Retention in HIV Care

Interpretation, interventions, & identifying those in need of support.

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Objectives

Why

Health outcomes
HIV transmission

Challenges

Definitions
Measurement
Comparison
Limitations

Who

Health disparities
Scope
Risk factors

Solutions

Interventions
Tools

Some things to consider…
it's not just about remembering appointments.

Discrimination.

In a study of HIV+ Latino MSM, those who reported being treated differently based on their sexual orientation were less likely to be retained in care.

Whol et al 2011

HIV Status Disclosure & Support.

Individuals who report never telling anybody about their HIV status have been shown to be twice as likely to be poorly retained.

Elopre et al 2015

No shows have clinical significance.

Poor retention in care and no shows are associated with increased mortality risk.

Mugavero et al 2014

Why does retention matter?

Why

Patients who are poorly-retained in care are:

- More likely to have detectable viremia.
- More likely to have prolonged viral burden.
- Less likely to maintain access to ART.
- At higher risk of death.

Crawford ,Sanderson, Thornton 2013.
Mugavero et al. 2014,**2012, 2009**
Rebolledo et al. **2011**;
Horberg et al. 2013

Why

NATIONAL HIV/AIDS STRATEGY:

UPDATED TO 2020

More Information

AIDSinfo

Guidelines for the Use of Antiretroviral Agents in
HIV-1-Infected Adults and Adolescents

https://www.whitehouse.gov/administration/eop/onap/nhas
https://aidsinfo.nih.gov/guidelines

Why
Public health and health disparities

Individuals who are retained in care are **less likely to transmit HIV** to someone else, even when they are not on ART.

Improving retention among those most affected **could help lessen health disparities** because retention behaviors contribute to health disparities.

Racial disparities in viral suppression lessen when you account for no shows.

Zinski 2015
Skarbinksi et al 2015
Rosenberg et al. **2014**
Marks et al. **2010**

Challenges

Challenges

- Retention is complex, difficult to define, hard to measure.
  - Fluid vs Static
  - "Churn"

- Multiple definitions:
  - **Missed visits**
  - **Visit Constancy**: Time intervals with at least 1 visit.
  - **Gaps in care**: 6-month intervals that contain no appointments.
  - **Visit adherence**: Proportion of kept visits/scheduled visits
  - **HRSA/HAB measure**: "At least 1 medical visit in each 6 month period within a 24 month period (2 months apart)."

Gill & Krentz 2009
Rebeiro et al. 2013
Mugavero et al. 2012
US Department of Health and Human Services 2013 http://hab.hrsa.gov/deliverhivaidscare/habperformmeasures.html

Challenges

Limitations and considerations

- Churn, geographic mobility, transfer.
- Measures and endpoints.
- Data origin.
- Population captured: Difficult to measure people you can't find.
- Comparison between studies/measures.
- Evolving treatment recommendations.

Rebiero et al. 2013, 2014, 2015
Mugavero et al. 2012
Crawford et al. 2013
Horberg et al. 2015
Medland et al. 2015

Who is affected?

Scope, impact, risk factors

Who

Scope & impact

- Meta-analysis of multiple different studies on retention found that only 69% of individuals included had 2 or more visits during 6-month intervals.
- NA-ACCORD: 25% of individuals who accessed care from 2000-2008 had one or more “out of care” episodes.
- Good news: improved trends over time across the nation.

Marks et al. 2010
Rebeiro et al. 2013, 2015

Who

Poor engagement among new patients:

