2018 NATIONAL RYAN WHITE CONFERENCE ON HIV CARE & TREATMENT

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Using a Data-To-Care Framework to Locate, Re-Link, and Re-Engage Out of Care Patients

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Learning Objectives

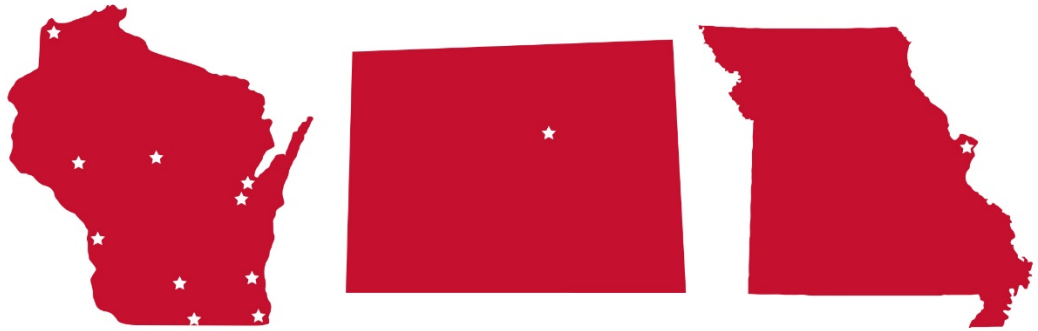
- Understand the contextual appropriateness of conducting discreet, HIPAA-compliant unannounced home visits
- Understand how the Electronic Health Record (EHR) can be used to identify possible patient whereabouts, alternate contact information, and appropriate collateral contacts
- Understand how social media can be implemented in order to establish a line of communication with patients who are transient or difficult-to-reach
- Identify common barriers to ongoing engagement in HIV medical care and possible Case Manager responses to those barriers

AIDS Resource Center of Wisconsin

ARCW
AIDS Resource Center of Wisconsin
Excellence in HIV Health Care

Rocky Mountain CARES
Excellence in HIV Health Care

Saint Louis Effort for AIDS



- Wisconsin -10 Locations
  - Services Cover All 72 Counties
  - Medical Clinics in Milwaukee, Madison, Green Bay and Kenosha
  - Statewide Pharmacy Services
- Colorado – Denver
- Missouri – St. Louis

Medical Home – Integrated Care Model

RECOGNIZED
NCQA
PATIENT-CENTERED MEDICAL HOME

ARCW Patient/Client Demographics (WI)

Gender	%
Male	76.3
Female	22.3
Transgender	1.4

Race	%
American Indian/Alaska Native	2.0
Asian	1.7
Black/African American	42.6
Native Hawaiian/Pacific Islander	0.3
White	51.1
Unknown/Other	3.3

2017 Overall ARCW Patient Data

- **3,900** total patients served
- **3,017** unduplicated Case Management clients
- **2,479** Medical Center HIV+ patients

ARCW Patient/Client Demographics (WI)

Risk Factor	%
Men Who Have Sex With Men (MSM)	53.2
Heterosexual Contact	33.9
Injection Drug Use (IDU)	6.4
Blood Transfusion/Blood Products	1.8
Mother to Child	1.1
Unknown/Unreported	11.5

Age	%
<=24	4.5
25 to 44 years	36.8
45 to 64 years	52.6
65 or older	6.2

2017 Overall ARCW Patient Data

- 66.3% of patients under Federal Poverty Level
- 56% of patients covered under Medicaid
- 27% of patients have AIDS diagnosis

Data to Care Project - Background

- Collaboration began in 2016 between ARCW & State of Wisconsin Division of Public Health to pursue Data to Care project
- ARCW awarded Ryan White HIV Care Supplement grant to hire 4 staff;
  - One supervisor and three full-time Outreach Case Managers (OCMs)
- First group of target patients identified via ARCW Quality Dept. in May 2017
- Data sharing with State of Wisconsin paused after one exchange in June 2017

Identifying Target Patients

- Director of Quality Management runs reports from EPIC (EHR) to identify:
  - Patients who have not completed an appointment with their Primary Care Provider (PCP) in over a year
  - Patients' provider has identified them as "Lost to Follow-Up"
  - Patients who scheduled a "New Patient" appointment, did not attend, and do not have another appointment scheduled

Identifying Target Patients

- Care Teams may refer patients who are not necessarily “out of care” by definition, but who are currently unable to be located
- Linkage to Care Specialists (LTCS) may refer patients if the LTCS has exhausted their maximum required contact attempts with no success in locating the patient
- Pharmacists may refer patients who are non-adherent with filling their ARVs after several months
- Patients identified via weekly Viral Load Suppression monitoring
  - Previously virally suppressed (<200 copies) and have become virally unsuppressed (>200 copies) as of their last lab draw

