CHAIR'S CHALLENGE

UNITE TO END THE EPIDEMICS 2017-2018

# Link-Up Detroit Engages PLWH Not Enrolled in Medical Care

TARGET POPULATION: People living with HIV (PLWH) in Detroit who are not enrolled in medical care
LOCATION: Detroit, Michigan
PROGRAM DESIGN: Data to Care (D2C)
ESTIMATED COST: $300,000 per year
FUNDING SOURCE: Ryan White HIV/AIDS Program rebates

## SUMMARY

"Link-Up Detroit" is a Data to Care (D2C) program that uses

data to identify people who are living with HIV (PLWH) but are not in medical care (NIC) and connect them with medical providers and community-based organizations (CBOs). The program uses letters, texts, and phone calls to reach NIC individuals, and the response so far has been positive.

## CORE ACTIVITIES

D2C utilizes HIV surveillance data to determine individuals who have been diagnosed, but are NIC. Contact is attempted to each NIC individual through letters, calls, texts, and emails. Upon reaching the individual, a script is used to confirm their identity and status, followed by a discussion about why they are NIC and barriers they have faced in the past. Then, clients are referred to existing Ryan White HIV/AIDS Program (RWHAP) agencies to address these barriers and to start medical care. Lastly, updated contact information is reported back to surveillance.

Detroit was chosen to pilot D2C in Michigan because, like many urban areas, Detroit is disproportionately impacted by HIV. Approximately one-third of the state's total PLWH and one-third of NIC individuals live in Detroit. As of August 2016, there were 1,126 known NIC individuals in Detroit.

In preparation for D2C, the Detroit Health Department (DHD) and Michigan Department of Health and Human Services (MDHHS) performed extensive community engagement. From 2014 to 2016, D2C was presented numerous times to PLWH, medical providers, and CBOs. In 2016 alone, the DHD and MDHHS conducted 16 D2C

presentations. The presentations were meant to promote the program and obtain feedback. For example, PLWH did not like the word "data" in a linkage program, so the program was renamed "Link-Up Detroit."

Before starting Link-Up Detroit, two important issues needed to be addressed:

(1) Provider capacity and availability of timely medical appointments
(2) Solutions for non-medical barriers (e.g., transportation, housing, and insurance)

Feedback at community meetings provided solutions for these issues. For medical appointments, a referral system and point of contact were determined for each medical clinic. For non-medical services, a rotating schedule was developed for referrals to existing Ryan White Part A-funded agencies for Early Intervention Services (EIS) and case management. Each week, one agency is "on call" to receive Link-Up Detroit referrals. The agency contacts clients within 24 hours of the referral. Link-Up Detroit started contacting NIC individuals in February 2017. As of September 2017, both referral systems were working well.

In addition to standard D2C outreach practices where surveillance data is used to engage NIC individuals, Link-Up Detroit has also worked to inform the community that a program exists to assist PLWH access services. Link-Up Detroit developed promotional materials to spread the program's name throughout the community. A website and brochures were developed and distributed to various medical and non-medical programs (e.g., homeless centers, treatment programs, and churches). NIC individuals and other social service providers are encouraged to contact the program directly. After six months, 59 referrals had been received through these channels.

## DATA

The D2C team (i.e., DHD and MDHHS), with input from community groups and PLWH, determined contact priority for NIC individuals. Priority was given to individuals diagnosed:

(1) In the past year, but never linked to care
(2) Over one year ago, and never linked to care

From February to August 2017, the program initiated outreach to 390 individuals with 1,127 letters, 1,162 phone calls, and 156 texts. As of August 2017, 362 (93%) of the 390 cases were successfully closed. Of the 362, it was determined that 83 (23%) are likely individuals that utilized Michigan's anonymous testing option, where individuals can use an alias and birthdate. They are likely duplicates and are captured in surveillance by their correct name when they later utilize care services. However, there is no way to verify, because these 83 individuals do not have locating information on their original case report form and have no records in TLO, an online search database that combs various personal record systems to provide updated contact information. Many of these individuals were first tested from 1988 – 2000.

Outcomes for the other 279 cases were:

- 143 (51%) Unable to locate
- 36 (13%) Linked to care
- 26 (9%) Already in care
- 17 (6%) Not positive
- 17 (6%) Deceased
- 16 (6%) Moved out of state
- 15 (5%) Other
- 5 (2%) Declined services
- 4 (1%) Institutionalized (likely out of state)

Updated contact information has been returned to surveillance for 131 (47%) of these 279 individuals.