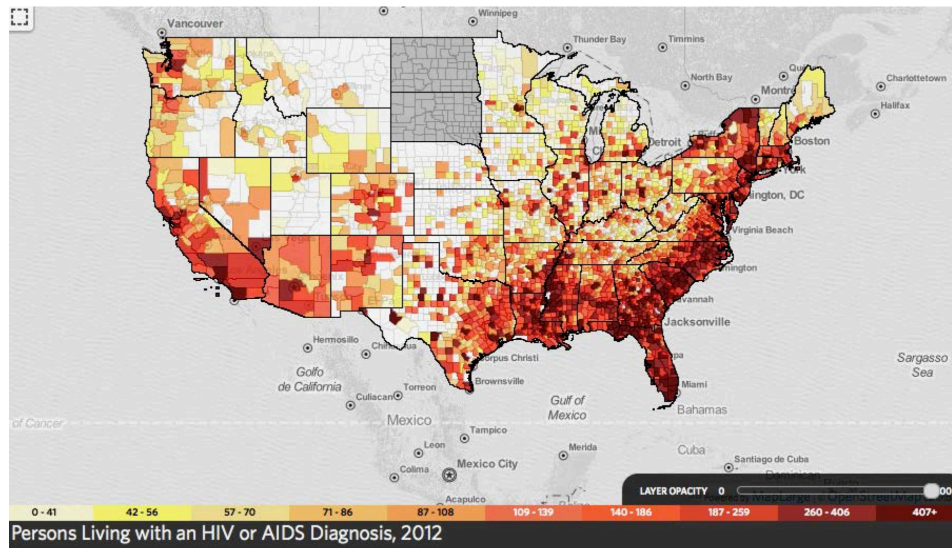
- A study of 581 newly diagnosed patients from 2004-2011 found that **63% had at least 1 gap in care**.
- A study using the 1917 Clinic Cohort found that **60% of new patients missed a visit during the first year** of care. These patients also had higher **mortality risk**.

Mugavero et al. 2009
Rana et al. 2015

Who

Geographic & regional differences

Just as distribution of disease differs geographically, rates of retention vary by region.



Chances of being poorly retained are higher for people living in the South and the West.

http://aidsvu.org/map/

Rebeiro et al. 2016

Who

Geographic & regional differences

Culture, risk factors, socioeconomics, political structures, and healthcare vary by region.

0 - 41 | 42 - 56 | 57 - 70 | 71 - 86 | 87 - 108 | 109 - 139 | 140 - 186 | 187 - 259 | 260 - 406 | 407+

Persons Living with an HIV or AIDS Diagnosis, 2012

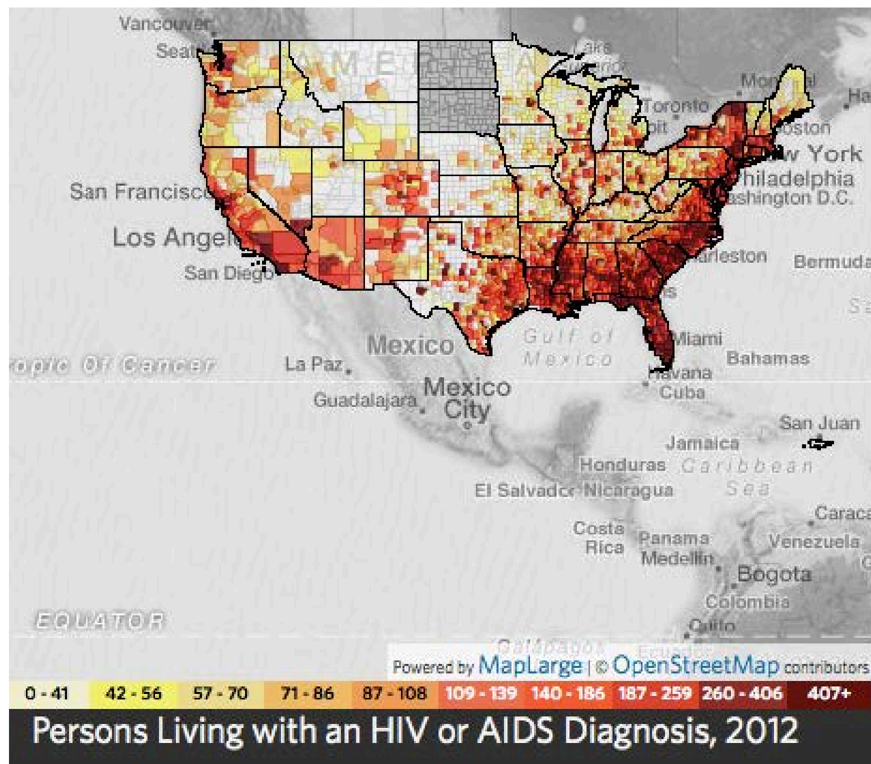
0% - 12.4% | 12.5% - 16.3% | 16.4% - 20.9% | 21.0%+

