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Data to Care in the Field

FREQUENTLY-ASKED QUESTIONS (FAQs)

The University of Washington Public Health Capacity Building Center (UW PHCBC) and NASTAD hosted a peer-to-peer videoconference with a group of health department D2C staff (surveillance, prevention, care, and D2C field staff including Disease Intervention Specialists) and Capacity Building Assistance providers in September 2016. This FAQ document summarizes the questions and group discussion during the videoconference as a resource for other health department D2C programs. The FAQ responses included in this document include specific examples shared by the D2C program in King County during the videoconference, as well as general lessons learned about D2C from other health department programs and CBA providers.

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COLLABORATIONS IN D2C

Many D2C programs work closely with medical providers. There are advantages and disadvantages to this approach (see chart). Other potential partners to coordinate with on D2C-related efforts and individual patient care coordination include Ryan White medical case managers and community-based organizations (CBOs).

COLLABORATING WITH MEDICAL PROVIDERS ON D2C

ADVANTAGES	CHALLENGES
• Providers have up-to-date contact information	• Takes time to contact providers
• Up-to-date labs	• Providers may attempt to block contact with patients (rare)
• Build relationships to facilitate relinkage and case reporting	
• May be able to help reach out to patients	

With which partners should health departments have a data sharing agreement? What about former providers or case managers who have previously had contact with that client?

Requirements for data sharing agreements will vary by jurisdiction. Health departments can consider having their compliance officers talk to staff from major providers about the need for data sharing agreements if patients don't have up-to-date release of information forms. Two-way communication may be permissible if the purpose is ensuring continuity of care. CBOs present a bigger challenge for sharing client-level surveillance data. Even for CBOs that are funded by the health department, sharing information on patients who weren't previously receiving care at that CBO could cause confidentiality concerns and ultimately erode trust in the D2C program. However, working to coordinate the health department's D2C program with existing linkage activities at CBOs can be explored and may be beneficial.

How should D2C field staff engage clients who would prefer to get linkage services through a CBO or someone besides the D2C field staff working with them? Can you transfer the patient to someone else if you have trouble contacting them?

Involving other organizations or CBOs can be helpful if they will better serve that individual or if they will be able to successfully engage with that individual. Sometimes the client may need a different messenger than a D2C field staff. However, confidentiality of surveillance data needs to be maintained when involving outside organizations.

How should health departments ensure a coordinated response around D2C for the specific key populations they serve?

It's often easier for individuals to talk to someone they can relate to, so it's important to have people on staff that reflect the same communities your health department serves. Staff should also be familiar with the language and messages that will resonate best with different key populations. Before meeting with a client in person, field staff should also research the client thoroughly (for example, reading prior case notes and risk information) to be prepared with a sense of the client's background, which field staff might be best able to build rapport with them, their possible barriers to care, and an idea of the other referrals they may need (e.g., drug user health services).

KEY TRAINING/SKILLS FOR D2C FIELD STAFF

1. Case investigation: DIS or other D2C staff need to have background investigation skills and access to multiple data sources (e.g., electronic health records from medical facilities, HIV/STD databases, death records, people search tools for most current address, social media, etc.).

2. Ability to describe contemporary HIV care & treatment: identify any outdated misinformation that may be a barrier to accessing treatment and describe modern advances in regimens and unlikelihood of transmissibility if one remains virally suppressed.

3. Healthcare systems and insurance navigation: DIS/D2C field staff should be able to give active referrals (i.e., help schedule a medical appointment) and understand eligibility requirements for Medicaid, Ryan White, etc. in their jurisdiction.

4. Communication with health care teams about D2C: to actively improve the process and communicate the barriers and status of re-linkage back to the team.

MEASURES, DATA, AND EVALUATION

D2C programs should decide whether they want to measure re-linkage (completion of first medical appointment), re-engagement (continuing appointments over a certain period), or both. In the long-term, tracking viral suppression of D2C clients can also be an evaluation indicator. At a minimum, staff should follow clients until they complete their first medical appointment. Programs will need a database to track their work in the field (including a mechanism to track case completion and open cases over time) and provide data back to the surveillance database, and should carefully consider which case "disposition" categories to use.