In addition to the 36 linked to care through standard D2C outreach, an additional 10 individuals were linked to care after they contacted the Link-Up Detroit Program requesting help getting into medical care.

## EVALUATION

Monitoring and evaluation metrics were incorporated into every aspect of Link-Up Detroit to ensure the process is optimal. Adjustments have been made when necessary. One key evaluation tool is a follow-up survey done with each individual one month after they are referred to care. Answers to this survey are meant to improve the outreach process and overall client experience.

Data management and evaluation were discussed in-depth during the planning stage. After several rounds of work group discussions and technical assistance from NASTAD, a robust data tracking system was developed that utilizes eHARS, CAREWare, and ACCESS. In addition, an evaluation plan with approximately fifty data tracking points was finalized. Custom reports have been built into CAREWare that allow the team to very quickly see the measurements and outcomes on a regular basis. These data points include: number of letters sent, phone calls made, number of letters returned, referrals to non-medical services, date for call back, most recent lab date and value, and numerous others. MDHHS successfully implemented the import of laboratory data from eHARS into CAREWare prior to the initiation of D2C. The tracking of lab values is of particular importance to monitor the long-term success of Link-Up Detroit. Over time, the D2C team will be able to determine if individuals who accepted linkage services are retained in care, and the effect care has on their CD4 count and viral load.

All data systems were developed and tested before the program started to ensure that data was accurately captured and easy to query from the start of the program. Link-Up Detroit was intentionally rolled out in a tiered manner in order to assess any issues before reaching out to a larger population. In addition, the D2C team has weekly dialogue to discuss issues or opportunities for improvement. These discussions have led to many modifications in the outreach process, data system, and data reporting.

## OUTCOMES

Since this population can be transient,the D2C Coordinator looks up each NIC person in TLO and the State STD database. Letters are sent to every address listed for the past two years. TLO also provides a list of likely phone numbers for each person. Calls are made and texts sent to every phone number with more than a 60% likelihood of matching. Only after three letters are sent to each address and three phone calls and texts attempted for every number is a case dispositioned as “unable to locate.” Results have shown that it can take multiple calls and letters to reach one person.

Upon reaching an individual, a script is used to verify identity (DOB) and to guide the NIC person to a point where they inform the caller that they are living with HIV. Once the individual shares their status, there is a discussion about the importance of HIV care and reasons why they might be out of care. Almost all (>90%) of the NIC individuals successfuly linked to care are dealing with one or more barriers to care (lack of transportation, health insurance, mental health issues, homelessness), so linkage to social support programs have been integral to assist these individuals successfully (re)engage in care. So far, NIC individuals have been very receptive of Link-Up Detroit’s services and excited to be linked back into care. After linkage to care is completed, updated contact and demographic details are documented and sent to surveillance.

## FUNDING & COST

Link-Up Detroit has a budget of $300,000 and is funded using RWHAP Part B program rebate dollars. The budget includes funding for 2.36 FTEs at DHD. This pays for a full-time coordinator and linkage specialist, and partially for the HIV program coordinator (.2 FTE), data analyst (.1 FTE), assistant (.05 FTE), and administrator (.01 FTE). The funds cover participant incentives of $25 for each person who accepts linkage services, client transportation and emergency financial situations, and administrative costs such as office supplies, travel,

promotional materials, and typical overhead charges (e.g., rent, printing).

## STRENGTHS

- Extensive community engagement has resulted in buy-in from PLWH and HIV service providers, as well as a positive reputation in the community.
- Since 2009 MDHHS surveillance has participated in CDC's Medical Monitoring Project (MMP). This experience was integral in helping develop Link-Up Detroit's contact methods and materials, including both the phone script and letter.

## LIMITATIONS

- The D2C team did not restrict the individuals to be contacted to those diagnosed in recent years. This has resulted in time-intensive record searches to find locating information and/or determine if the person tested decades ago under an alias.

## STAKEHOLDERS

Michigan Department of Health and Human Services; Detroit Health Department; people living with HIV (PLWH); HIV medical providers; and HIV community-based organizations.

## PROGRAM CONTACT

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