



NATIONAL QUALITY CENTER *Improving HIV Care*

Strategies to Improve Patient Retention: Experiences from Grantees

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Funded by HRSA
HIV/AIDS Bureau

Overview

- Introduction
- Measurement
- Quality improvement and retention
- Strategies and conclusions

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Why is Retention Important?

- Medical Care
 - The heart of the patient-provider relationship; *“medical home”*
- The Primary Care Model
 - Access
 - Coordination
 - Continuity
 - Comprehensiveness
 - Quality

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Why is Retention Important?

- Public Health
 - Retention likely to help prevent and control chronic disease, reduce morbidity and premature mortality leading to improved population health

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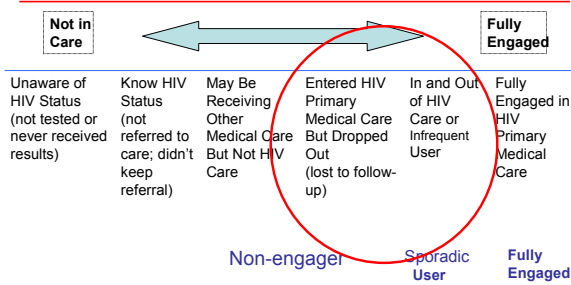
Retention and Outcomes: The Evidence Base for HIV

- Multiple studies demonstrate that patients who are retained in care have better likelihood of viral load suppression
- Conversely, patients who miss appointments frequently are more likely to have virologic failure
- Patients who miss visits have longer hospital stays and use emergency services more

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Continuum Engagement in Care



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Approaching Retention from a QI Perspective

- **Perfectly suited to system-level interventions and quality improvement**
 - Measurable
 - Improvable
 - Team-based approach
 - Multiple processes: system
 - Patient-centered

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Measurement

- What is the extent of the problem?
 - No-shows
 - Retention rates

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No-Show Rates: *aka* "DNKA"

- No-show rates range from 25% to >40% in published studies
- Limitations:
 - Patients may be counted for multiple visits
 - Type of clinic visit not uniform
 - Time frame accepted for prior cancellation
 - Rescheduling: does it count?
 - What about walk-ins/open access?

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Retention Rates

- Require precise definitions of expected number of visits during a specified time interval
- Eligible population required for the denominator which requires determination of visit type and determination of active caseload of the clinic

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Constructing a Retention Measure

- Consider variations in practice standards regarding expected number of visits and interval between visits
- Understand what contributes to practice standards at your clinic – e.g., patient stability, geography
- Define and test a measure that reflects the minimum standard for your practice

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New York State Measure for Retention in Care

Number of unique HIV-infected clients with at least 1 HIV primary care visit in each half of the calendar-month year

Number of unique clients with at least 1 visit during the calendar year

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Considerations in Implementing a Retention Measure

- A basic retention measure alone provides a limited look at the important issue
- Further investigation and analysis are usually required, for example -
 - after determining baseline measurement, "look back" at the patients who did not meet the definition of being retained
 - the second measurement cycle will require identifying patients who were retained the first cycle but did not return for care during the second

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Data Sources

- Is the universe of patients captured in the available database?
- Data sources are usually imperfect: *Improving them is a top priority*
- Retention rates range from 70-85% in NYS HIV clinics: *Who is not retained?*
- Who is at risk for not being retained?

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Why Don't Patients Come? (From the Literature)

- Younger Age
- Education level
- Lack of insurance
- Lower income
- High CD4 count
- No AIDS diagnosis
- History of IDU or current IDU
- Lower perceived social support
- Shorter interval between baseline visit
- Less engagement with provider
- Minority communities, particularly African-Americans
- Heterosexual patients
- Work conflict
- No transportation
- Family illness
- Forgetting
- Conflicts
- Feeling too ill
- Feeling well

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One NYC Hospital's Experience