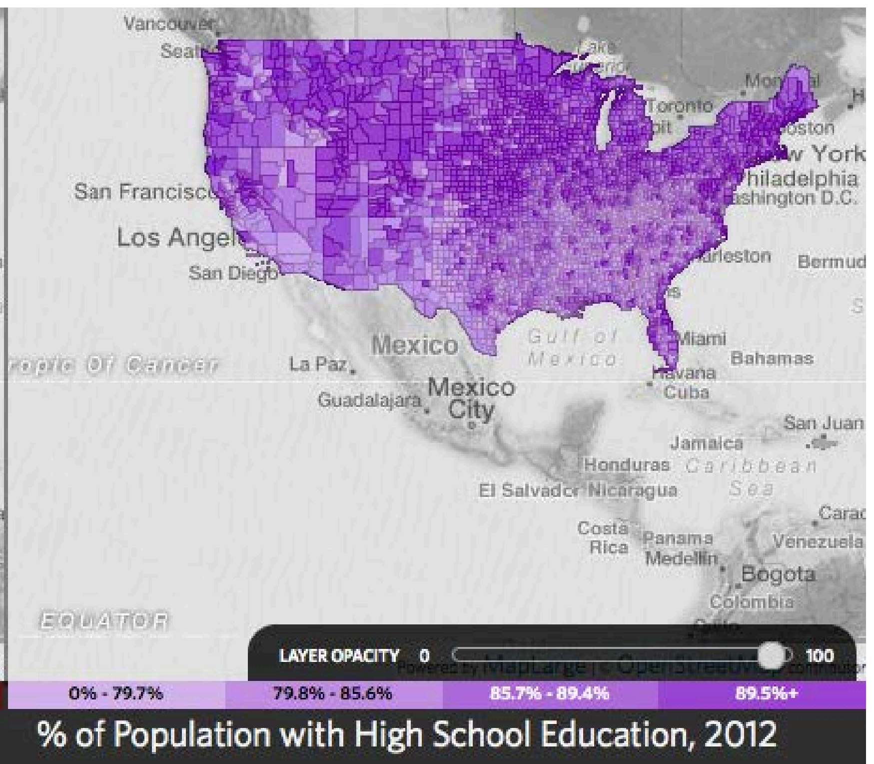
% of Population Living in Poverty, 2012

http://aidsvu.org/map/

Who

Geographic & regional differences





http://aidsvu.org/map/

Who

Geographic & regional differences

Considering geographic differences in retention is a critical component of evaluating and implementing interventions.

A “one size fits all” approach will not be effective.

When considering interventions, we need to **ask whether efficacy has been shown in the South**.

Good news: Many of the nations leading retention experts live and practice in the South!

Who

Social disparities of health

Risk for poor retention is not equally distributed.

- Race (Black)
- Age (young)
- HIV Risk Factor & substance abuse (IVD and hetero)
- Neighborhoods
- Quality of life (pain)

Rebeiro et al.2013, 2015, 2016
Taylor et al. 2014
Mugavero et al. 2009
Eberhart et al. 2013
Whiteside et al. 2014
Westergaard et al. 2013
Wohl et al. 2011
Merlin et al. 2012

Who

Stigma & Social Support

- From Birmingham, Alabama: 1917 Clinic found that patients who reported never disclosing their status to another person were twice as likely to be poorly retained in care.
- Poor retention in care was also independently associated with living alone.
- Smaller study linked increased internalized stigma to gaps in care.
- From Atlanta, Georgia: Patients who always attended appointments reported knowing someone else who was HIV+.

