houses a subset of information from HIV-related care databases, HIV and STD Surveillance databases, and HIV Prevention program databases to improve data linkage across HIV and STD data systems

- FDOH uses a home-grown system that is connected to the HIVDW to assign and monitor HIV linkage to care activities

Florida 2

Florida identified that there was a need to address their large out of care population that need care re-engagement.

However, due to the unique situation with their six (6) RWPA programs as well as legal barriers, external data matching with the Part A programs had not occurred prior to this project.

GOAL

Routine data matching between FDOH, directly with the six RWPA programs, through formal data sharing agreements.

Florida 3

Process

GU supported FDOH and the six RWPA programs through a series of collaborative efforts such as:
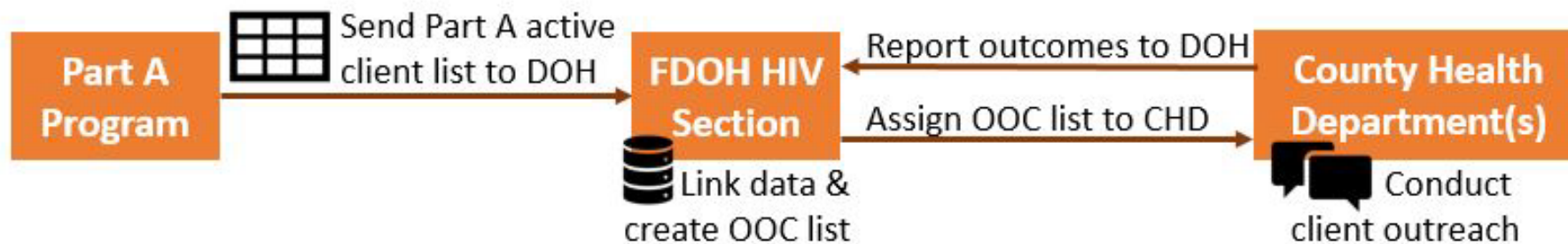
- Multiple collaborative meetings and retreats

- In depth needs assessment of Part A systems and program operations

- Developed process flows, SOPs, and DSA drafts

- Workshop and brainstorm opportunities for outreach coordination between state health department, county health departments, and Part A programs for optimized client outreach

Florida 4

Process

While the DSA was pending, FL and the Part As identified a "work around" to facilitate data sharing.

- FDOH piloted a data sharing process with Palm Beach and Orange Part A areas, leveraging the respective County Health Departments to circumvent legal restrictions for sharing data with the Part A directly

Florida 5

Successes

- Legal approval
- Increased collaboration/communication
- Data cleaning

Challenges

- Getting all 6 Part A's to sign the same DSA
- Long legal approval process

Louisiana

- The LDH Office of Public Health is comprised of 1,100 professionals across Louisiana who are charged with protecting and promoting the health of the communities of our state.

- The STD/HIV/Hepatitis Program (SHHP) is a unit of the Bureau of Infectious Diseases (BID) within the Office of Public Health. The STD/HIV/Hepatitis Program has integrated HIV and STI work since 2010 and incorporated viral hepatitis in 2019.

- SHHP's Surveillance unit is charged with oversight of all HIV, gonorrhea, chlamydia, syphilis, congenital syphilis, hepatitis B and hepatitis C diagnoses and accompanying laboratory values and data points.
  - SHHP conducts surveillance using six different surveillance systems and laboratory management systems, that are continuously data managed, quality controlled, and matched to each other and additional data systems for accurate, timely, and complete reporting.

Louisiana 2

SHHP has always conducted data matching with some of the larger HIV providers, but it was done on a more "as needed basis" with no real guidelines set.

However, due to some staffing constraints SHHP realized there was a need to standardize the process to lessen the load on their staff. By formalizing the process, it could also be expanded to a wider network of providers.

GOAL

To create a more streamlined approach for how SHHP conducts surveillance data matches with HIV care providers in Louisiana.

Louisiana 3

Process

- Held multiple internal meetings to identify who the matches would be tailored to, what variables needed to be provided/returned, format, file exchange

- Worked with GU to draft a data sharing agreement which outlined the parameters for the data exchanges; which was then sent to the LDH legal team for review and approval

- Started to roll out the streamlined revamp of this process by presenting to the members of the CQI group

Louisiana 4

Process

- Worked with GU to develop a "toolkit" which contains sharable documents for those interested in participating in the data matching. Inclusive of documents such as: FAQ, sample variable input/output file, best use document

- Held two webinar sessions for HIV providers to explain the process to them

- DSAs were sent out to the HIV providers for signatures

Louisiana

Successes

- Fast DSA approval from legal
- Eases the burden of the workload on staff
- Created a fully defined process

