LOW INFORMATION,
LOW AWARENESS

"INVINCIBLES"

Dropping
OUT OF
CARE risk
factors

VULNERABLE
POPULATIONS

COMPETING
PRIORITIES

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How to use this guide

The infographic and accompanying addendum discuss individual level characteristics of persons at high risk of dropping out of medical care. This information is based on research, literature reviews and interviews with HIV services providers in Texas.

The profile has been split into 4 different generalized areas – **Low Information/Low Awareness**, **"Invincibles", Vulnerable Populations**, and **Competing Priorities**. While there may be other characteristics associated with clients who have a history of dropping out of care, these have been identified as the characteristics most frequently seen across the care service delivery system regardless of geographic location, agency size/type, or funding source.

This guide has two components – an infographic providing an overview of the profile characteristics, and an addendum providing more detail about each individual characteristic, how it impacts clients' health outcomes, and what agency staff can do to be proactive in regards to mitigating the impact of the characteristic.

The presence of one of these characteristics shouldn't cause staff to assume that person is going to drop out of care, but it should be a trigger for the staff to investigate further, and/or to refer that individual to case management services for assessment. The more characteristics an individual possesses, the higher their risk of dropping out of care.

Outside of the information presented in the addendum, here is some general information to assist your work with clients to help them be engaged in their medical care.

- Build rapport (using simple language).
- Meet the client where they're at by using a strengths-based client-centered approach.
- Understand and acknowledge how your client defines themselves. Ask them how they identify (name preference, gender identify/pronoun preference, race/ethnicity, sexual orientation) and ensure that is respected at all agencies your client has contact with. (Here are two short videos about gender identity, gender expression and sexual orientation - https://www.youtube.com/watch?v=Vlx9iZ9g_9I and https://www.youtube.com/watch?v=DINFlAbff8c.
- Collaborate with other agencies that work with your client to ensure all the client's needs are being met – multi agency case staffing of clients who are at risk of falling out of care helps ensure contact across the continuum of care.
- Studies show that strong linkage and ongoing access to care within the first six months of a new diagnosis is indicative of improved maintenance in care and viral suppression.

THE DOMAIN: LOW INFORMATION, LOW AWARENESS

- **Negative Health beliefs** - Feels that a negative health condition can't be addressed or avoided, doesn't believe that taking a recommended action will avoid a negative health condition or will be effective in addressing the issue (i.e. taking HAART will improve my health), doesn't believe that they can successfully pursue a recommended health action (i.e. don't think they can take medicine every day). Negative health beliefs can include stigma, distrust of medical providers, lack of understanding of HIV/AIDS, and lack of awareness of healthful behaviors. Negative health beliefs can also include a patient's level of expectancy that attending appointments will prevent/treat infection or yield substantial benefits – patients who do not believe attendance will improve their health have little motivation to remain engaged.
- **Low self-efficacy** – Don't believe in one's ability to succeed in certain situations (i.e. not believing that you'll be able to adhere to a medication regimen)
- **Low Educational Attainment** – High school education or less
- **Low levels of social Support** – This can also include low levels of *perceived* social support. Clients may think their support system won't be there for them if they disclose their status, so perceive that they have low levels of support, but may not know for sure that their support system won't be there for them.
- **High Levels of Stigma** – This can also include high levels of *perceived* stigma
- **Low levels of engagement with health care systems** - perceptions of access to health care, patients' mistrust in the health care system, patients' trust in providers,

HOW DO I RECOGNIZE IT DURING OUR ENOUNTERS?

- Low Self-efficacy:
  - Confidence to ask questions/confidence that I can get the answers that I need.
  - "Making my appointments will be hard because of…. Work/kids/transportation…."
  - "I've never taken meds regularly before."
- Low literacy
  - "I can't read or write"
  - "I don't understand what the doctor is saying" (language, words)
- Negative health beliefs
  - "I don't like how the meds make me feel and I don't think they're helping me"
  - "I saw on the internet/heard on the news that…" (false information from media)
- Low levels of support/high stigma
  - "I don't want to go to the clinic, because everyone will know I'm HIV+"
  - "I don't have anybody to talk to about my HIV+ status"

WHAT IMPACT COULD THIS HAVE ON MY CLIENT'S HEALTH?

