How can we improve the Care Cascade – the Macro Level

Carlos del Rio, MD

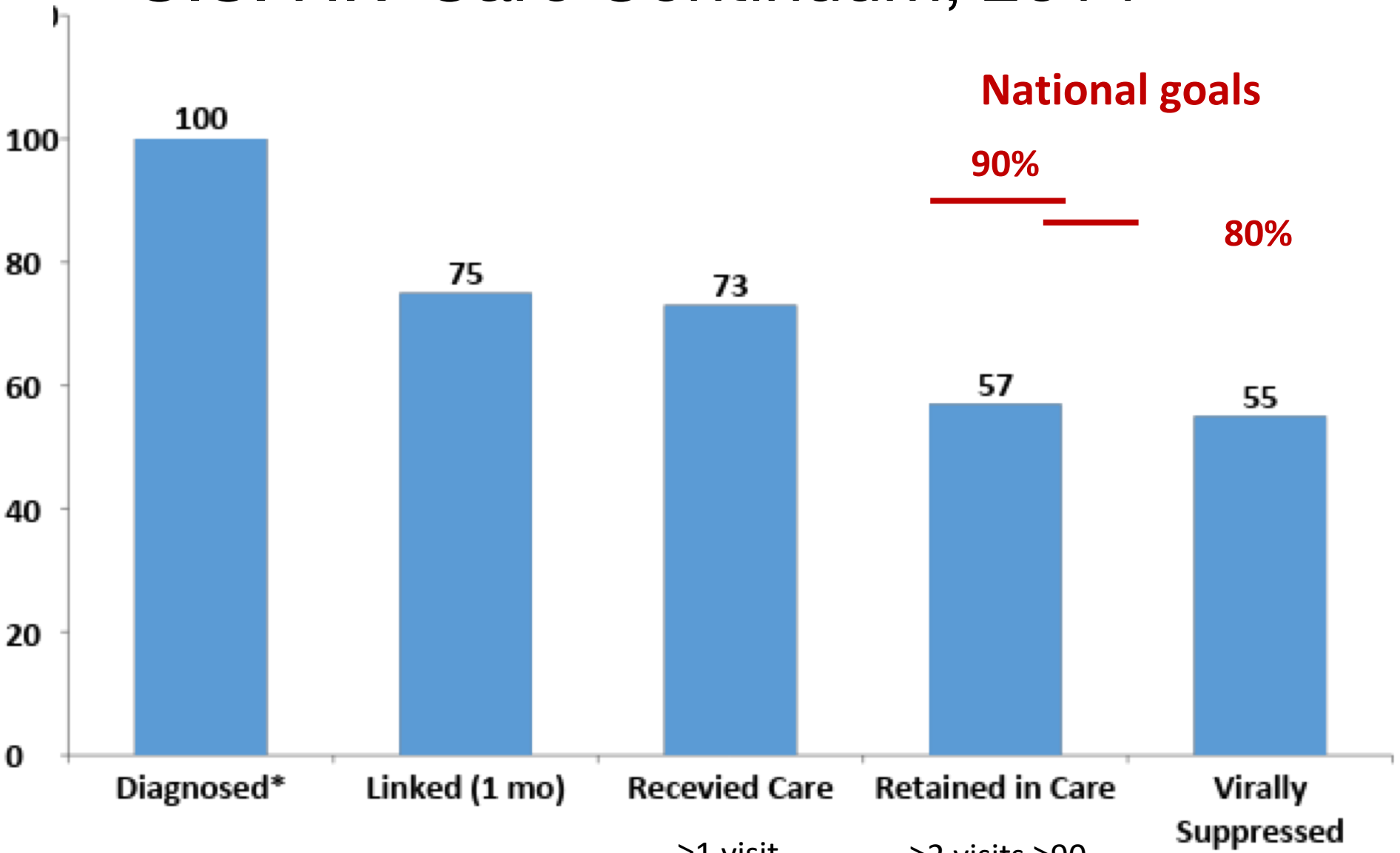
Emory University

Center for AIDS Research

Disclosures

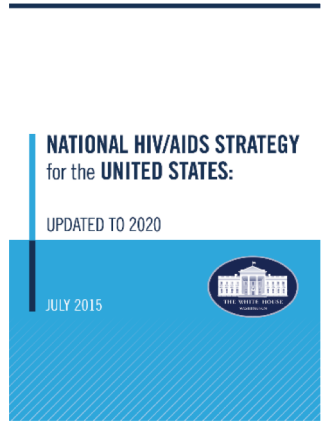
Dr. del Rio has served as a consultant for ViiV Healthcare and is a member of the Board of Directors of IASUSA and ACTHIV

U.S. HIV Care Continuum, 2014



Source: CDC. HIV Surveillance Report. Supplemental Report. 2017;22(2)

National HIV/AIDS Strategy indicators based on Care Continuum



90% Diagnosis

Indicator 1: ↑ % of people living with HIV who know serostatus to 90%

85% Linkage to Care

Indicator 4: ↑ % of newly diagnosed persons linked to care within 30 days of dx to 85%

90% Retention

Indicator 5: ↑ % of persons with diagnosed HIV who are retained to care to 90%

80% Viral Suppression

Indicator 6: ↑ % of persons with diagnosed HIV who are virally suppressed to 80%

NHAS: Updated to 2020. July 2015

Challenges to improving outcomes and interventions to address them:

- Not enough testing:
  - increase testing (New USPSTF recommendations)
- Delays in Care:
  - Linkage to care (ARTAS)
- Drop out of Care:
  - Retention and re-linkage interventions

Mascolini M. The three biggest HIV problems in the United States: Late testing, late care, and early dropout. *Research Initiative: Treatment Action!* 2011;16:1-73.

HIV TESTING AND KNOWLEDGE OF SEROSTATUS

- Knowledge of HIV serostatus is the pivotal step in directing interventions to prevent HIV infection.
- Approximately 50% of people infected with HIV worldwide don’t know their serostatus.
  - In the US now < 20%
- In the US infected persons unaware of their serostatus account for 45% of new infections.

Barriers to Testing

- Thought not at risk
- Feared HIV+ diagnosis
- Lack of symptoms
- Failure of provider to suspect diagnosis
- Low level of literacy about disease or self-care

Possible Causes for late testing

- Stigma, fear of discrimination
- Poor performance of testing programs
  - Not targeting testing to high risk populations
  - Missed opportunities for testing in healthcare settings
- Administrative barriers
  - Requirement for written informed consent
  - Requirements for pre-test counseling
  - Requirements to have physician authorize test

Recommendations from the USPSTF

Annals of Internal Medicine | CLINICAL GUIDELINE

Screening for HIV: U.S. Preventive Services Task Force Recommendation Statement

Virginia A. Moyer, MD, MPH, on behalf of the U.S. Preventive Services Task Force*

Description: Update of the 2005 U.S. Preventive Services Task Force (USPSTF) recommendation statement on screening for HIV.

Methods: The USPSTF reviewed new evidence on the effectiveness of treatments in HIV-infected persons with CD4 counts greater than 0.200×10^9 cells/L; effects of screening, counseling, and antiretroviral therapy (ART) use on risky behaviors and HIV transmission risk; and long-term cardiovascular harms of ART.

Population: These recommendations apply to adolescents, adults, and pregnant women.

Recommendation: The USPSTF recommends that clinicians screen adolescents and adults aged 15 to 65 years for HIV infection. Younger adolescents and older adults who are at increased risk should also be screened. (Grade A recommendation)

The USPSTF recommends that clinicians screen all pregnant women for HIV, including those who present in labor who are untested and whose HIV status is unknown. (Grade A recommendation)

Ann Intern Med. www.annals.org

For author affiliation, see end of text.

* For a list of the members of the USPSTF, see the Appendix (available at www.annals.org).

This article was published at www.annals.org on 30 April 2013.