How should you confirm the clients attended their medical visit?

Methods could include calling the clinic or provider to confirm, a search of electronic medical records (if accessible), or verifying via CD4/VL lab results reported to surveillance.

What are some recommended disposition codes and definitions?

To best evaluate your program, be clear about definitions differentiating someone who was erroneously coded as not-in-care versus someone who was truly not-in-care and relinked through your D2C program (see text box for some examples of suggested codes).

When do you stop trying to contact people if they're not responding?

In King County, the Care and Antiretroviral Promotion Project (CAPP) tries to reach individuals who are not-in-care through three phone calls, followed by a letter if they don't respond (which also tests whether their address is valid), and then an in-person visit if they don't respond to the calls or letter. See the following publications for more information about the development of the CAPP program and common barriers to care reported among CAPP participants, or contact uwphcbc@uw.edu for more details. Doing a face-to-face visit first may work well to develop rapport, but isn't as time efficient as phone outreach. Some D2C programs also have timelines to close out cases if clients don't respond to any type of contact within a certain period (e.g., 30 days).

EXAMPLES OF DISPOSITION CODES AND DEFINITIONS

- Data error (duplicate case, or not HIV positive)
- Died
- In care during surveillance period (i.e. missing lab report)
- Moved – confirmed (with another surveillance jurisdiction)
- Moved – presumed (if not able to verify with surveillance records)
- Out of care – confirmed or presumed (none of the above)
- Out of care during surveillance period, but relinked to care

What databases can D2C programs use?

To investigate contact information, Accurint™ is a helpful resource. However, it's most helpful to look up contact information as close as possible to the date the actual field work will occur so D2C field staff are working off the most recent information. To track data and outcomes, health departments are using a variety of databases including custom-made Access systems, REDCap systems, EpiInfo™ (in low prevalence areas), and those integrated into other health department databases. Suggested data fields are available from CBA providers.

What can health departments do with clients who appear to have moved out-of-jurisdiction?

Ideally, the health department should contact the other jurisdiction's health department to verify whether the client was truly receiving care in the other jurisdiction. However, the ability to do this for all people living with HIV (PLWH) who appear to be out-of-jurisdiction is dependent on time and resources.

CASELOAD

D2C field staff caseload should be one of the indicators tracked by D2C programs. This will vary by morbidity, staffing level, geography, and other factors. King County DIS handle 300-500 cases per year, per staff member and typically have 30-40 open cases at one time.

How can programs determine appropriate caseload for field staff?

Caseload will depend on whether staff are mainly in the office or out in the field, as in-the-field staff will be able to see fewer cases per person. Other factors that impact caseload include the degree of intensity involved in re-linkage (an hour-long intervention vs. a phone call), and stage of the D2C program (newer programs will likely have more clients on the list who have relocated out of the state and won't require field visits and linkage services).

METHODS FOR LOCATING OUT-OF-CARE INDIVIDUALS

Health departments often use a combination of the approaches in the chart below.

METHODS FOR LOCATING

METHOD	KEY ADVANTAGE	KEY CHALLENGE
Telephone call	Quick, cost effective	Phone info often incorrect/ outdated; client may not answer an unknown number
Video call	Face-to-face interaction	Usually need to call first
Text	Quick and convenient for both D2C field staff and client	Health department regulations around texting can be challenging
Social media	Useful for investigation	Usually cannot contact an individual without an account or paying per message
Letters	Tests validity of address	Rarely generate a response
In-person	May generate rapport	Inefficient and expensive

Social media (specifically Facebook) can be challenging since you sometimes need to be a person's "friend" to send them a message. What are some best practices to get around social media barriers?

Facebook can be very effective in locating individuals, particularly youth. Some health departments have had great responses sending Facebook messages asking individuals to call the health department back. If D2C programs get approval, one outreach method is to create a professional "profile" of a field staff from the health department to send messages without friending clients. Depending on that individual's privacy settings, direct Facebook messages can sometimes get through.

Are D2C programs doing routine field visits if phone calls don't work? If so, are they having success?