Preliminary Data Scrub

- Review patient's record in case management database for information
- Review patient's EHR for evidence of care at another clinic or in another state
- Search for possible patient incarceration
  - VINElink (Victim Information and Notification Everyday)
    - www.vinelink.com
  - CCAP (Wisconsin Circuit Court public database)
    - Offers charges/sentencing information but not necessarily incarceration status

“Re-Engageable” Patients

- Presumed to be living in Wisconsin
- Presumed to not be in HIV medical care anywhere else
- Not eliminated via the initial data scrub

2017 Out of Care Patient Data	
Initial # of Patients on List	**96**
In Care Elsewhere, Deceased, Out of State, Incarcerated	33
Re-Engaged @ ARCW On Their Own	36
*Not HIV+	10
Total # of Patients to Re-Link/Re-Engage	**17**

*Note: Patients sometimes make an appointment with ARCW after a positive rapid test, and ultimately receive negative confirmatory results. These patients are removed manually from our list.

Patients Identified – Now What?

- Outreach Case Managers complete a thorough review of the patient's known situation prior to making any contact attempts

- A good understanding of the patient's history provides valuable insight into how the patient should be approached for re-linkage to care
  - If a patient has documented literacy issues, it will change how/if the Case Manager writes an outreach letter
  - If a patient has expressed a lot of shame/stigma around HIV in the past, the Case Manager may choose to discuss the patient's "situation" rather than saying "HIV" in conversations

Outreach Process

- Phone contact attempts
  - Case Management, Medical, and Pharmacy databases may all have different information; make contact attempts using all numbers on file

- Outreach letter – DISCRETION IS KEY!
  - Plain paper/envelopes – No agency letterhead
  - Use PO Box instead of agency street address for return address
  - Do not reference the specific Doctor/NP
  - Do not reference HIV/AIDS

Unannounced Home Visits

- Outreach Case Managers wait roughly 2 weeks after sending an outreach letter to see if it is “returned to sender”

- If the letter is not returned, the Outreach Case Manager will attempt an unannounced home visit at the addresses associated with the patient
  - Visits are done during daylight hours and in pairs to ensure safety
  - Supervisor has copy of visit itinerary, addresses, ETA beforehand
  - Text check-ins before/after each visit

  - Outreach Case Managers may call off a visit at any time if there are safety concerns

Unannounced Home Visits

If there is no answer, or if someone other than the patient answers and confirms the patient lives there/is not home, Outreach Case Managers leave a discreet business card that looks like this:

Unannounced Home Visits

- Family members/friends of patients will often give unsolicited information to Outreach Case Managers
  - Updated phone number for patient
  - Updated address for patient
  - Work schedule/best time to reach patient at home

- Information can be accepted/used as long as Outreach Case Manager does not share any PHI under any circumstances

EHR Investigation

- The EHR may contain information related to care at other clinics or in other states:
  - "Care Everywhere" allows access to view clinic appointments, hospitalizations, test results, etc. at other clinics
  - If there is evidence of an infectious disease/HIV medical appointment, or HIV labs drawn since the last visit to ARCW, the patient is assumed to be in care elsewhere
  - If there have been appointments, hospitalizations, tests in another state since the last visit to ARCW, the patient is assumed to be out of state