Recommendations

- All adults and adolescents should be offered HIV testing at least one. **Rating: AIII**

- All persons should be informed prior to undergoing HIV testing however pretest counseling should be sufficient only to meet the individual's needs and to comply with local regulations. **Rating: AIII**

Linkage to Care

Monitoring HIV Care in the United States
Indicators and Data Systems

INSTITUTE OF MEDICINE
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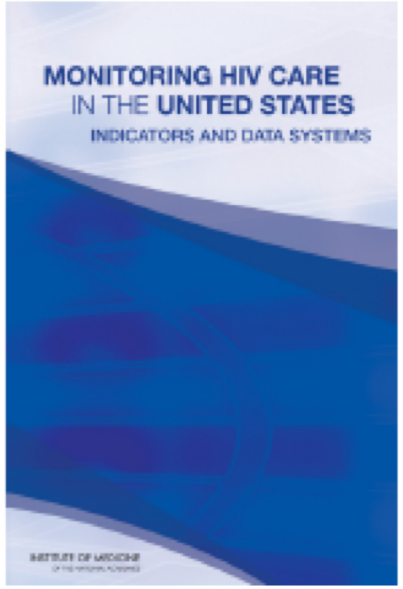
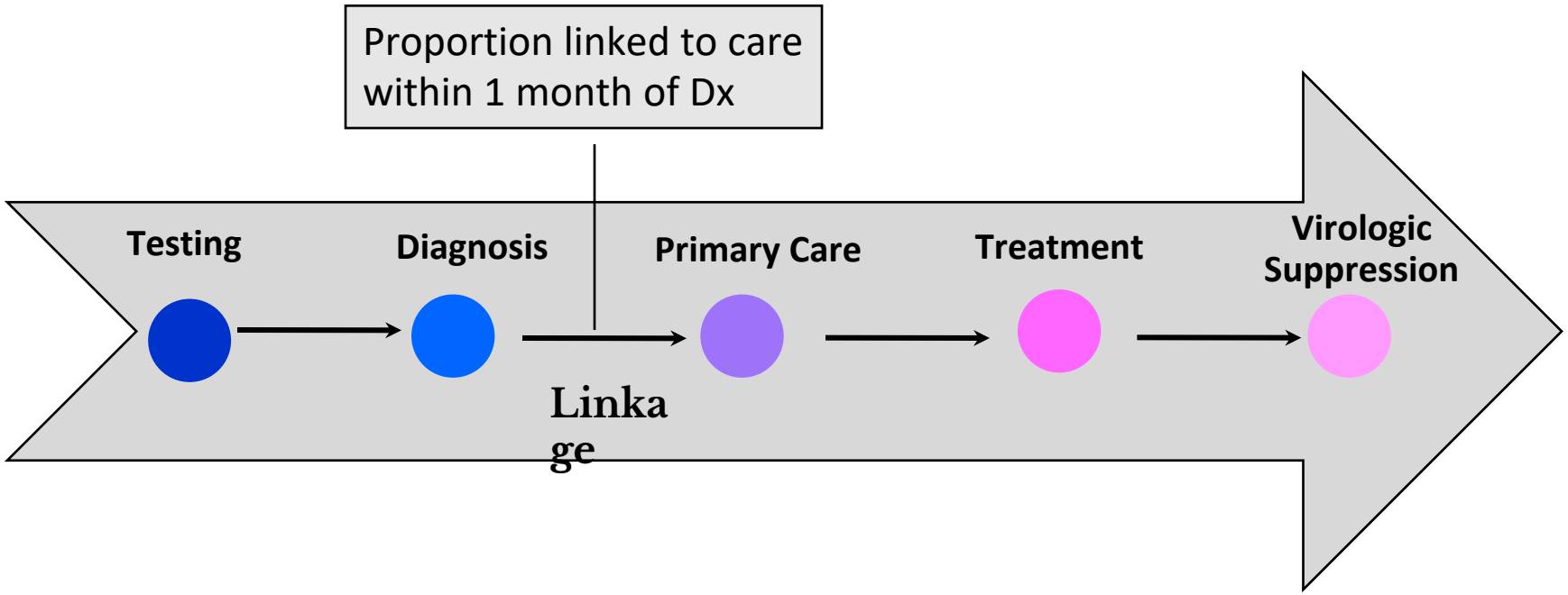




Entry into HIV care: US

- Failure to initiate timely HIV care after diagnosis is common
  - ~75% of newly diagnosed link to care within 6-12 months
- Between 45-55% of individuals fail to receive HIV care during any year.
- About one third of individuals fail to access care for 3 consecutive years in some communities
- 25-44% of HIV+ are entirely lost to follow up in some settings

Gardner, et al., Clinical Infectious Diseases, 2011

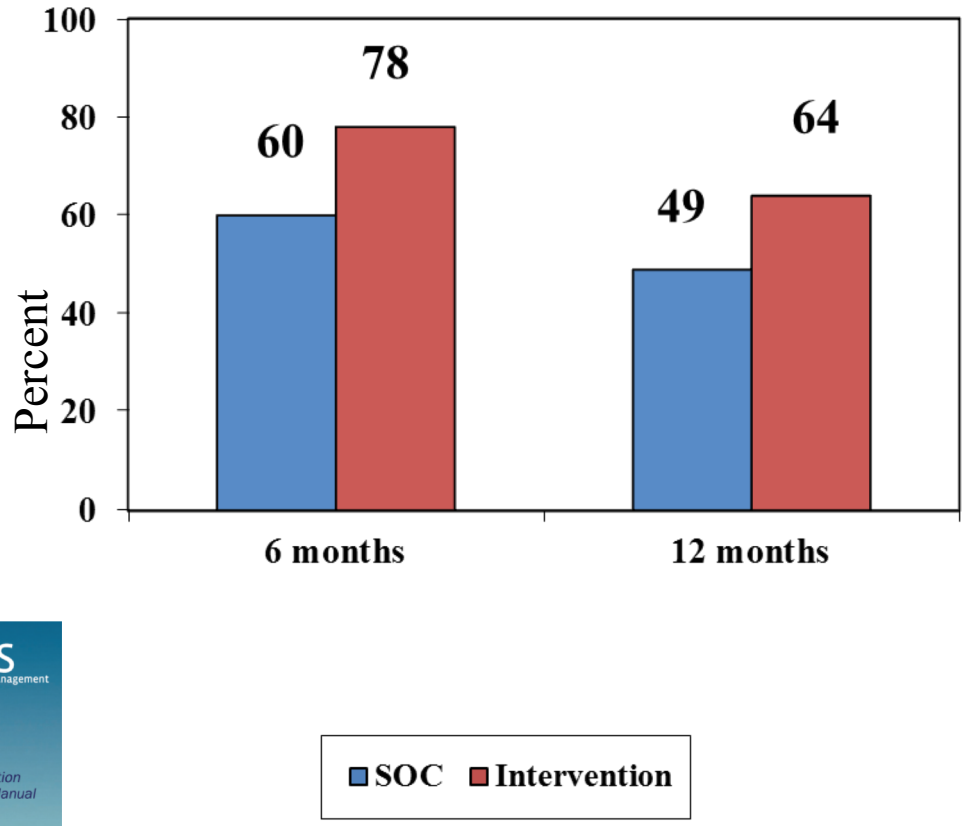
Linkage To HIV Care: Vulnerable Groups

- Delay to treatment is more common in:
  - African Americans[1,2]
  - Women (especially with children at home)[1-3,5]
  - Uninsured[2]
  - Immigrants[4]
  - Less well educated[2]
  - Injection drug users[2]

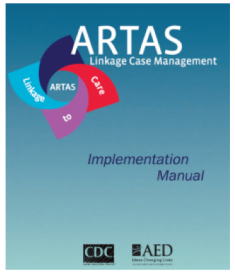
1.Bhatta. Am J Med Sci. 2010;339(2):133-40. 2. Anthony. AIDS Care. 2007 Feb;19(2):195-202. 3. Stein MD. Am J Public Health. 2000;90(7):1138-40. 4. Rodriguez. J Acquir Immune Defic Syndr. 2007 Aug 15;45(5):529-34. 5. Sohler. AIDS Patient Care STDS. 2009;23(9):775-83.

Intervention to Improve Linkage: ARTAS

- 273 participants, 4 cities
- 78% diagnosed <6 m
  - more likely to enter care
- 90 d of strength-based case management (CM)
- Older clients, those with much outside help and non-crack users more likely overall to enter care.



