Data to Care is a new public health strategy that aims to use HIV surveillance data to identify HIV-diagnosed individuals not in care, link them to care, and support the HIV Care Continuum.

CDC and John Snow Inc. (JSI) developed a D2C toolkit located on: https://effectiveinterventions.cdc.gov/en/HighImpactPrevention/PublicHealthStrategies/DatatoCare.aspx

Resources include:
- List of important considerations
- Health Department Case Studies
- Tools and Resources
Goal of D2C Community of Practice

- CoPs are working to strengthen public health as members learn, share expertise, and work together on solving common problems in their communities’ domains.

- D2C CoP pilot is a series of interactive conversations between jurisdictions on strategies, challenges and practices.

Desired outcomes:
- Create a comprehensive list of best practices and challenges
- Select an idea, challenge or practice to work on as a team
- Create an active forum to share ideas and develop template for products
D2C CoP Idea Sharing Series

**Today**
D2C Case Studies in Implementation (South Carolina and Hawaii)

**Webinar #2**
*Thursday, April 16, 2015*
Developing polies and procedures for D2C Implementation (Colorado)

**Webinar #3**
*Thursday, May 14, 2015*
Community Engagement: “Necessary Conversations” (Massachusetts)

**Webinar #4**
*Thursday, June 4, 2015*
Operationalizing Data: Data and Data Systems used in D2C (Washington state, Colorado, Massachusetts)
**Current Roles in CoP: User Generated Content**

- **CoP Participants**: (Everyone): Active, open, honest participation in virtual discussions and polls. Express their ideas and discuss challenges and potential solutions.
- **Co-leaders of CoP** (South Carolina): Manage the community and ensure delivery of meaningful content and solutions.
- **CoP Facilitator**: (Hawaii): The facilitator is responsible for managing meetings, keeping conversations on track, and ensuring each member’s voice is heard.
- **Cop Subject Matter Experts (SME)**: Massachusetts, Colorado and Washington State: Sharing technical approaches, tools, best practices and challenges to start dialogue during each community meeting.
- **Community Sponsor (NASTAD)**: Facilitate communication and distribution of content to stakeholders.
- **Technical Support (DARE Global Innovations)**: Support development of community content.
D2C Capacity Survey: Readiness Activities

COMPLETED

- Conducted ongoing assessment and monitoring of timeliness and completeness of HIV surveillance data, including laboratory reporting, to ensure minimum data quality standards are met. (70%)
- Assessed internal and external compliance with CDC’s NCHHSTP data security and confidentiality guidelines. (70%)
- Met with relevant health department stakeholders (e.g., HIV prevention/care, HIV surveillance, STD surveillance, etc.) and consider ways to strengthen program integration. (57%)
- Reviewed state laws/regulations related to bi-directional sharing of individual-level HIV surveillance case data. (57%)

NOT STARTED

- Developed a protocol for how data will be used and reported to stakeholders (dissemination plan). (52%)
- Assessed internal and external training needs and developed/implemented trainings respective to identified needs. (48%)
- Developed and implemented program evaluation plan. (57%)
- Developed and implemented quality assurance (QA) plan including a plan for assessment of ongoing risks and benefits (effectiveness). (57%)
D2C Capacity Survey:
D2C Models Being Implemented (as of 3/17)

- Combination Health Department/Healthcare Provider Model 61.5%
- Health Department Model 23.1%
- Other, please specify 15.4%
D2C Capacity Survey: Collaboration between HIV Prevention, Care, Surveillance Programs (as of 3/17)
Today’s Learning Objectives

- Share Case Studies from the Field including preliminary steps, tools developed and lessons learned
- Share data from D2C Status Survey
- Preview content from upcoming calls
- Discuss between call engagement
Participation in today’s call

- Phones are muted
- **Today’s call is an interactive discussion forum.** Please ask questions during the presentation via chat box.
- We encourage all participants to respond to questions and share their experience via chat box as we move through the presentation.
- Please participate in polling throughout the call.
South Carolina & Hawaii: A Case Study

Monetha Gaskin, MPH, CHES & Eric Jalonen (South Carolina), CoP Co-Leaders
Michelle Wozniak, MPH (Hawaii) - CoP Facilitator
As of December 2013, South Carolina has over 6,000 people living with HIV/AIDS currently out of care.