Challenges

- DSA Signatures
- Staffing turn over

District of Columbia Data Exchanges between Surveillance and Ryan White Program

Rupali K. Doshi, MD, MS

Medical Epidemiologist

HIV/AIDS, Hepatitis, STD and TB Administration
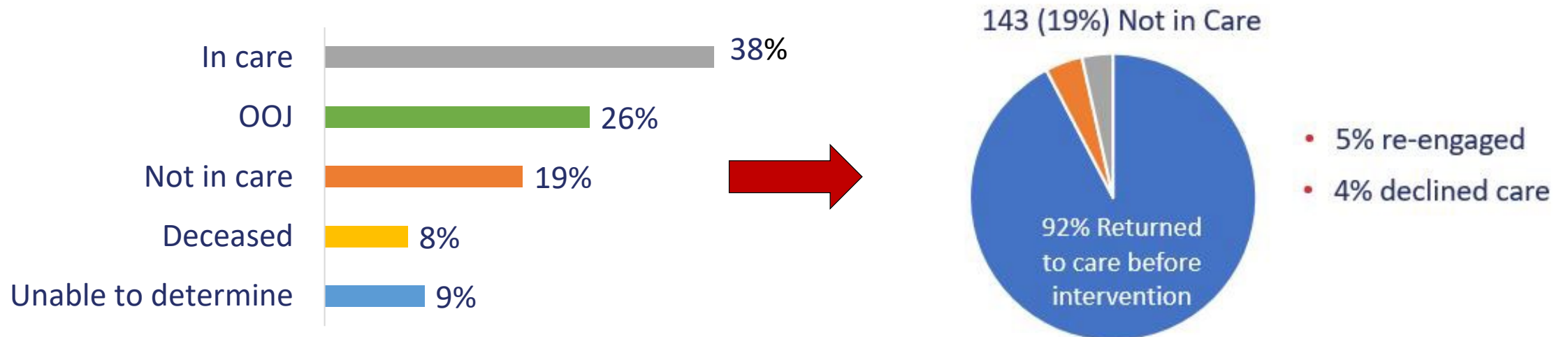
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District of Columbia

- Goals
  - Improve collaboration between Ryan White and Surveillance Divisions
  - Enhance data feedback on RW clients with STI
    - Feedback loop between RW and both components of surveillance databases
  - Enhance Data to Care Activities in collaboration with Ryan White

- HIV/AIDS, Hepatitis, STD and TB Administration
  - Strategic Information Division – surveillance and epidemiology
  - Care and Treatment Division – Ryan White program

District of Columbia 2

- HIV prevalence: 12,408: 1.8%
- Clients who received RW OAHS services in 2019: n=905
- Data-to-Care outcomes 2019, n=747 total cases

143 (19%) Not in Care

- 5% re-engaged
- 4% declined care

92% Returned to care before intervention

District of Columbia: Roles and Responsibilities

CAREWare Administrator

- Extracts initial CW data for specified timeframe
- Distributes data to QI staff for validation
- Reviews and validates matched data added into CW by QI staff

Epidemiologist

- Validates data from CW
- Performs CW data match against surveillance databases
- Shares matched data with QI staff for CW upload