Replicated in ARTAS II



Gardner, *AIDS* 2005, 19:423; Gardner *AIDS Pt Care STD* 2007, 6:418

Retention in Care

Monitoring HIV Care in the United States
Indicators and Data Systems
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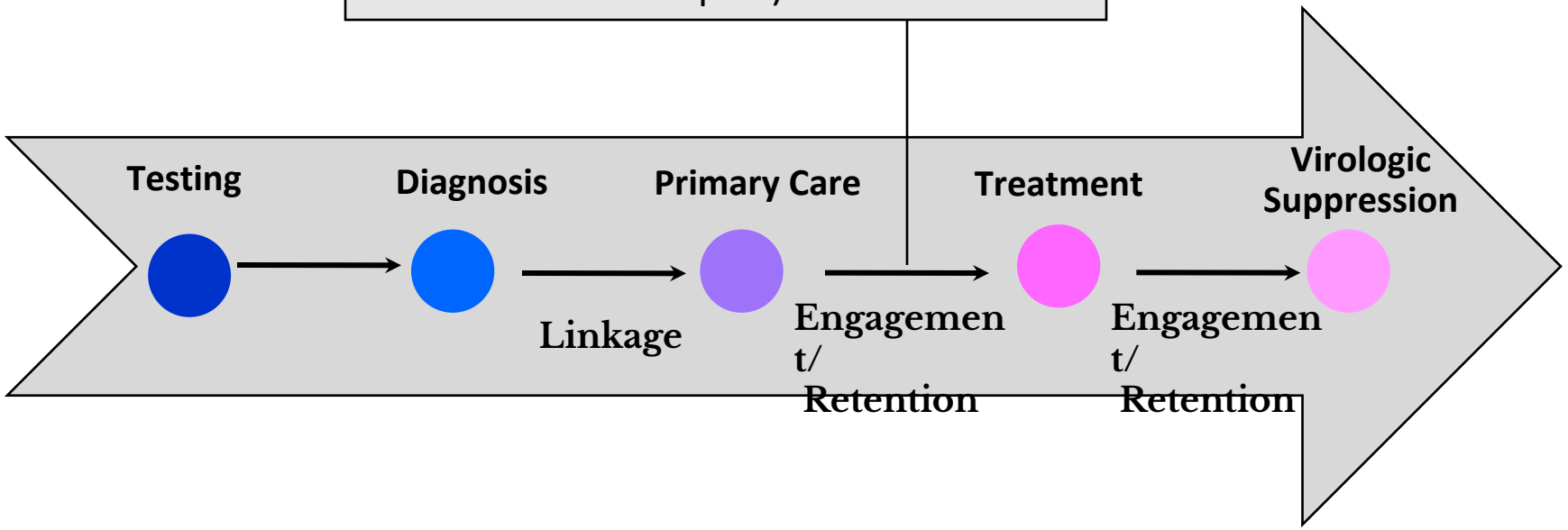
Proportion in continuous care
(2 or more visits in preceding 12 months at least 3 months apart)



Early retention in care

- The first year in outpatient HIV medical care is a dynamic, formative & vulnerable time
- Poor early retention in care associated with:
  - Delayed / failed antiretroviral therapy (ART) receipt
  - Delayed time to VL suppression and greater cumulative HIV burden
  - Increased sexual risk transmission behaviors
  - Increased risk of long-term adverse clinical events
  - Worse ART adherence, CD4 & VL response and increased long-term mortality following ART start

Ulett et al. *AIDS Pt Care STDS* 2009;23, Giordano et al. *JAIDS* 2003;32, Metsch et al. *Clin Infect Dis* 2008;47, Mugavero et al. *Clin Infect Dis* 2009;48, Giordano et al. *Clin Infect Dis* 2007;44

Retention is critical…as it predicts virologic suppression

- However:
  - No great way to measure retention
    - IOM, HRSA, DHHS, etc…
  - We do not know much about who is lost to care
  - We have no tools to predict who will be at risk of poor retention
  - There are no interventions that have proven to be effective for retention

Viral load suppression, Retained vs. not retained

Retention status	Viral load suppressed (<200 copies/ml at most recent test)
Retained in medical care	75%
Not retained in medical care*	50%

*Received at least 1 RW-funded medical visit but not retained in medical care

Doshi RK et al. CROI 2013, abstract 1031a.

Measure	Need missed visit data?	Ease of calculating	Follow-up time needed	Potential for misinterpretation*	Proximity to "retention in care"
Missed visit	Yes	Easy	>6 m	High: if no scheduled visits, will be falsely low; if automatic rescheduling, will be falsely high	Patient: moderate; Clinic: distant
Appointment adherence	Yes	Moderate	Pt: >1 yr Clinic: 1 d	High: if no scheduled visits, will be falsely high; if automatic rescheduling, will be falsely low	Patient: moderate; Clinic: distant
No-show rate	Yes	Moderate	Pt: >1 yr Clinic: 1 d	High: if no scheduled visits, will be falsely high; if automatic rescheduling, will be falsely low	Patient: moderate; Clinic: distant
Persistence: 3, 4 m intervals	No	Moderate	>6 m	Mod: will underestimate RIC for patients not needing frequent visits	Close
Persistence: 6 m intervals	No	Moderate	>1 yr	Moderate: will overestimate RIC for patients needing frequent visits	Moderate
Persistence: HRSA/HAB	No	Moderate-to-difficult	>1 yr	Moderate: will overestimate RIC for patients needing frequent visits	Moderate
Gaps	No	Pt: Easy Clinic: Diff.	>1 yr	Low	Close

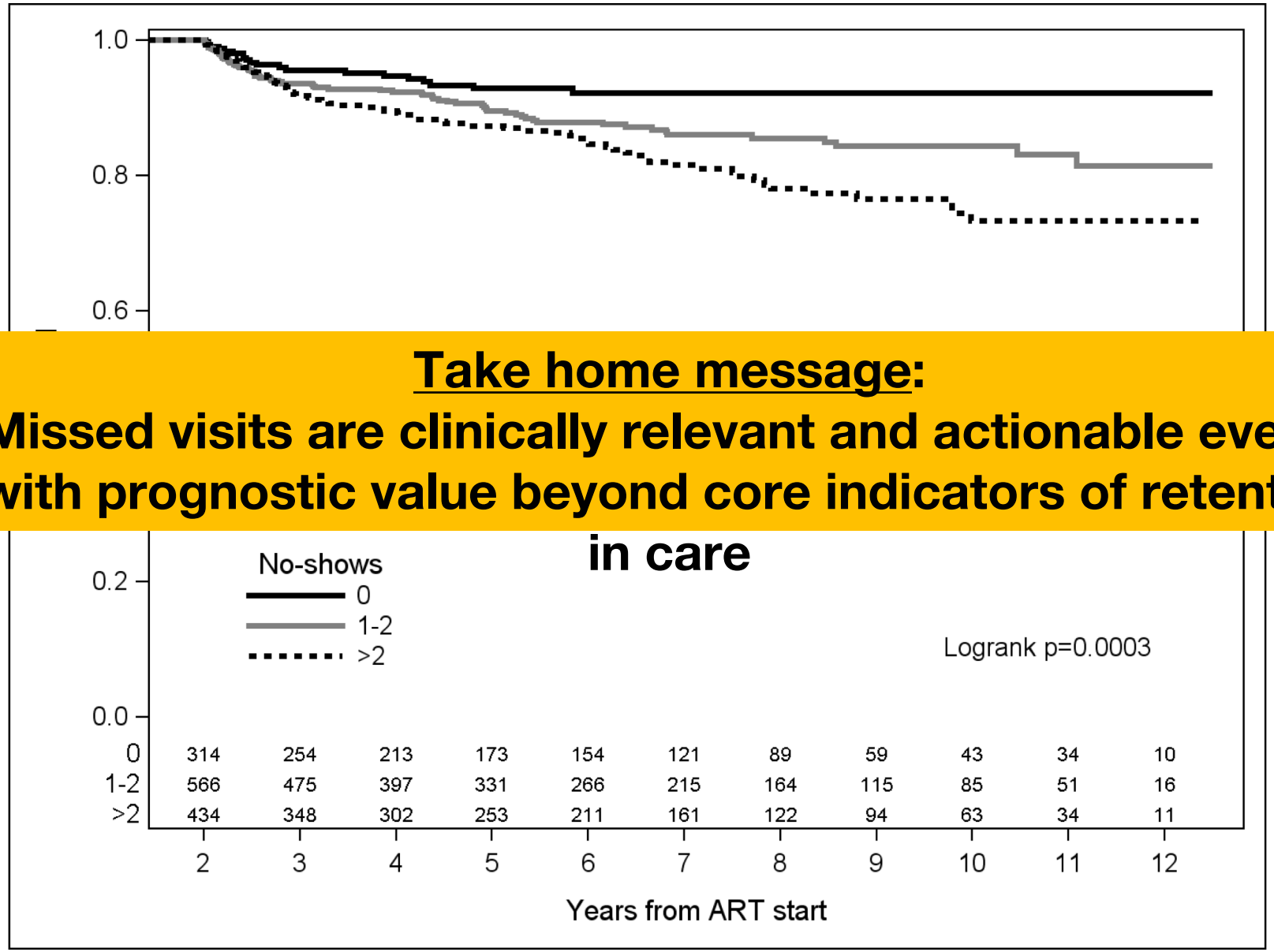
*All can be misinterpreted if patients unknowingly transferred care elsewhere, were incarcerated, or died.