Elopre et al. 2015
Earnshaw et al. 2013
Rebolledo et al. 2011
Wohl et al. 2011

Solutions

Population Level	Collaborations between public health and academic research
Individual Level	Clinic-based interventions

Solutions
Partnerships & Collaboration

Tennessee Center for AIDS Research (TN CFAR)

Tennessee State Department of Health
Meharry Medical College
Vanderbilt University Medical Center

Continuum of Care Working Group

- Joined forces for analysis and interpretation of surveillance data
- Community engagement with ASOs
- Writing groups and joint submissions of abstracts to conferences

Solutions

Rates of Retention in Care in Tennessee

Clinical Retention (based on CD4, VL)

Counties of TN

- <27%
- 27-43%
- 44-60%
- 61-72%
- >72%

0 50 100 200 Miles

Presentation: Rebeiro P. Vanderbilt HIV/AIDS Symposium 2015, Nov

Solutions

Evidence-based interventions

CDC Home

Centers for Disease Control and Prevention
CDC 24/7: Saving Lives. Protecting People.™

SEARCH

A-Z Index for All CDC Topics

HIV/AIDS

HIV A-Z Topics

HIV/AIDS
- HIV Basics
- Who's at Risk for HIV?
- HIV Testing
- Prevention Research
  - Programs
  - Research
    - Pre-Exposure Prophylaxis (PrEP)
    - Prevention Benefits of HIV Treatment
    - Replicating Effective Programs Plus (REP)
    - **Compendium of Evidence-Based Interventions and Best Practices for HIV Prevention**

HIV/AIDS > Prevention Research > Research

Recommend Tweet Share

Compendium of Evidence-Based Interventions and Best Practices for HIV Prevention

- **NEW Linkage to, Retention in, and Re-engagement in HIV Care (LRC) Chapter**
- Medication Adherence (MA) Chapter
- Risk Reduction (RR) Chapter

NEW Linkage to, Retention in, and Re-engagement in HIV Care (LRC) Chapter

- Background
- LRC Best Practices Review Methods
- LRC Best Practices Criteria
- Complete List of LRC Best Practices
- Stratified List of All LRC Best Practices, by Characteristic

- Print page
- CDC HIV
- CDC HIV/AIDS
- Get email updates
- Subscribe to RSS
- See RSS
- Listen to audio/Podcast

View page in Spanish

VIH En Español (Spanish)

Get Tested

Enter ZIP code or C

GO

Find an HIV testing site

Solutions
Enhanced Personal Contact

- Compared “enhanced contact” with the routine appointment reminders (standard of care).
- Population: Patients with a history of missed visits and new patients.
- Intervention lasted 12 months.

Gardner et al. 2014

Solutions
Enhanced Personal Contact

The Intervention:

- Face-to-face meeting to establish relationship
- Brief meetings at each HIV appointment
- Phone call halfway between scheduled appointments
- Reminder call 7 days before scheduled appointment
- Reminder call 2 days before scheduled appointment
- No show call within 24 hours of missed appointment

Gardner et al. 2014

Solutions

Enhanced Personal Contact

- **1st study:**
  - **Increased visit constancy.**
  - **Increased visit adherence.**