QI Staff

- Extracts initial CW data for specified timeframe
- Distributes data to QI staff for validation
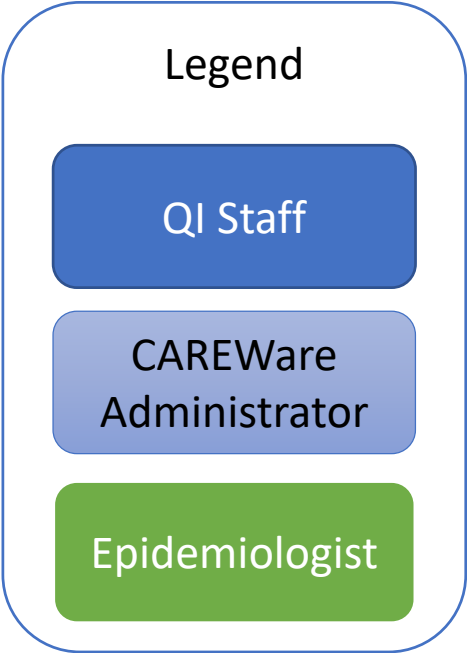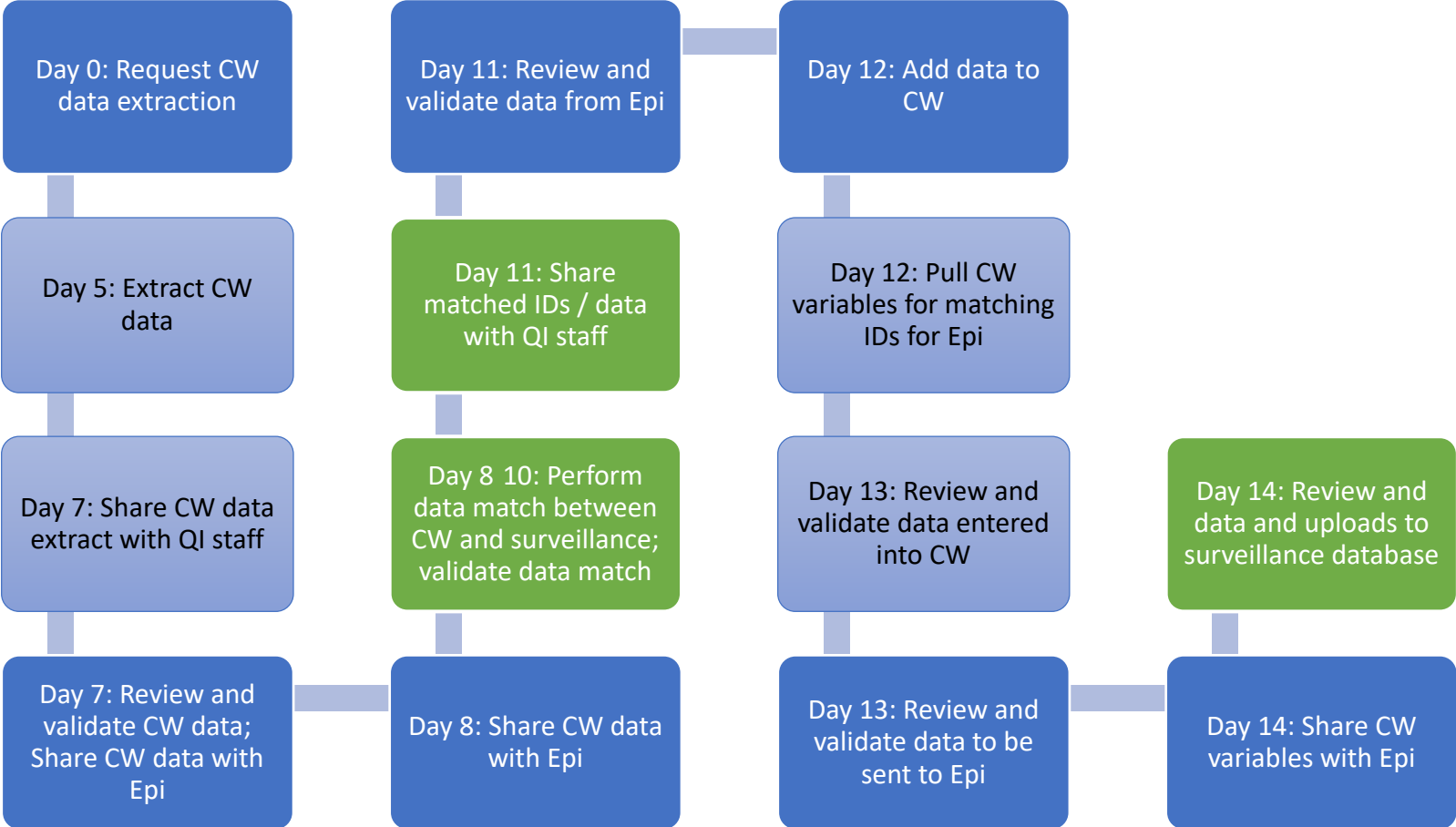- Reviews and validates matched data added into CW by QI staff

District of Columbia: Quarterly Data Exchange

Day 0: Request CW data extraction

Day 5: Extract CW data

Day 7: Share CW data extract with QI staff

Day 7: Review and validate CW data; Share CW data with Epi

Day 11: Review and validate data from Epi

Day 11: Share matched IDs / data with QI staff

Day 8 10: Perform data match between CW and surveillance; validate data match

Day 8: Share CW data with Epi

Day 12: Add data to CW

Day 12: Pull CW variables for matching IDs for Epi

Day 13: Review and validate data entered into CW

Day 13: Review and validate data to be sent to Epi

Day 14: Review and data and uploads to surveillance database

Day 14: Share CW variables with Epi

Legend

QI Staff

CAREWare Administrator

Epidemiologist

District of Columbia: Successes and Challenges

Successes

- Developed a process mapping document and protocol
- Developed quality assurance reports
- Routinized RW/EHARS matches – sustainable after project ends
- Developed a SAS program to automate some of the process making it more efficient
- Increased completeness of RW data

Challenges

- Coordinating activities across different teams
- Data harmonization
- Navigating security and confidentiality of data systems across divisions
- Staff detail during COVID-19 and turnover

Conclusion

- There are multiple approaches that can be taken to reach the same outcome

- As long as the approach is tailored to the needs and the capacity of the organization, the goals can be reached

- Communication and collaboration across all departments involved help to make the process more efficient

- Keep in mind, how the process will help to trigger effective linkage to care or care re-engagement

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Thank You

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