Giordano TP (2012) Measuring retention in HIV care. www.medscape.com.

The value of the missing clinic visit

- 3,672 HIV-infected patients in CNICS sites (2000 – 11):
  - 64% and 59% met IOM and DHHS retention indicators
  - 32% had zero missed visits following ART initiation
  - 333 died (8.5%) during follow up
- Failure to achieve the IOM indicator (HR = 2.2); the DHHS indicator (HR = 2.4) and missed clinic visits at 24 months (HR = 3.2) were all associated with increased mortality
- Increased mortality risk among patients classified as retained in IOM and DHHS indicators among those with more missed clinic visits.

Mugavero M, et al. Beyond Core Indicators of Retention in HIV Care. CROI 2014 (Abst # 983)



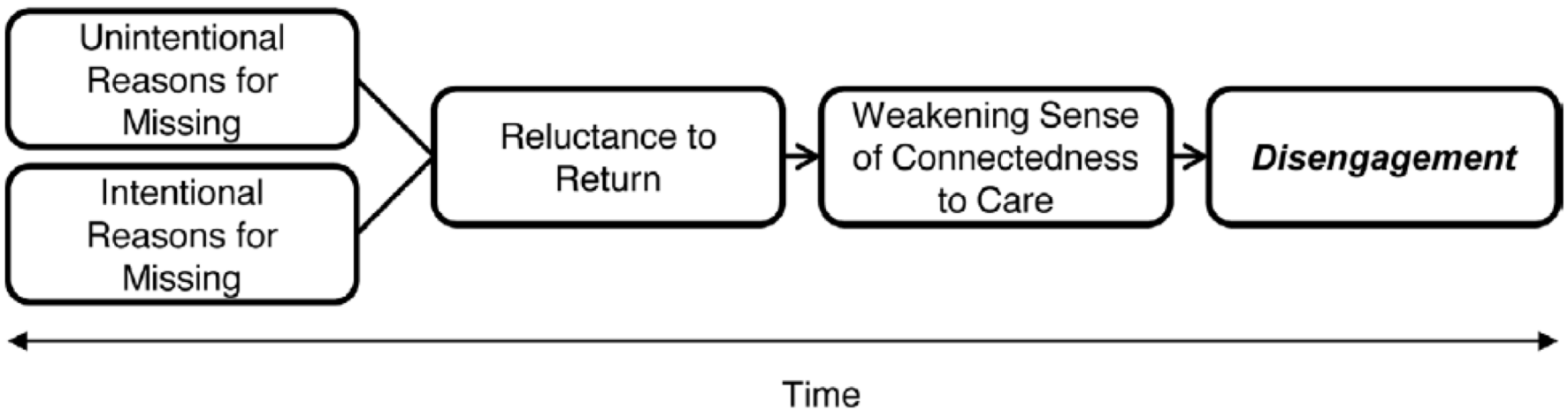
Take home message:

Missed visits are clinically relevant and actionable events with prognostic value beyond core indicators of retention in care

Mugavero M, et al. Beyond Core Indicators of Retention in HIV Care. CROI 2014 (Abst # 983)

Toward an Understanding of Disengagement from HIV Treatment and Care in Sub-Saharan Africa: A Qualitative Study

Norma C. Ware[1]*, Monique A. Wyatt[1], Elvin H. Geng[2], Sylvia F. Kaaya[3], Oche O. Agbaji[4], Winnie R. Muyindike[5], Guerino Chalamilla[6], Patricia A. Agaba[4]



HIV/AIDS MAJOR ARTICLE

Clinical Infectious Diseases 2012;55(8):1124–34

A Low-Effort, Clinic-Wide Intervention Improves Attendance for HIV Primary Care

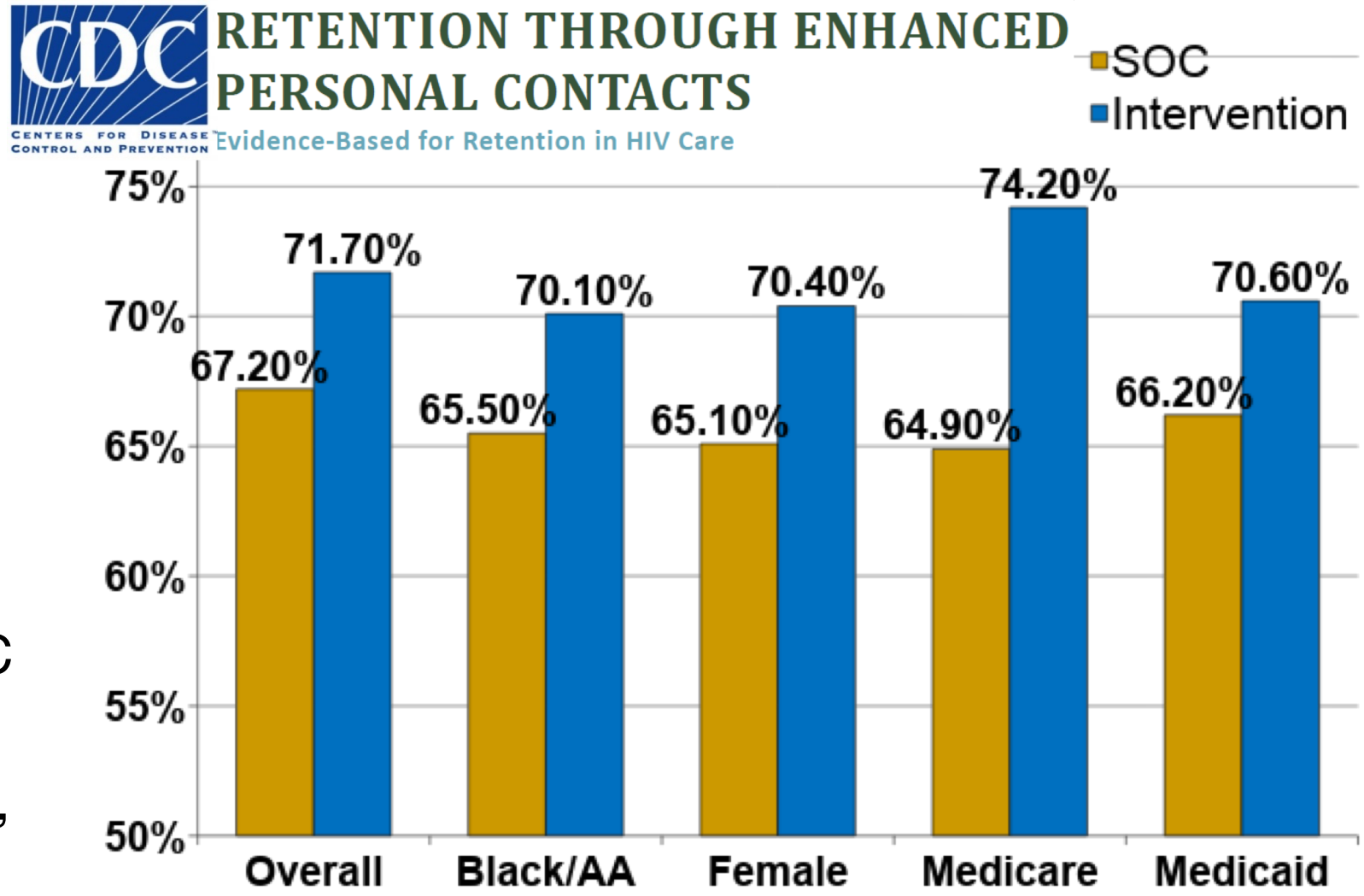
Lytt I. Gardner,[1] Gary Marks,[1] Jason A. Craw,[1,2] Tracey E. Wilson,[3] Mari-Lynn Drainoni,[6,7,8] Richard D. Moore,[9] Michael J. Mugavero,[11,12] Allan E. Rodriguez,[13] Lucy A. Bradley-Springer,[15] Susan Holman,[4,5] Jeanne C. Keruly,[9] Meg Sullivan,[8] Paul R. Skolnik,[16] Faye Malitz,[10] Lisa R. Metsch,[14] James L. Raper,[11,12] and Thomas P. Giordano,[17,18] for the Retention in Care Study Group[a]