King County typically does an in-depth investigation followed by telephone outreach and an in-person visit if needed to develop rapport with the client. To maximize the likelihood of reaching individuals successfully on the phone, be sure to try calling at different times of day. Another D2C program found more success in certain geographical areas rather than others. For example, they found Accurint™ data and visits were less successful in urban areas than in the rural areas as people moved around more frequently in the city.

Can you locate clients through their family members?

Some field staff have had success contacting family members while they were trying to locate client on field visits. Programs should have a standard practice in place to ensure patient confidentiality when communicating with family members. For example, a script for identifying that the field worker is with the health department and seeking the individual for a health-related matter, or leaving a generic letter that doesn't disclose the client's specific health issue.

INTERACTING WITH CLIENTS

Field staff working on D2C should be prepared to describe the eligibility and documentation requirements for Medicaid, ADAP, and the Ryan White HIV/AIDS Program in their jurisdiction so clients know about the services they may qualify for if cost is a barrier to care. When referring into care, it's ideal to get the patient back in to see their original provider if they had a good relationship with that doctor. If they want a new doctor, D2C field staff should have relationships with "back line" staff at clinics who can help patients navigate the onerous appointment system to schedule with their provider as soon as possible. For clients that want new providers, field staff should also know which providers work best with which populations (e.g., people who use drugs, young black gay men) to set them up for success once they're relinked to care.

How should you respond to individuals who wonder how the D2C field staff got their personal health information?

If individuals are suspicious of why the health department has their name, field staff can talk about how their job function is to engage PLWH back into services and their goal is to make sure the client has access to the array of high-quality services they want or need. They could also describe how the patient's health data are stored securely and only a small subset of staff at the health department have access to this data for specific purposes. Be aware that if you talk about HIV surveillance the term "surveillance" can make people wary and it may be better to call it medical or case reporting and point out that the data are collected to improve prevention and care. D2C field staff who are living with HIV can also empathize and talk about the case reporting process from a personal standpoint.

What strategies should staff consider for someone who doesn't want to talk to the D2C field staff, or someone who will engage with D2C field staff but is still resistant to going back into care?

Building rapport with clients by listening and having client-centered conversations can help identify their barriers. For example, a client with depression may need help addressing their mental health before successfully re-engaging, or someone who needs housing may be more receptive to going back on HIV medications once their other needs are met. Addressing needs outside of HIV care, especially for clients who have been out of care for a very long time, can also help build trust between clients and the health department staff. Internally at the health department, holding standing meetings for DIS/D2C field staff to discuss challenging cases with a group of peers can help with problem solving and sharing best practices.

How can D2C field staff handle someone who is still resistant to care?

If clients are angry after being contacted, it's their right to not be contacted again. But if possible, "leave the door open" by leaving the D2C field staff person's phone number in case they have questions in the future.

If a client isn't responsive, what's an appropriate time to try them again if they reappear on future not-in-care lists?

If a client doesn't respond after three phone calls, a letter, and a visit, King County will wait a year before re-contacting them if they appear to still reside in the area. The ability to re-contact individuals who aren't responding will also depend on how many new names appear on your not-in-care lists. With limited resources, it's a better use of time and resources to prioritize new cases rather than focusing on those who were not successfully linked.

When is it worth attending a provider appointment with a client?

This is a very resource-intensive approach and should be considered for specific instances when a client requests that the field staff attend their first appointment with them.

What if a client needs additional support services?

The primary focus for field staff should be getting clients back into HIV care, but many individuals may need referrals for additional services. Mental health services, drug treatment, and housing are in short supply across the U.S. and waitlists may be long in many jurisdictions. If they are eligible for case management support, a case manager can help them access more comprehensive services. Alternately, D2C field staff can refer to ancillary services like peer programs or support groups if mental health services and drug treatment beds aren't immediately available.

How can you handle linkage for young patients who are still on their parent's insurance?

Explanation of Benefits (EOB) policies vary by insurance plan and state, and not much can be done by the health department to control this. Because there are several states that include ways for adolescents and young adults to protect their confidential health information, clients should be advised to check with their plan on these options. Field staff without specific expertise in insurance can also get guidance from case managers on this issue.