- South Carolina defines out of care as persons with no subsequent tests ≥30 days after initial diagnosis or no CD4 or VL test on record in 270 days (≥9 months)
Why are we implementing Data to Care in South Carolina?

- South Carolina recognized a problem of PLWHA not in Care
- Division collaboration (Prevention, Surveillance and Care)
- Two goals:
  - 1. Increase the number of HIV positive persons in care
  - 2. Increase Viral Suppression
In Hawaii, there are 2,208 people living with HIV (PLWH)

- **Only 44%** are retained in medical care
- **Only 52%** are virally suppressed

What is the health department responsibility to act on this information?
Why did we implement D2C in Hawaii?

- Received Category C in 2012, project to use HIV Surveillance for HIV Partner Services
- Developed Data Sharing Agreement between HIV Surveillance and HIV Prevention for use of new HIV cases
  - Expand this to cases not retained in care or with high viral load
- DOH HIV testing efforts finding very few new positives, new effort to change focus of HIV prevention
How are we doing D2C in South Carolina?

- SC received Technical Assistance from JSI to pilot D2C in 2014
- JSI and CDC provided guidance on surveillance data security and confidentiality
- SC DHEC developed a draft comprehensive Data to Care Program Model
  - Who will provide outreach, how the Out of Care (OOC) line list will be shared with outreach staff, and what interventions will be used to link/re-engage
- JSI and SC DHEC created protocols for generating the OOC line list
  - Included information on the working OOC definition, processes for documenting OOC outcomes, and prioritization of cases
  - Build an additional database to store OOC demographics/outcomes, working on prioritization process (CD4/VL, 9-12months, location, age etc.)
- SC used general community and provider Data to Care information and promotional materials provided by JSI for formative engagement of stakeholders
Polling Question

How does your jurisdiction define out of care when generating lists for follow up?
Considerations for implementing D2C: The South Carolina Experience

Considerations:
- Select a framework that worked for our state
- Assess surveillance’s ability to run Out of Care list
- Collaborate on breaking down silos within the division
- Sought out advice from Office of General Counsel (Legal Review)
- Actively sought community and provider buy-in for the strategy
- Assessed availability of current staff
- Document additional staff needed to fulfill requirements
Does your jurisdictional surveillance team have the capacity to generate out of care lists routinely?
In Progress: Steps toward implementing D2C (South Carolina)

- Think Tank Groups formed to guide implementation
  - Formulating workgroups comprised of community partners, providers, PLWHA, SC DHEC staff
  - Drafting Data Sharing Agreements
  - Developing Policy and Procedures
  - Developing Job Descriptions, Marketing and Notice of Privacy
Polling Question

Does your jurisdiction need or have data sharing agreements that allow the sharing of client level data between surveillance, care and prevention programs?
Tools developed in South Carolina

- Access Database: Working up cases and updating data
- Purpose: Monitor progress of OOC list
- Users: Coordinators who are contacting PLWHA
- Added Value: Used to monitor case disposition, update data from field
- Updating existing systems: Data exported from database and imported into eHARS
- Data is securely shared via portal accessible by surveillance and prevention on DHEC servers
Process Maps, SC (Share Screen)

- **Purpose:** To document how data securely flows through SC DHEC
- **Audience:** Prevention, surveillance and care staff
- **Use:** Define new business rules within the administration
- **Message:** Secure data sharing can be complex but possible
Share Screen
South Carolina
Tools Needed in South Carolina

- Technical Assistance for Policy and Procedure Manual
- Synced Data Systems
Polling Question

Has your jurisdiction started mapping out D2C business rules and process flow diagrams?
Polling Question