[1]Division of HIV/AIDS Prevention, Centers for Disease Control and Prevention, and [2]ICF International, Atlanta, Georgia; [3]Department of Community Health Sciences, and Colleges of [4]Medicine, and [5]Nursing, SUNY Downstate Medical Center, Brooklyn, New York; [6]Center for Health Quality, Outcomes & Economic Research, Edith Nourse Rogers Memorial VA Hospital, Bedford, [7]Department of Health Policy and Management, Boston University School of Public Health, and [8]Department of Medicine, Boston University School of Medicine, Massachusetts; [9]Department of Medicine, Johns Hopkins University School of Medicine, Baltimore, and [10]Division of Science and Policy, Health Resources and Services Administration, Rockville, Maryland; [11]1917 HIV/AIDS Clinic, and [12]Department of Medicine, University of Alabama at Birmingham; [13]Division of Infectious Diseases, Miller School of Medicine, and [14]Department of Epidemiology and Public Health, University of Miami, Florida; [15]School of Medicine, University of Colorado Denver; [16]Department of Medicine, University of Connecticut School of Medicine, Farmington; [17]Department of Medicine, Baylor College of Medicine, and [18]DeBakey VA Medical Center, Houston, Texas

- Six HIV-specialty clinics
- Pre-intervention (2008-09) vs intervention (2009-10) periods
- Clinic attendance improved 7% during the intervention period for keeping 2 consecutive visits and 3% for all visits kept

CDC/HRSA REPC Efficacious for HIV Care Engagement

- RCT at 6 HIV clinics
- N=1838
- 3 study arms (1:1:1)
  * Enhanced Contact (EC)
  * EC + skills (EC+)
  * SOC
- Outcomes @ 12-months:
  * Visit adherence
  * 4-month visit constancy
- EC & EC+ superior to SOC
- Efficacy in subgroups
- Not efficacious with youth, substance use, unmet needs



Gardner LI et al. *Clin Infect Dis* 2014;59; Shrestha RK et al. *JAIDS* 2015; 68

How to Stay Connected

- Keep all of your scheduled clinic appointments.
- Work as a team with your health care providers.
- Talk openly and honestly with your health care team.
- Ask questions that are important to you.

Why Is It Important to Keep All of Your Clinic Appointments?

Your Health Depends on It!

At your appointments

- We can check your health and make changes to your treatment plan if needed.
- We can give you the best medical care.
- You can take control of your health.

In one large study, people with HIV who attended all of their clinic appointments lived longer.

Source: Clinical Infectious Diseases, 2007.

Remember—it is important to come to all of your clinic appointments whether you feel sick or feel well.

Ways to Remember Your Clinic Appointments

- ❑ Write all of your appointments in a calendar.
- ❑ Put reminders or alerts in your cell phone.
- ❑ Put your reminder card in a place where you will see it often.
- ❑ Make sure we have your correct telephone number and address.
- ❑ Let us know right away if your telephone number or address changes.

If something comes up and you can't keep a clinic appointment, please call us at least 2 days in advance. It is important to reschedule if you miss an appointment.

Gardner, *Clin Infect Dis*. 2012 Oct;55(8):1124-34

Engagement in care is associated with decreased sexual risk behaviors

Variable	Proportion (%) of patients
Unprotected vaginal or anal intercourse with HIV-negative or unknown status partner within the previous month	
Baseline	84/305 (27.5)
6-Month follow-up	31/258 (12.0)
12-Month follow-up	36/254 (14.2)
Receipt of medical care for HIV infection at least 3 times within 6-month period	
Period between baseline and 6-month follow-up	139/258 (53.9)
Period between 6-month and 12-month follow-up	116/254 (45.7)

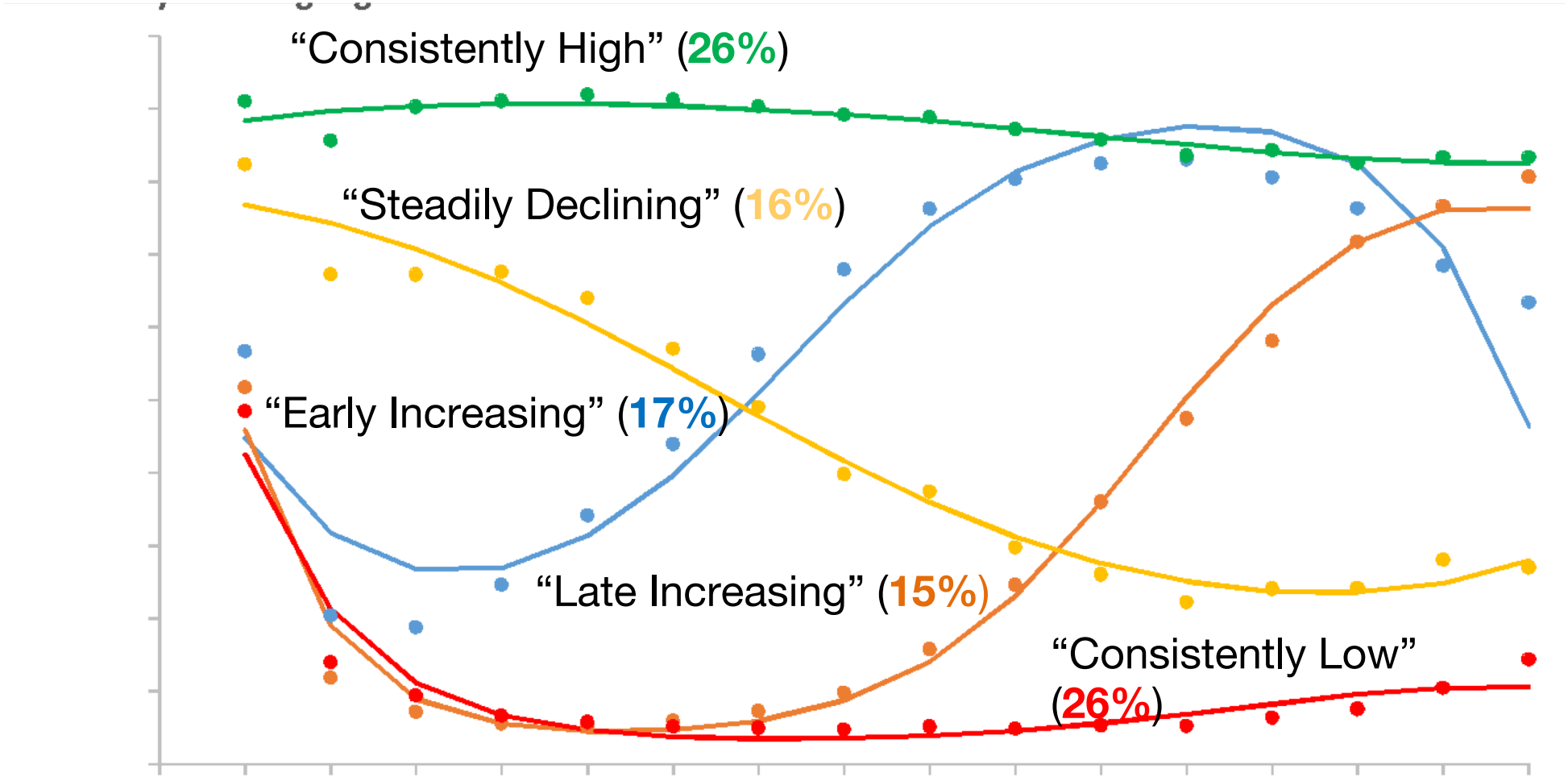
Clinical Infectious Diseases 2008; 47:577–84

Challenges to Linkage and Retention

- Providing newly diagnosed patients with timely appointments with HIV care providers
- Resources for short-term case manager/system navigators to support follow-up for patients who need it
- Capacity of care system to meet demand for HIV care
- Complexity of patients' lives, including many with serious co-morbid conditions and many in potentially vulnerable groups (eg, African Americans, women, IDU, low education, immigrants)

1. Torian et al. Arch Intern Med. 2008 Jun 9;168(11):1181-7.
2. Ulett et al. AIDS Patient Care STDS. 2009 Jan;23(1):41-9.
3. Gardner et al. AIDS. 2005 Mar 4;19(4)423-31.