- **One-Visit Study** – *Queens General Hospital**
 - Exclude those who moved, transferred or died
 - 15 patients not "retained":
 - Unable to contact 7
 - Contacted 8:
 - 2 reported active substance abuse, 1 returned to care
 - 1 fear of recognition, referred to other HIV clinic
 - 1 psychiatric history, attends multiple HIV clinics
 - 1 looking for a job, returned to care
 - 1 refused outpatient treatment despite extensive outreach efforts (frequent QHC hospitalizations)
 - 2 feeling well, are early in HIV and refused frequent medical visits

Jazila Mantis, MD, Jean Fleischman, MD, Kathleen Aratoon, NP, Maria Szczupak, RPh, Diana Jefferson, RN, Terri Davis, MSW, Maria Buccellato

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Keep the Balance...



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Quality Improvement and Retention

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Improving Retention

- Understand the patient level and system level factors associated with retention in care
- Look to the literature for evidence based strategies and decide whether they apply to your population
- If they apply, test them in your population
- Target improvement efforts

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Improvement Strategies to Retain Patients in Care: Examples from the Field

- Improve clinic operation & information systems
- Obtain consumer involvement to identify barriers & solutions
- Increase staff & patient awareness
- Develop focused case management resources (internal & external)

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Improvements: Current Status

- **Patient Factors**
 - May or may not be amenable to change
 - Supportive services may be beneficial
 - Outreach programs effective but expensive
- **System Factors**
 - Amenable to change
 - Do changes result in improvement?
 - QI methods well-suited to improving retention and testing strategies

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Practical Strategies to Connect Patients to Care

- Partnerships with community-based agencies offer great potential
- Supportive services, including navigation and case management, help increase retention by removing barriers and meeting needs
- Provider engagement and behavior affects levels of and retention and decrease sporadic use: fortify relationships

Outreach Initiative: HRSA SPNS Multi-site Evaluation, 2007

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Practical Strategies (2)

- Use peers
- Target new patients
- Help patients access needed services to remove barriers to care: transportation, mental health support, drug treatment
- Reduce drug use
- Dispel negative health beliefs

Outreach Initiative: HRSA SPNS Multi-site Evaluation, 2007

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What can we do now?

- Use a common measure
- Identify proven strategies: **Measure!**
- Focus efforts on those not fully engaged or not retained
- Learn from patients
- Learn from each other
- Consider the context of your organization, patient population and community

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Policy Issues

- Looking beyond the clinic:
 - Patients may seek care from multiple providers
 - VAH, Corrections, NFs, Residential drug treatment, migrants, visitors
- Services
 - Outreach
 - Maintenance in Care
 - Field Services Unit
 - List searching

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Policy Issues

- Responsibility of treating institution
 - Calls, letters, legal issues
 - Should certain patients be sought more than others?
 - What is a "reasonableness" standard?
 - When is the search "closed"?
 - "Whose patient is it anyways?"

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Way Forward

- Coordination of clinical and non-clinical service agencies
- Collaboration between city and state initiatives

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Acknowledgements

- Bruce Agins, MD, MPH
- The New York City Health and Hospitals Corporation HIV Quality Learning Network
- Margaret Palumbo
- Elizabeth Horstmann
- Phoebe Arde-Acquah

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Grantee Example 1:

Using Quality Improvement to Improve Patient Retention in HIV Care

A Tri-State Regional Quality Group Approach
(Ohio, WV, PA)

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Background

A Regional QI Workgroup of multiple Ryan White grantees under the sponsorship of the National HIVQUAL Project was initiated to reduce barriers to retention, track patients who drop out of care and share best practices of successful improvement strategies

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Background

- 9 Ryan White-funded grantees (10 service providers) in Southwest PA, Ohio and West Virginia
- Caring for over 3,000 patients; unduplicated patients in care ranges from 100 to 1200
- Variation in years of Ryan White funding (3 to 12)
- Variation in QM experience and understanding
- Variation in information systems sophistication and ability to collect and report data routinely