- Decreased confidence/comfort level regarding asking their doctor questions
- Decreased medication adherence due to not believing it will make them better; may lie about taking medicine
- Missed appointments without calling to reschedule
- Decreased ability to take medicine correctly because they don't understand the instructions/can't read the label
- Stop taking medications because of side effects without talking to doctor or other staff

- Stop taking medicine/going to doctor, without talking to doctor or other staff, because they feel healthy
- Decreased knowledge regarding how HIV treatment works, the goals of HIV treatment, or what "undetectable viral load" means

WHAT CAN WE DO ABOUT IT?

- Assess for literacy, if client has trouble reading, simplify prescription label (ex. pictures)
    - Screening tools for adult literacy: http://www.nchealthliteracy.org/instruments.html
    - Screening tools and interventions for adult literacy: http://guides.lib.umich.edu/c.php?g=283033&p=1885791
- Assess for health literacy, use motivational interviewing to advance client towards positive health beliefs
    - CDC Health literacy site: http://www.cdc.gov/healthliteracy/
    - HRSA Health Literacy site(including free training): http://www.hrsa.gov/publichealth/healthliteracy/
    - Motivational Interviewing - http://motivationalinterviewing.org/
- Text message/ email reminders about upcoming appointments
- Help the client in advance to prepare:
    - Role play talking to the doctor and asking questions.
    - Contact client prior to appointments to run over questions client has for doctor
    - Follow-up after appointment to get update from client on appointment. Follow-up with clinic staff when appropriate.
- Assess knowledge of HIV health, including understanding of how HIV treatment works, what viral suppression is and how it impacts overall health, and how to achieve viral suppression. Provide education as appropriate.
- Get client to do regular teach backs with new medication regimens until they can tell you what each pill is for, and how/when they take it
- Regularly ask client about potential side effects during initial new medication regimen period. Communicate with clinic staff when appropriate
- Talk to client about barriers with taking medication, determine interventions based on barriers (ex. alarm reminders, pill boxes, pill counts)
- Use Patient or Peer Navigator
    - National AETC Patient Navigator Program Tools: http://aidsetc.org/resource/patient-navigator-program-tools
- Talk with clients about their sexual health and help them understand how to improve it.

LEARN MORE ABOUT IT

- HRSA/NQC In Care campaign - http://www.incarecampaign.org/
- Target Center: Integrating Innovative HIV Practices - https://careacttarget.org/ihip
- Understanding Sexual Health - http://journals.sagepub.com/doi/pdf/10.1177/00333549131282S101
- Benefits of Viral Suppression - https://youtu.be/RIAOGXOGNOo
- Treatment as Prevention (TasP) - http://www.cdc.gov/hiv/prevention/research/tap/

THE DOMAIN: "INVINCIBLES"

- Younger age – People under the age of 35 think less about long term health, and have significantly lower retention in care/continuous care rates than other age populations. In a 2012 CDC report, "15% of those between 25 and 34 years of age had undetectable viral loads, compared with 36% of those between 55 and 64 years of age. In terms of regular care, 28% of those between 25 and 34 years of age were retained in care, compared to 46% of those between 55 and 64 years of age."
- Not feeling sick
    - High CD4 count – A CD4 count > 350 copies/ml is predictive of poor retention in care.
    - No AIDS diagnosis – Not having an AIDS diagnosis is predictive of poor retention in care.

HOW DO I RECOGNIZE IT DURING OUR ENCOUNTERS?