Engagement in Care is Dynamic



Powers et al, *JAIDS* 2017; 74(S2)

San Francisco RAPID: Same Day ART Initiation

Time from HIV Dx to:	RAPID (n=39)	SOC (n=47)
ART	1 (0-7)	22 (14-48)
Clinic referral	6 (2-11)	11 (3-4)
VL<200 c/mL	65 (52-119)	170 (79-363)

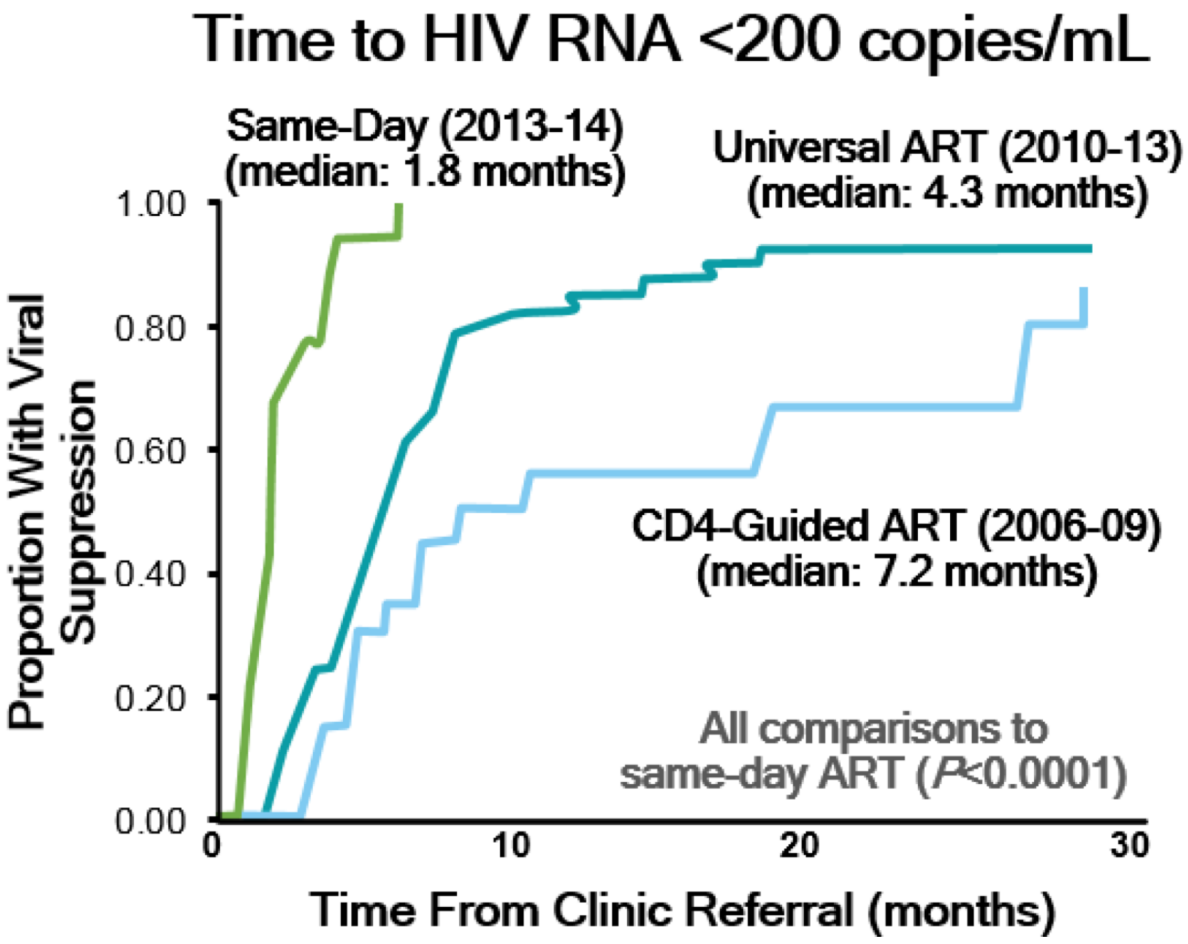
Prospective cohort (consecutive pts with new HIV diagnosis, 2013-2014).

Same-day ART initiation cohort: pts with acute or recent infection (<6 months) or CD4 <200 cells/mm^3.

Global rapid ART start trials:

RapIT RCT (n=377, South Africa): RR 1.36 (95% CI:1.24, 1.49) for ART, 1.26 (1.05, 1.50) for VS w/ rapid ART initiation[2]

GHESKIO Centers RCT (n=703, Haiti): improved 12-mo in care w/ VS (53% vs 44%, p=0.008) and mortality (3% vs 6%, p=0.03) in same day ART group[3]



[1]Pilcher C, et al; *JAIDS*, 2017;74, [2]Rosen S, et al. *PLoS Med* 2016;13(5), [3]Koenig S, et al. *PLoS Med* 2017;14(7)

Open Forum Infectious Diseases

MAJOR ARTICLE

Implementation of a Rapid Entry Program Decreases Time to Viral Suppression Among Vulnerable Persons Living With HIV in the Southern United States

Jonathan Colasanti,[1,2,3,4] Jeri Sumitani,[4] C. Christina Mehta,[5] Yiran Zhang,[5] Minh Ly Nguyen,[1,2,4] Carlos del Rio,[1,2,3,4] and Wendy S. Armstrong[1,2,4]

[1]Division of Infectious Diseases, Department of Medicine, Emory University School of Medicine, Atlanta, Georgia; [2]Emory Center for AIDS Research, Atlanta, Georgia; [3]Hubert Department of Global Health and [5]Department of Biostatistics and Bioinformatics, Rollins School of Public Health, Emory University, Atlanta, Georgia; [4]Infectious Diseases Program, Grady Health System, Atlanta, Georgia

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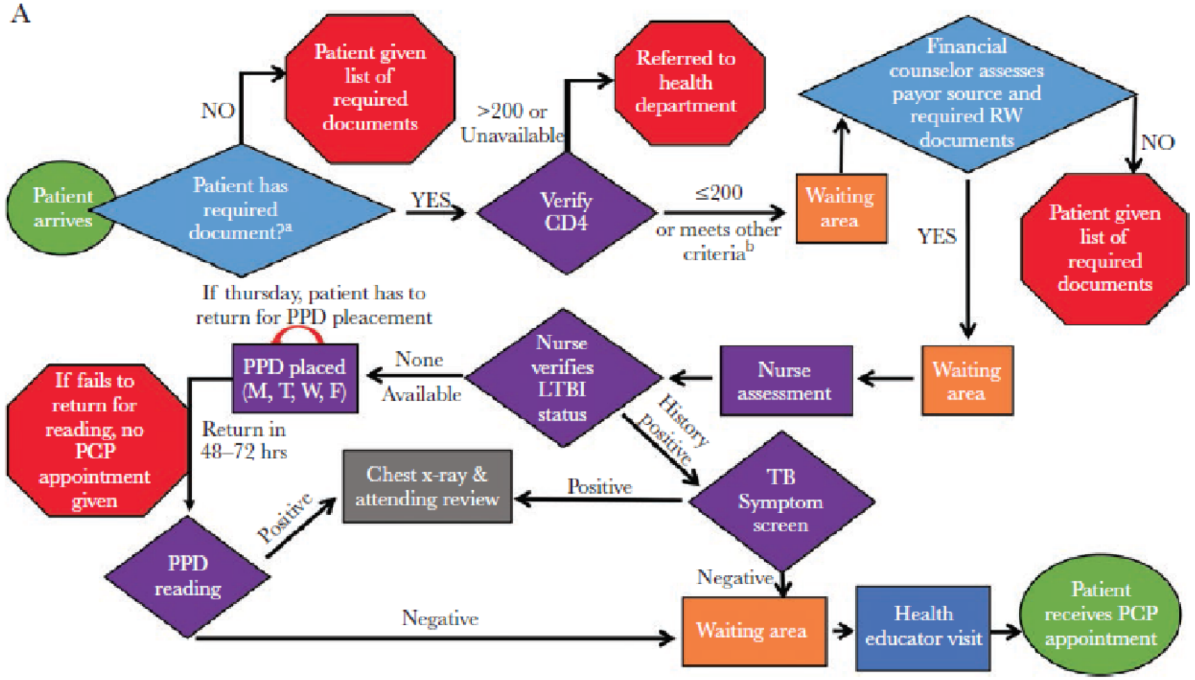