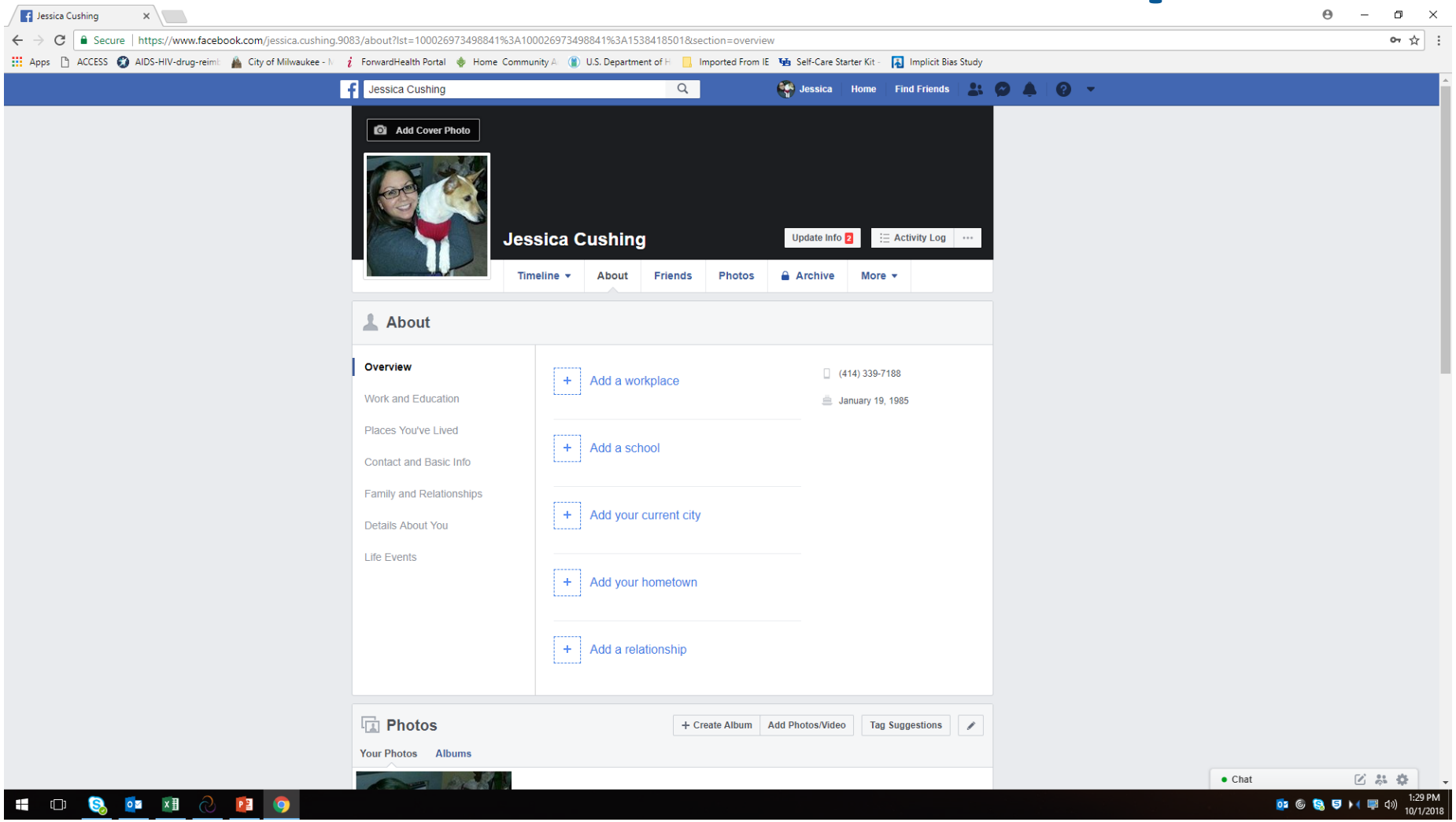
EHR Investigation

- Often, the EHR contains alternative contact information for the patient:
  - The patient may have checked in at a hospital/clinic using a different address or phone number than what was previously on file
  - The visit notes may contain information related to the patient's location:
    - The doctor notes that patient is currently homeless and living with a friend at an address that patient did not give at check in
    - The doctor notes that patient is moving to another state
    - The doctor notes that patient has a follow-up appointment scheduled with non-ARCW provider for HIV care

Social Media Outreach

- Facebook selected as approved method of social media outreach by ARCW
  - "Work" profiles created, separate from personal profiles
    - Created using non-ARCW email addresses for extra privacy
  - Spelling of name changed slightly to prevent Google searching, prevent patient contact from personal profile
  - Access permitted via work computer only, no Facebook app on phones
  - Profiles include photo, location, and dedicated cell phone number only
    - Photo included to increase likelihood of response – We are not robots/spam!