- Younger age:
    - "I don't need help."
    - "I am strong, I work out every day, I don't need to be in care, I'm not sick."
    - "I'm too busy to make appointments, I'll just take my medicine and be fine"
- High CD4 count/No AIDS Diagnosis:
    - "I don't have AIDS so I don't need to see a doctor until then"
    - "My CD4 count is good, so I don't need to keep taking my medicine"
    - "I feel healthy, so I don't need to go to the doctor"

WHAT IMPACT COULD THIS HAVE ON MY CLIENT'S HEALTH?

- Clients who have been engaged in care for a shorter period of time since their baseline appointment are at a greater risk for missing appointments and becoming disengaged (i.e., dropping out of care is much more likely to occur during the first sixth months following the baseline appointment). Missing a first or second follow-up appointment is a strong indicator of drop-out risk. People who appear 'healthy' on paper (i.e. high CD4 count, no AIDS diagnosis) are often not prioritized for follow-up after missing appointments.
- Health services are usually not set-up to cater to younger people, and there are often structural barriers that keep younger people from engaging in care (including a fear of disclosure if they are still on their parent's insurance)
- Clients may be in and out of care – they only engage in care when they're sick, then drop out once they start feeling better.

WHAT CAN WE DO ABOUT IT?

- Be flexible with walk-ins, make medical appointments easier for those at risk of falling out of care
- Extend hours of operations to nights and weekends when possible to accommodate clients with alternative schedules
- Increase the frequency of case manager initiated contact during the first 6 months of the client's care (doesn't have to be face to face – phone calls, texts and e-mails are fine with client authorization)
- Determine client's priorities (often other supportive service needs) that will help establish a relationship of trust with the client.

- For younger clients, decrease structural barriers whenever possible (coordinate care with other programs the client is accessing to get the client's necessary eligibility paperwork rather than making the client duplicate eligibility requirements at multiple agencies)
    - NASTAD Publication on working with HIV+ youth: https://whatworksinyouthhiv.org/
- Determine the most effective method of communication with the client (text, email, facebook, etc.) and get the appropriate releases of information to use this contact method.
- Provide ongoing education about treatment as prevention
    - CDC page on Treatment as Prevention (TAP): http://www.cdc.gov/hiv/prevention/research/tap/
- Use Motivational Interviewing to assist client in gaining confidence and readiness to access and maintain medical care.
    - http://motivationalinterviewing.org/
- Increase staff training around working with a younger population to ensure cultural competency.
    - Advocates For Youth Cultural Competency portal: http://www.advocatesforyouth.org/cultural-competency-home
- Use Peer Navigators that are younger in age to help engage the newly diagnosed young HIV+ client and help them access care.
    - National AETC Patient Navigator Program Tools: http://aidsetc.org/resource/patient-navigator-program-tools

LEARN MORE ABOUT IT

- Study - Retaining HIV Infected Patients in Care: Where Are We? Where Do We Go From Here? http://cid.oxfordjournals.org/content/50/5/752.full.pdf+html
- Training Manual - Innovative Approaches to Engaging Hard-to-Reach Populations Living with HIV/AIDS into Care: http://careacttarget.org/sites/default/files/file-upload/resources/Outreach_trainingmanual_final.pdf

DOMAIN: **VULNERABLE POPULATIONS**

- Minority Race/Ethnicity – Multiple studies indicate that having a minority race/ethnicity is predictive of low retention in care, specifically among African-Americans. In Texas, in 2014, 66% of African-Americans and 68% of Latinos were retained in care[1], compared to 75% of Whites.
- Lack of Health Insurance – Clinics whose client populations are mostly uninsured or indigent should not use this indicator to identify which clients are less likely to remain retained in care (i.e. this indicator is more appropriate for clinics who serve a population where the majority of clients are insured). *Retention In Care Literature Review (2014), UT-Austin Health Promotion Team*
- Mental Health Issues – People with HIV experience mental health issues at a far greater rate than the general population – almost 4-5 times as often. The most common mental health issues among HIV+ individuals are Depressive Disorders and Anxiety Disorders.
- Lack of Steady Employment/Housing/Transportation
- Low Income (relative to community) – Clinics whose client populations are mostly uninsured or indigent should not use this indicator to identify which clients are less likely to remain retained in care (i.e. this indicator is more appropriate for clinics who serve a population where the majority of clients are insured). *Retention In Care Literature Review (2014), UT-Austin Health Promotion Team*
- Low levels of social Support – This can also include low levels of *perceived* social support. Clients may think their support system won't be there for them if they disclose their status, so perceive that they have low levels of support, but may not know for sure that their support system won't be there for them.
- High Levels of Stigma – This can also include high levels of *perceived* stigma