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Project Aim

- Reduce the number of patients with “unmet” need as defined by HAB: “Individuals who are living with HIV, are aware of their HIV+ status, but are not engaged in regular medical care”
- Increase the number of patients who have connected to a medical provider and are seen for trimester medical monitoring visits
- Share best practices across regional Part C/D grantees

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Methods

- Retention defined as patients seen in the last 4 months (trimester)
- Each clinic developed mechanisms to produce case lists and track retention utilizing existing data systems (CAREWare, LABTRACKER, hospital billing)
- Utilized standard QI methodology

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Standard Measure

- All patients will be seen by a medical provider every 4 months (trimester)
 - **Denominator:** Number of unique patients in care
 - **Numerator:** Number of unique patients seen 1x in last 4 months
- Adjusted for patients who have expired, currently incarcerated, relocated or changed provider

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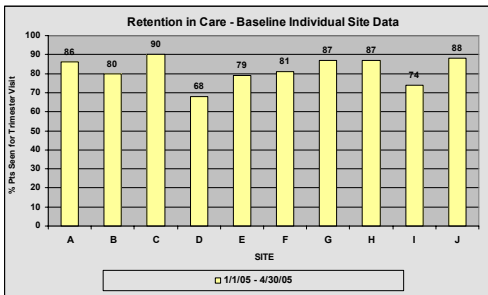
Reasons identified for patients not being seen every trimester

- Active Mental Illness
- Active Substance abuse
- Transportation
- Unstable Housing
- Too sick to keep appt
- If well, may not perceive appointments as necessary
- Lack of family and other social supports
- Inflexible working schedules
- Inflexible clinic appointment schedules
- Incarceration
- Lack of "connection" to medical provider
- Fear of disappointing medical provider if not adherent to tx

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Retention in Care – Baseline Data



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Improvement Intervention Examples

- Perform aggressive follow-up for patients who miss appointments
- Use of peer advocates to support retention
- Provide flexible appointment schedules including more access to walk-ins and evening appointments
- Assure early identification of patients at high risk for dropping out of care, i.e., active substance use, unstable housing and link to more intensive individualized support services (peer advocate/case manager)

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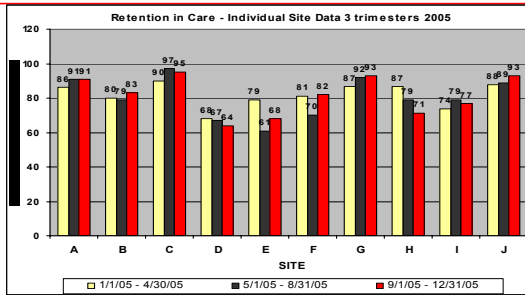
Improvement Intervention Examples (continued)

- Target individuals with more acute illness and greatest needs, specifically those on HAART with detectable viral load levels
- Improve continuity between research and treatment programs
- Initiate Case conferencing with focus on those patients at risk for dropping out of care
- Provide targeted patient education
- Improve clinic efficiency/reduce wait times
- Offer more evening appointments

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Follow-up Results



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Summary of Group Results

- Initial retention rates ranged from 68% to 90%
- After one year 7 of 10 sites (70%) showed improvement in retention rates ranging from 1 to 6% from baseline
- 3 sites showed no improvement in overall retention
- Sites with no improvement identified problems with data retrieval and lack of sufficient time to fully implement improvement strategies
- All sites applied CQI methodology to address retention

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Summary of Group Results (cont.)

- Limited resources calls for good understanding of which interventions are most effective BUT
- In the case of retention it is difficult to assess which intervention has the greatest impact
- Group felt a “package” of interventions was important

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Lessons Learned

- Know your patients, know your data, so that you don't go down the wrong path
- Don't ignore your hunches but try to test your interventions before full implementation

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Participating Organizations

- Allegheny General Positive Health Clinic, Pittsburgh, PA
- Community Health Net, Erie, PA
- Clarion University, Clarion, PA
- West Virginia University, Morgantown, WV
- Charleston Area Medical Center, Charleston, WV
- Case Western University, Cleveland, OH
- Comprehensive Care Clinic, Youngstown, OH
- University of Pittsburgh, Pittsburgh, PA
- Columbus AIDS Task Force, Columbus, OH
- Nationwide Childrens Hospital, OH