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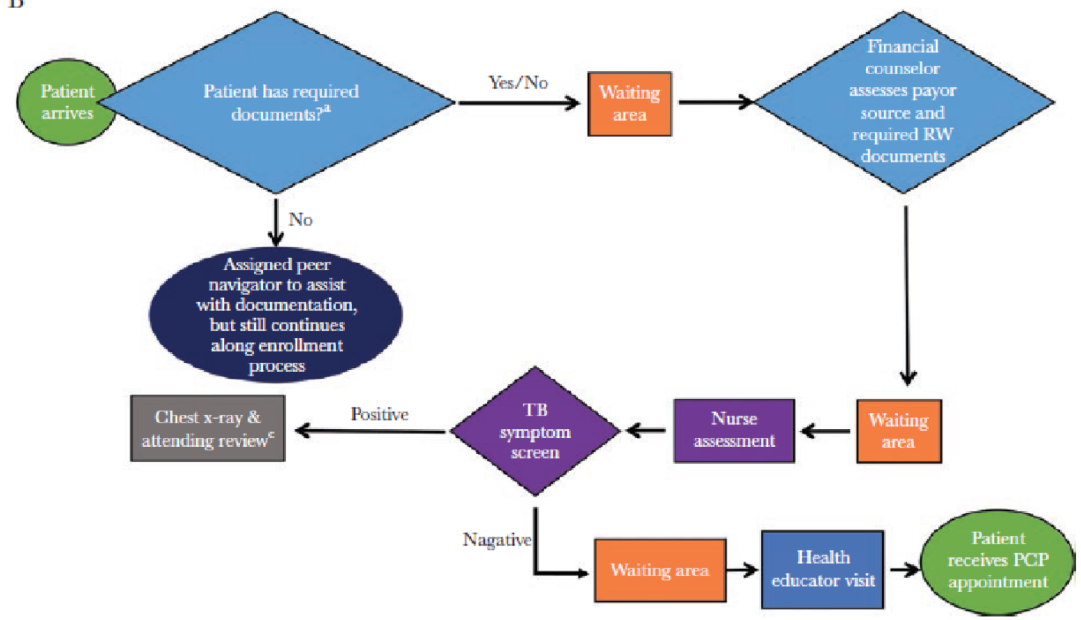
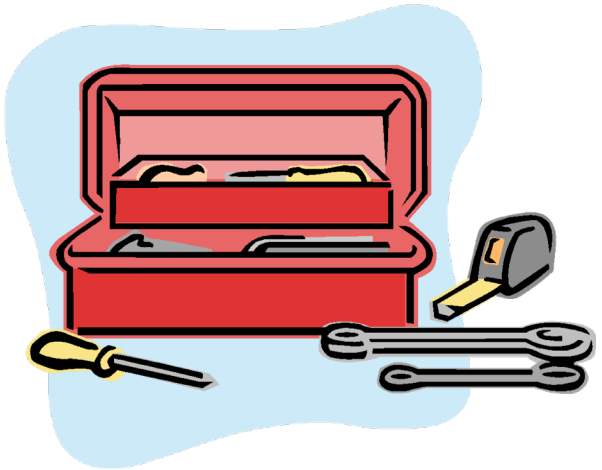


What else is in your toolbox of interventions?



Patient navigators

- In 1990 Harold Freeman joined forces with the American Cancer Society and developed the first patient navigation (PN) program which was implemented in Harlem.
- The primary goal of PN is to assist patients in moving through the entire system of medical care.
- PN have been found to be improve outcomes in patients with cancer

Patient Navigators

The Opinion Pages | OP-ED CONTRIBUTOR

The New York Times

Why Black Women Die of Cancer

By HAROLD P. FREEMAN MARCH 13, 2014

At Harlem Hospital, we provided free breast cancer screening beginning in 1979. But screening alone was not enough. Patients — who not only often lacked health insurance, but also struggled with a limited education and distrust of doctors — needed help making their way through the medical system. So in 1990, we pioneered the patient navigation program, which provided one-on-one support to patients with abnormal findings. The navigators helped patients obtain insurance, made sure they understood what was recommended, guided them through appointments and allayed their fears. Applying the two interventions in Harlem — breast cancer screening and patient navigation — raised the five-year breast cancer survival rate from 39 percent to 70 percent in 2000.

Patient navigators

- **Coordinate treatment care**
  - by assisting patients with completing necessary medical paperwork; scheduling, confirming , rescheduling and also accompanying patients to medical and treatment appointments; and facilitating communication between patients and care providers
- **Provide health education**
  - by providing written information, discussing diagnostic tests and treatment options and answering questions
- **Assist patients to overcome personal barriers**
  - by addressing lack of transportation, lack of childcare, lack of insurance, and lack of health knowledge
- **Provide psychosocial or emotional support**
  - either directly or by making appropriate referrals to social workers or support groups

Contingency Management

- The systematic reinforcement of desired behaviors and the withholding of reinforcement or punishment of undesired behaviors
- Effective strategy in the treatment of alcohol and other substance use disorders
- Has also been found to be useful in cocaine addiction
- Used in other chronic conditions

By Nora D. Volkow and Julio Montaner

ANALYSIS & COMMENTARY

The Urgency Of Providing Comprehensive And Integrated Treatment For Substance Abusers With HIV

HEALTH AFFAIRS 30,
NO. 8 (2011): 1411–1419

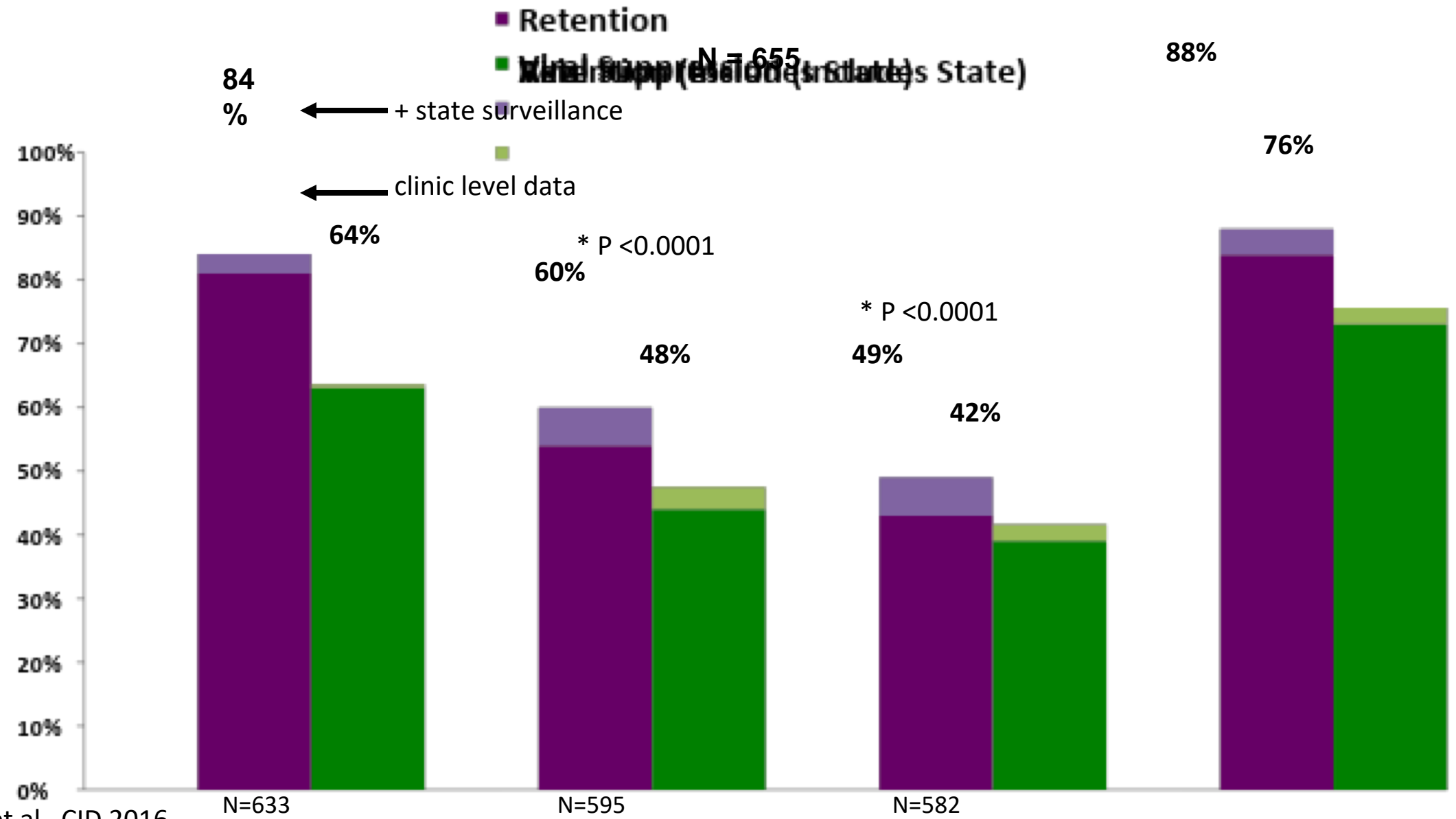
Poor access to effective substance abuse treatment is a major factor fueling HIV transmission.