HOW DO I RECOGNIZE IT DURING OUR ENCOUNTER?

- Minority Race/Ethnicity – In Texas, this is African-American and Latino
- Lack of Health Insurance – No insurance or underinsured
- Mental Health Issues
- Lack of steady Employment/Housing/Transportation
- Low Income
- Low Levels of social support
    - "I haven't told anyone I'm HIV+"
    - " I'm afraid to tell my (partner, family member, friend)"
    - "I don't have anybody to help take care of my child when I go to appointments"
- High Levels of Stigma
    - "My doctor said that she didn't want to provide care to HIV+ people because her other patients would leave"
    - "My doctor said he didn't know how to provide care for a transgender woman"
    - A lot of organizations are LGBT (Lesbian, Gay, Bisexual, Transgender) focused so might lead to people who don't identify as LGBT to dropping out of care.
        - "They sent me to a clinic for gay people and I said I wasn't gay."

[1] Retention in care is defined as two contacts with the medical system (doctor visit, CD4 count or Viral Load, or filled HIV prescription) at least 90 days apart

WHAT IMPACT COULD THIS HAVE ON MY CLIENT'S HEALTH?

- People with mental health issues are more likely to have increased costs due to their utilization of inpatient and emergency services
- African Americans also have lower rates of viral suppression compared to other races, with missing clinic visits being the most important factor for failure to suppress viral loads

WHAT CAN WE DO ABOUT IT?

- Screen for mental health issues
    - There are a variety of validated, reliable mental health screening tools available. DSHS recommends the Substance Abuse and Mental Illness Symptom Screener (SAMISS): https://www.dshs.state.tx.us/hivstd/contractor/cm.shtm
- Determine your client's eligibility for health insurance and assist them in the application process and navigating the health insurance system.
- Use Peer Navigators that are reflective of your client's racial/ethnicity/cultural group to help them navigate the system
    - National AETC Patient Navigator Program Tools: http://aidsetc.org/resource/patient-navigator-program-tools
- Increase staff training around working with minority racial/ethnic groups to increase culturally competent care
    - National Minority AETC: BE SAFE – A Cultural Competency Model for African Americans - http://www.aidsetc.org/sites/default/files/resources_files/BESAFE_AfrAmr.pdf
    - HRSA Cultural Competency portal - http://www.hrsa.gov/culturalcompetence/index.html
- Provide Health Education and Risk Reduction (HE/RR) by peer; offer services to related affected (https://www.dshs.state.tx.us/hivstd/taxonomy/herr.shtm)
- Refer to anonymous chat rooms for HIV+,(this protects client's identity but still allows them to get peer support)
- Provide training for providers (doctors, CM, social workers, counselors, etc) on how to use simple language and when to identify when clients doesn't understand, but are unable to explain this. Use simple analogies to help clients understand.
- Come together as a community and do "out of the box" activities that obtain the community's attention, in order to reduce stigma (community health fairs targeting vulnerable communities, HIV 101 in non-traditional settings such as barber shops and salons).