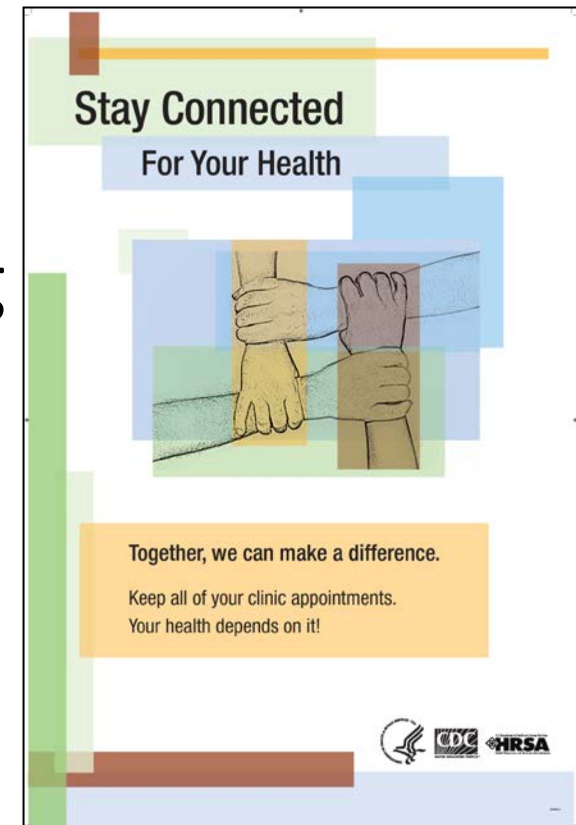
- **2nd study on higher risk patients:**
  - Highlighted challenges reaching high risk patients
  - Those who received adequate “dose” of intervention benefited.

- **Cost analysis:** Can be implemented at low cost and could result in financial benefits based on improved attendance.

Gardner et al. 2014; 2016
Shrestha et al. 2015

Solutions
Stay Connected

- Clinic-wide messaging campaign.
- Focused on health benefits of keeping appointments and staying in care.
  - Printed: posters, brochures
  - Verbal: consistent messages



Gardner et al. 2012

Solutions

- Improved attendance to future appointments.
- Especially effective among patients with detectable VL.
- Found to lower financial risk and improve revenue for the clinic.
- All materials available online.

Gardner et al. 2015

AETC NATIONAL RESOURCE CENTER

Supporting HIV Education for Health Care Professionals

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Home | About | Directory | Calendar | Resource Library | ShareSpot | AETC Community

Home › Resource Library › A Low-Effort, Clinic-Wide Intervention Improves Attendance for HIV Primary Care: Publication and Corresponding Tools

- Library Home
- Clinical Reference Tools
- Guidelines
- HRSA Clinical Guide
- Training Materials
- Training Program Resources

A Low-Effort, Clinic-Wide Intervention Improves Attendance for HIV Primary Care: Publication and Corresponding Tools

Publish date: October 15, 2012

Lytt Gardner (Author); Lucy Bradley-Springer, PhD, RN, ACRN, FAAN (Author); Michael Mugavero, MD (Author); Faye Malitz, MS (Author); Gary Marks (Author); Jason Craw (Author); Tracey Wilson (Author); Mari-Lynn Drainoni (Author); Richard Moore (Author); Allan Rodriguez (Author); Susan

Stay Connected

For Your Health

We adapted the Stay Connected posters and placed them in clinic exam rooms and other patient areas.

Stay Connecte

Come to all of your appoin

Keeping your clinic appointment
health and help you live longer.

Stay Connecte

Come to all of your appoint

Keeping your clinic appointments
health and help you live longer.

HRSA CDC

Stay Connected

Come to all of your appointments.

Keeping your clinic appointments can improve your
health and help you live longer.

HRSA CDC

Solutions

Healthcare Systems & Providers

Patient-provider relationships

- Greater trust in physicians associated with better retention among newly-diagnosed patients.

Provider Constancy

- Provider constancy has been associated with improved retention among HIV+ IVD users.

Graham et al. 2015
Westergaard et al. 2013

Solutions
Real World Challenges

- Treatment guidelines and expert panels recommend monitoring retention in care and identifying patients at-risk.
- How do we choose who to target in our world of limited clinical resources?