Facebook Profile Example

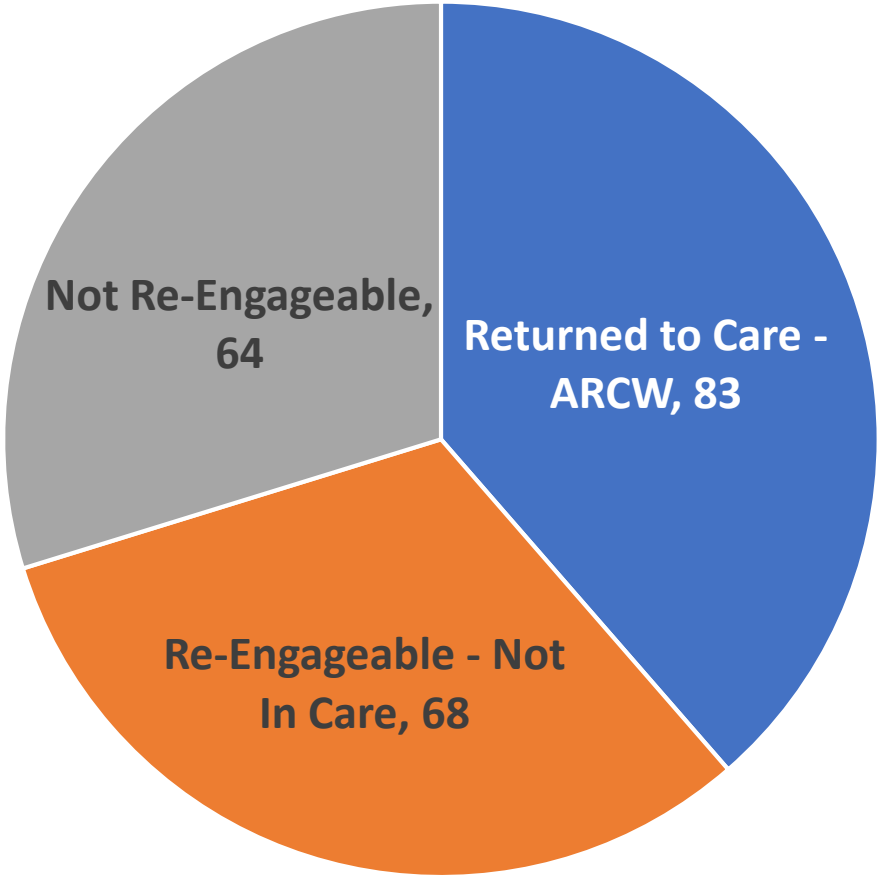


Facebook Message Examples

"Hi (Patient), this is Jessica from your doctor's office. Please call me as soon as possible at 414-339-7188. Thank you."

"Hi (Patient), please contact me as soon as possible regarding an important healthcare matter. 414-339-7188. Thank you."

Outcomes (As of Q3 2018)



Of patients considered re-engageable, **55%** have returned to care

N=215 Patients

Commonly Cited Barriers to Care

- Transportation
- Prioritizing other medical care
- Not feeling sick
- Still receiving ARV refills/not understanding why they need to come in
- Unstable housing situations
- Familial obligations
- Mental Health challenges
- AODA use/abuse
- Stigma/Fear Competing priorities
- Distrust of the medical system
- Lack of insurance, and lack of understanding re: ongoing service availability

Addressing Barriers to Care: Transportation

- OCMs provide rides
  - Medical appointments, DMV, Social Security Office, Court Appearance, Housing Search
  - Patient often will not agree to medical care until their other immediate needs are resolved
- Patients are transitioned from OCM transportation as soon as possible
  - Medicaid-provided cab rides
  - Teach patient how to navigate the bus system
  - Assist patient with paperwork/appointments necessary to resume legally driving themselves

Addressing Barriers to Care: ARV Refills

- Medical Providers face a difficult decision re: continued authorization of ARV refills for patients they have not seen in a year or more
- Medical Providers may be more likely to continue authorizing ARV refills when the patient has been virally suppressed for a long time
- Often, patients' only motivation to schedule an appointment is knowing their ARV refills are ending
  - OCMs work with Medical Providers on a patient-by-patient basis to determine if it is appropriate to stop ARV refills until an appointment is completed

Addressing Barriers to Care: Stigma

- Patients may be fearful of being seen by their peers at or near the clinic
- OCMs can assist by escorting them via more private routes (alternate entrance, stairs to avoid elevator encounters)
- Patients can also be immediately placed in an exam room

Addressing Barriers to Care

- Patients have cited the following miscellaneous reasons for falling out of HIV care:
  - Pending criminal charges / possible incarceration
  - Lack of childcare or assistance with dependent adult family members
  - Irregular/unpredictable work schedules that interfere with appointment scheduling
  - Poor credit rating/concerns about medical debt
- OCMs will assist patient with overcoming these non-medical barriers HIV care

Lessons Learned/Changes Implemented

- Workflow for patients returning to care was different at each of the 4 WI clinics
  - Created a standardized statewide “out of care” patient workflow
- Patients had varying levels of knowledge/understanding about available services and how to access them
  - Implemented “New Patient Orientation”
- Inconsistent communication between service areas when a client becomes ineligible for services (i.e. moves out of state, passes away)
  - Developed mechanism to ensure that all areas are notified

Questions? Contact me!

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