LEARN MORE ABOUT IT

- Study - Retaining HIV Infected Patients in Care: Where Are We? Where Do We Go From Here? http://cid.oxfordjournals.org/content/50/5/752.full.pdf+html
- Training Manual - Innovative Approaches to Engaging Hard-to-Reach Populations Living with HIV/AIDS into Care: http://careacttarget.org/sites/default/files/file-upload/resources/Outreach_trainingmanual_final.pdf
- CDC guide to linkage and retention in care interventions - http://www.cdc.gov/hiv/prevention/research/compendium/lrc/

DOMAIN: COMPETING PRIORITIES

- Injection Drug Use – Multiple studies indicate that injection drug users (and those with a recent history of injection drug use) are more likely to miss appointments. Injection drug use is also predictive of lower rates of viral suppression.
- Alcohol/Drug Use – Multiple studies indicate that alcohol and drug use (both current use and admitted former drug use) is associated with difficulty in not only establishing clients in care, but also ongoing retention – substance use is associated with poor retention during the first 2 years of care due to clients cycling in and out of care
- Other Comorbidities – Clients with a co-infection of Hepatitis C have lower rates of retention.
- Chronic Missed Appointments – The probability of clients returning decreases rapidly in the first months after the baseline visit. Missed appointments during the first six months of the clients care is predictive of dropping out of care.

HOW DO I RECOGNIZE IT DURING OUR ENOUNCTERS?

- Substance Use
    - Clients acknowledge former drug use (both injection and non-injection)
    - Clients screen positive for substance use issues on substance use screening tool and subsequent comprehensive substance use assessment
    - Client's minimize drug use or justify it; facts of drug use change within assessment or appointments
    - Physical symptoms of substance abuse (teeth decay, sores on face, weight loss, needle marks, etc)
    - Change in behavior or inability to concentrate/sit still during office visit.
- Chronic Missed appointments
    - Unable to remember appointments
    - Frustrated with complications of medical system
    - Medication fatigue
    - History of in and out of care within providers

WHAT IMPACT DOES THIS HAVE ON MY CLIENT'S HEALTH?

- Financial struggles, lowering funds for medical care/medication
- Extended periods of no contact with agency and/or clinical staff
- Decreased utilization of resources because client is reluctant to ask for assistance
- Increased number criminal charges, which could put gaps in medical care/medication adherence
- Decrease level of self esteem/guilt about behaviors
- Increased judgment from providers when substance use is disclosed

WHAT CAN WE DO ABOUT IT?

- Implement a tracking system/and or coordinate with the client's clinical providers to receive notification of missed appointments
- Use Motivational Interviewing to move client towards small successes - http://motivationalinterviewing.org/
- Refer to supportive services that specialize in addressing the specific behaviors
- Do alternative groups targeting a behavior based population (with incentives) to teach this cohort about healthy coping mechanisms and/or self care
- Determine the most effective method of communication with the client (text, email, facebook, etc.) and get the appropriate releases of information to use this contact method.
- Risk reduction/harm reduction- Ensure that ALL staff are comfortable and knowledgeable with doing risk reduction/harm reduction with their clients. This should be done on a regular basis with an individualized plan that they revisit every time that they meet with the client (goal setting).
- Have a team approach to care. Make sure to make connections with all the agencies and community partners that your client accesses (with appropriate releases of information)
- Provide prevention for high risk positives, including working with clients so they can educate their partners about Pre-Exposure Prophylaxis (PrEP)
- Provide specialized care depending on client's individualized needs ("cookie cutter approach does NOT work with these individuals)
- Identifying small successes within this population and having them recognize their successes rather than what they need or do incorrectly
- Provide Health Education and Risk Reduction (HE/RR) by peer; offer services to related affected (https://www.dshs.state.tx.us/hivstd/taxonomy/herr.shtm)

LEARN MORE ABOUT IT

Harm Reduction - http://harmreduction.org/

Pre-Exposure Prophylaxis (PrEP) - https://www.dshs.state.tx.us/hivstd/preppositionstatement.shtm ; Client experience with PrEP - http://myprepexperience.blogspot.com/