Solutions
at the Comprehensive Care Clinic

CCC + Care and Prevention in the U.S. Project (CAPUS) Partnership

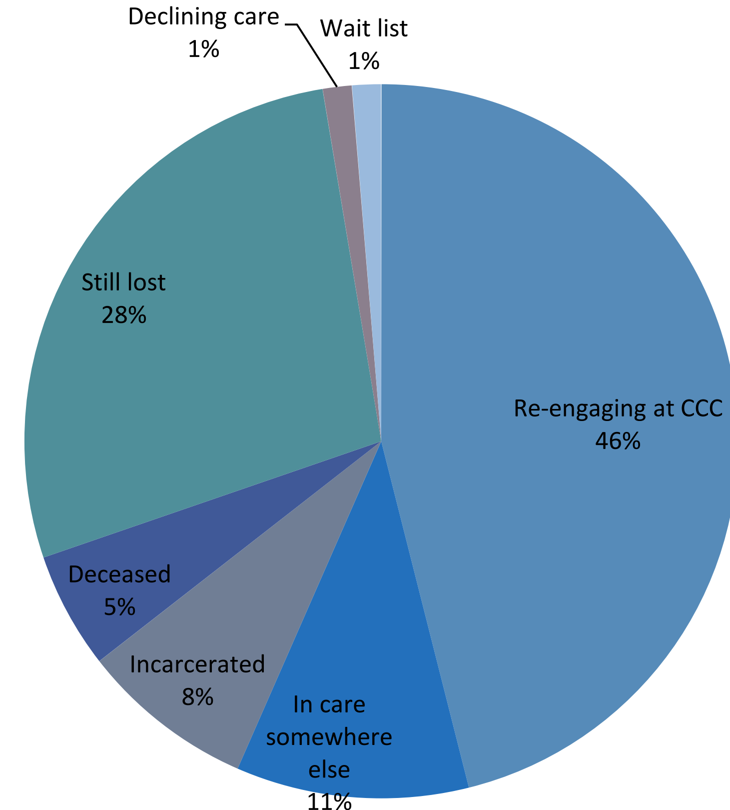
- Regular meetings between RN Case Manager and CAPUS DIS Worker.
- Direct referrals to CAPUS Program with ongoing follow-up.
- Face-to-face and designated contact person on both sides.
- Clear plan, including referral to CCC social worker when needed.
- So far, we have identified 76 patients as being lost to care.
- We have referred 60 of these to CAPUS in 18 months .

http://www.cdc.gov/hiv/prevention/demonstration/capus/

Solutions

Of all the patients we identified as “lost”:

- 35 (46%) are re-engaging at the CCC
- 21 (28%) are still lost
- 8 (11%) are in care somewhere else
- 6 (8%) are in jail and receiving care
- 4 (5%) have died
- 1 is declining care
- 1 is on the wait list for referral



Solutions

Of the patients we identified as “lost”:

Referred
79%

Not Referred

Died
2%

Came back in
on their own
4%

We got them
back in
13%

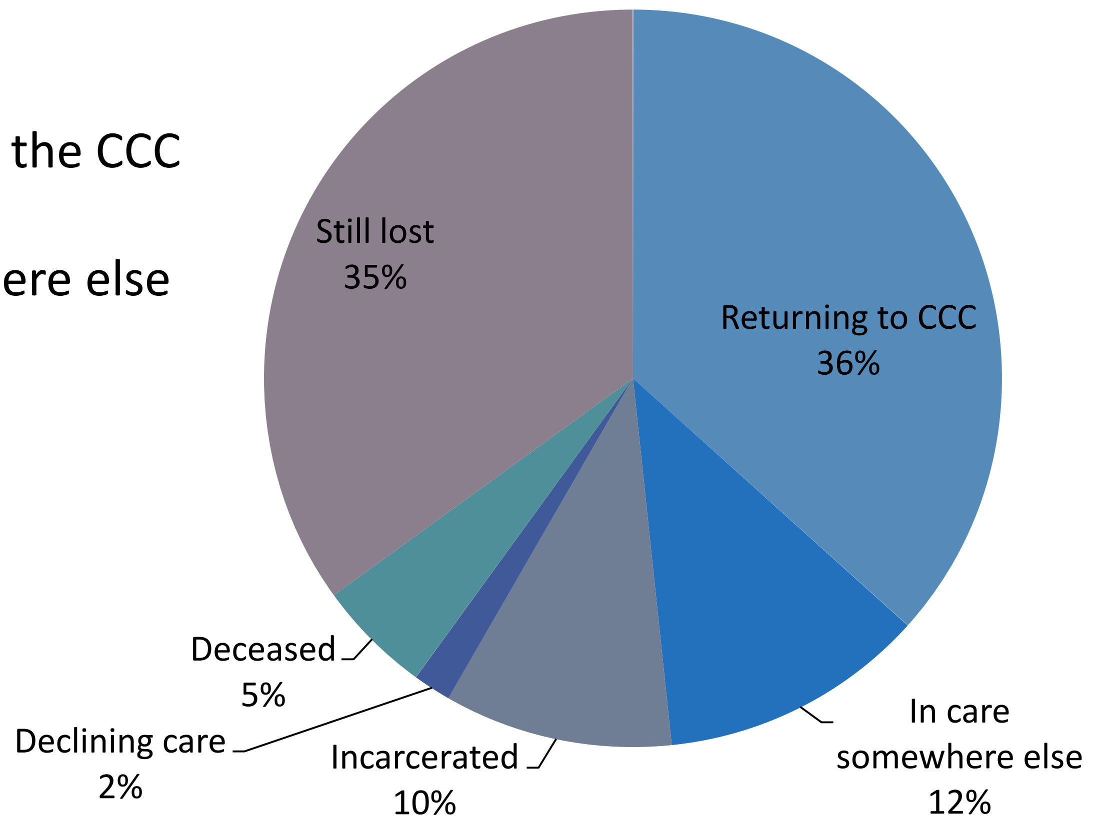
Wait list
1%

Transferred care
1%

Solutions

Of the patients referred to CAPUS (n = 60)

- 22 are re-engaging at the CCC
- 21 are still lost
- 7 are in care somewhere else
- 6 are incarcerated
- 3 are deceased
- 1 is declining care



Solutions
at the Comprehensive Care Clinic

Screening for at-risk patients

Scoring based on 7 risk factors → Scores associated with virologic failure risk and no show risk.

- Missed clinic visits
- Poor adherence to medications
- Heavy ART exposure
- Prior history of virologic failure
- Substance abuse
- CD4 <100
- Unsuppressed VL during previous 12 months

Robbins et al. 2009
Woodward et al. 2015

Solutions

Screening for at-risk patients.

Risk Factor	Points
Poor medication adherence: Documented during prior 12 month.	1 point for yes, 0 for no
Poor clinic attendance: Two or more "no-shows" during prior 12 months.	1 point for yes, 0 for no
Substance abuse: Documented within prior 12 months.	1 point for yes, 0 for no
Low CD4 count: CD4 count <100 copies/mm^3.	1 point for yes, 0 for no
Heavy ART exposure: Prior exposure to NNRTI, NRTI, and PI classes.	1 point for yes, 0 for no
Prior treatment failure: With genotypic confirmation showing resistance to previous regimen.	1 point for yes, 0 for no
Unsuppressed viremia: VL >200 copies/mL.	1 point for yes, 0 for no
	Total score: 0-1 = Low Risk 2-3 = Medium Risk **≥4 = High Risk**

Solutions

Routine screening for high risk patients

Pros:

- "Population triage": Reduced a large panel to a more manageable group.
- Focused resources.
- Helped develop our CAPUS Partnership
- Correlated with appointment patterns: High Risk patients were almost 10 times more likely to no show or cancel.

Limitations:

- Results of Program Evaluation showed no improvement in retention for the high risk group compared to the "medium risk" group.
- Likely highlight challenges intervening with high risk populations (similar to other studies).
- No control group, needed more data, "extreme" target group

Resources on the web

CDC Compendium of effective interventions:

http://www.cdc.gov/hiv/prevention/research/compendium/

Stay Connected:

http://www.aidsetc.org/resource/low-effort-clinic-wide-intervention-improves-attendance-hiv-primary-care-publication-and

Thank you.

Questions?