Re-engagement in care

- Less well studied than linkage & retention
- Typical focus: patients w/ prior HIV care LTFU
- HRSA SPNS Outreach Initiative
  - 10 demonstration projects featuring pt navigation
  - Loss to care: mental illness, SA, unstable housing
- Other priority populations for re-engagement
  - Recently incarcerated
  - Recently hospitalized

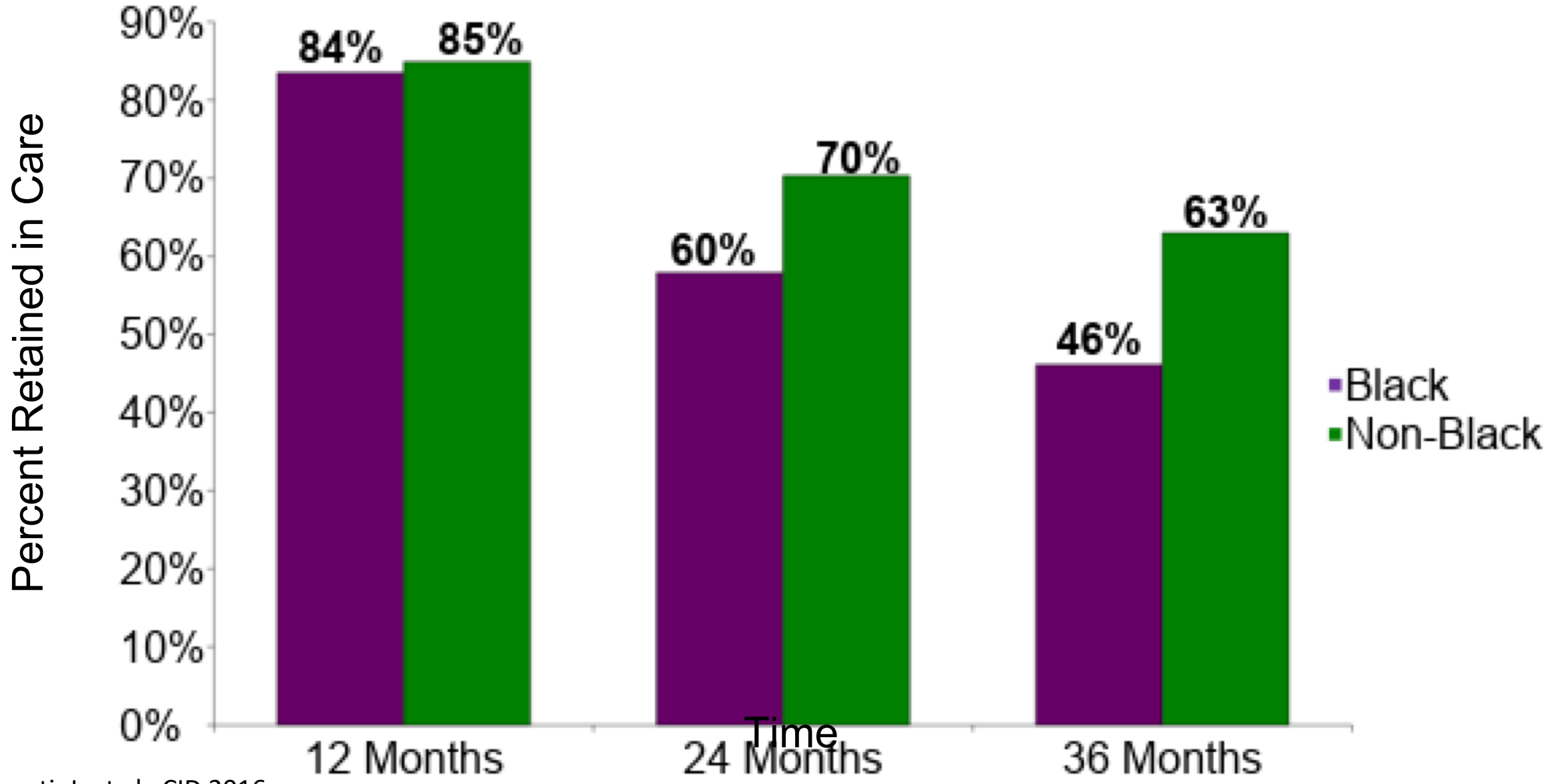
Tobias et al. *AIDS Pt Care STDS* 2007;21:S3, Rajabuin et al. *AIDS Pt Care STDS* 2007;21:S9, Bradford. *AIDS Pt Care STDS* 2007;21:S46, Zaller *J Health Care Poor Underserved* 2008;19, Draine *AIDS Care* 2011;23, Wohl et al. *AIDS Behav* 2011;15, Metsch et al. *AJPH* 2009;99

Longitudinal Retention and Viral Suppression



Colasanti, J, et al. CID 2016

Continuous View Unmasks Racial Disparity in Retention



Colasanti, J, et al. CID 2016

Annals of Internal Medicine | Clinical Guideline

Guidelines for Improving Entry Into and Retention in Care and Antiretroviral Adherence for Persons With HIV: Evidence-Based Recommendations From an International Association of Physicians in AIDS Care Panel

Melanie A. Thompson, MD; Michael J. Mugavero, MD, MHSc; K. Rivet Amico, PhD; Victoria A. Cargill, MD, MSCE; Larry W. Chang, MD, MPH; Robert Gross, MD, MSCE; Catherine Orrell, MBChB, MSc, MMed; Frederick L. Altice, MD; David R. Bangsberg, MD, MPH; John G. Bartlett, MD; Curt G. Beckwith, MD; Nadia Dowshen, MD; Christopher M. Gordon, PhD; Tim Horn, MS; Princy Kumar, MD; James D. Scott, PharmD, MEd; Michael J. Stirratt, PhD; Robert H. Remien, PhD; Jane M. Simoni, PhD; and Jean B. Nachega, MD, PhD, MPH

Description: After HIV diagnosis, timely entry into HIV medical care and retention in that care are essential to the provision of effective antiretroviral therapy (ART). Adherence to ART is among the key determinants of successful HIV treatment outcome and is essential to minimize the emergence of drug resistance. The International Association of Physicians in AIDS Care convened a panel to develop evidence-based recommendations to optimize entry into and retention in care and ART adherence for people with HIV.

Methods: A systematic literature search was conducted to produce an evidence base restricted to randomized, controlled trials and observational studies with comparators that had at least 1 measured biological or behavioral end point. A total of 325 studies met the criteria. Two reviewers independently extracted and coded data from each study using a standardized data extraction form. Panel members drafted recommendations based on the body of evidence for each method or intervention and then graded the overall quality of the body of evidence and the strength for each recommendation.

Recommendations: Recommendations are provided for monitoring entry into and retention in care, interventions to improve entry and retention, and monitoring of and interventions to improve ART adherence. Recommendations cover ART strategies, adherence tools, education and counseling, and health system and service delivery interventions. In addition, they cover specific issues pertaining to pregnant women, incarcerated individuals, homeless and marginally housed individuals, and children and adolescents, as well as substance use and mental health disorders. Recommendations for future research in all areas are also provided.

Ann Intern Med. 2012;156:817-833. www.annals.org
For author affiliations, see end of text.
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Recommendations for entry into and retention in HIV care

- Systematic monitoring of successful entry into HIV care is recommended for all individuals diagnosed with HIV (**II A**).
- Systematic monitoring of retention in HIV care is recommended for all patients (**II A**).
- Brief, strengths-based case management for individuals with a new HIV diagnosis is recommended (**II B**).
- Intensive outreach for individuals not engaged in medical care within 6 months of a new HIV diagnosis may be considered (**III C**).
- Use of peer or paraprofessional patient navigators may be considered (**III C**).

Conclusions

- Engagement in HIV care is increasingly recognized as a critical step in patient outcomes
- Linkage and retention are interrelated but distinct processes
- Early missed visits can identify patients at high risk of poor outcomes
- Just as we have gotten used to discussing medication adherence with our patients, we also need to discuss “clinic adherence”

Recommendations

- Track no-show rates and out of care
- Minimize unmet need:
  - Strengthen access to substance use, mental health, case management, and social services
- Streamline your clinic processes to reduce barriers for persons attending clinic:
  - Bringing patients back is much more difficult once out of care completely
- Improve the customer's experience

Modified from T.

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Atlanta collaborators:
Wendy Armstrong, MD
Melanie Thompson, MD
Jonathan Colasanti, MD, MPH

Other Colleagues
Thomas Giordano, MD, MPH
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Lisa Metsch, PhD
Moupali Das, MD, MPH
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