Has your jurisdiction developed policies and procedures manuals for D2C?
South Carolina Lessons Learned

- This is not an easy process
- Seek Legal Counsel first
- Make sure surveillance data is current and people are in place to assist with running OOC routinely
- Community engagement is critical
- Prevention, Surveillance and Care can work together for the common good
Considerations in Hawaii

• Using laboratory data versus eHARS
• Use of Lexis Nexis in verifying identifying information
  • Lexis Nexis is an “interactive tool that integrates medical and legal research with your case facts.”
  • Use Lexis Nexis to update case surveillance and OOC information
• Best Practice: Use of case management as part of the follow-up (Approx. 50% of PLWHA are enrolled in case management funded by RW and state funds)
How did we do D2C in Hawaii?

SUCCESS
- JSI TA
- Leadership
- Community involvement via CPG
- Integrated D2C team including HIV Prevention, STD Prevention, HIV Care, HIV Surveillance

CHALLENGES
- Time consuming
- Relationship building
- Data Sharing considerations
- Evaluation/Data collection
- Training for outreach staff
D2C In Progress in Hawaii

- Training of combined STD/HIV Partner Services staff
- Question to be answered: **What to use for data collection and evaluation?**
  - STD and HIV use different case collection
- Developing strategies for data sharing outside of DOH, specifically with case management agencies
Polling Question

Does your jurisdiction share D2C data (surveillance, laboratory data) outside of the health department?
Planning Group discussion questions

1. How should re-engagement to medical care be approached for different types of clients?
2. What are some of the resources/tools you use for re-engagement to medical care?
3. How do you handle clients who say “do not contact me”?
4. If a client is re-engaged in medical care, how do you ensure they are retained in medical care?
5. What happens when your client is fully engaged in case management and retained in medical care but is not virally suppressed?
Tools Developed:
Letter/Flyer to Providers
Share Screen Hawaii
Tools Needed in Hawaii

- Training materials for outreach staff
- Confidentiality and Security training for outside agencies
- Data Collection and Evaluation Tools
Lessons Learned in Hawaii

- It’s a marathon not a sprint
  - Don’t focus on outcomes in the beginning, process is very important
- Relationship fostering is very important
  - How does this project benefit all parties involved?
- Community buy-in is important
Highly Rated as Technical Assistance Needs

a. Identifying funding needs and secure additional funding, if needed. (48%)
b. Developing a protocol for how data will be used and reported to stakeholders (dissemination plan). (48%)
c. Developing and implement program evaluation plan. (48%)
d. Developing and implement QA plan including a plan for assessment of ongoing risks and benefits (effectiveness). (52%)

Best Practices

“...establishing a work group that meets regularly allows us to maintain momentum”

“It is extremely important to have timely, accurate HIV surveillance data.”

“The development of a very detailed data flow chart is one concrete example of what is critical to fully explain and get buy-in on the concept of D2C”.
Polling Questions

What is your greatest need in implementing D2C?

a. Identifying funding needs and secure additional funding, if needed.

b. Developing a protocol for how data will be used and reported to stakeholders (dissemination plan).

c. Developing and implement program evaluation plan.

d. Developing and implement QA plan including a plan for assessment of ongoing risks and benefits (effectiveness).
Polling Question

Are you willing to work in a CoP to develop tools by June 2015 to meet a specific need?
Thank you!

Questions?
Next Steps...

- Schedule a mind mapping session by April 4, 2015
  - Map documented challenges to potential solutions

- Map solutions and products
  - What are your thoughts on this matter?
  - How would you approach implementing solution?
  - Do you think this is the correct way to proceed?
  - What has your past experience shown you on this topic?
  - How do you think this project can proceed most effectively?
Reminder: Next D2C Webinar
Thursday, April 16, 2015

- 4/16: Colorado to discuss developing policies and procedures manuals for Data to Care.

- Please fill out survey at
  http://www.surveygizmo.com/s3/1990409/Data-to-Care