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Grantee Example 2:

FACES PROGRAM (FAMILY AIDS CLINIC EDUCATIONAL SERVICES) Columbus, Ohio

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FACES PROGRAM FAMILY AIDS CLINIC EDUCATIONAL SERVICES

- I. Overview of FACES PROGRAM
- II. Retention Project
 - A. Group Focus- New Patients
 - B. Barriers
 1. Transportation
 2. Childcare
 3. Fear of Disclosure
 4. Patients Couldn't remember
 4. Drug Addiction
 5. Readiness to accept Diagnosis
 - C. Improvement Efforts
 1. Reminder Postcards
 2. Reminder Phone Calls
 3. Incentive Program
 4. Hired a Consumer Advocate

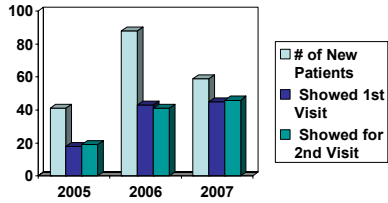
FACES Program Quality Management Program 2008

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FACES Program Retention Project

HIV Positive Retention Rate



Improvement Percentages

1st Visit= 33% Improvement
 2nd Visit= 31% Improvement

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FACES Program Retention Project

Action Plan to Improve Retention

Year	Action	Effectiveness	Challenges
2005	<ul style="list-style-type: none"> Phone calls Reminder Postcards Reminders 	<ul style="list-style-type: none"> Not Effective 47% Average Retention Rate. 	<ul style="list-style-type: none"> Disconnected Phone Return Mail Pts. Didn't want phone calls and/or mail going to the home.
2006	<ul style="list-style-type: none"> Incentives Plan Bus, cab, gas cards, food card 	<ul style="list-style-type: none"> Somewhat Effective 47% Average Retention Rate. 	<ul style="list-style-type: none"> Patients come only for the incentives.
2007	<ul style="list-style-type: none"> Consumer Advocate Incentive Plan 	<ul style="list-style-type: none"> Very Effective 76.5% Average Retention rate 	<ul style="list-style-type: none"> Consumer Advocate is out sick at times.

*The FACES Program also provide childcare services.

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Grantee Example 3:

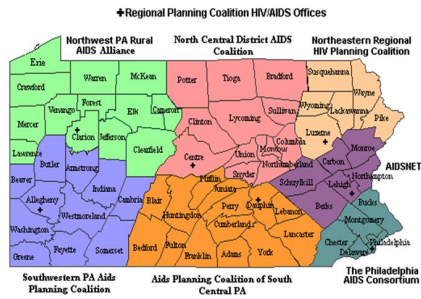
Northwest Rural AIDS Alliance - Clarion University
 Jeffrey A. Curtis, M.S., Executive Director



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Pennsylvania's Seven Part B Regions



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Very Rural Region



Provide HIV positive patients in this very rural region with the highest quality medical care, performed by trained, competent specialists in the field of HIV, utilizing the best available medical practices.

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The Northwest PA Rural AIDS Alliance

- Part of Clarion University (completely grant funded)
- Serve 13 county region (larger than 8 states)
- Serve as:
 - Fiscal Agent for Dept. of Health
 - Planning Coalition for Region
 - Largest Service Provider
- Part B and Part C Provider
- Services Provided:
 - Specialty Medical Care
 - Medical Case Management
 - Support Services
 - Prevention/Risk Reduction
- Clinics:
 - "Have bag, will travel"
 - 3 subcontracted physicians
 - 9 clinic sites
 - ~50 clinics per year
 - 125-150 unduplicated patients

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Aggregate Data for Analysis and Management

Erie	1/1/07-3/31/07	4/1/07-6/30/07	7/1/07-9/30/07	10/1/07-12/31/07	1/1/07-12/31/07
# of clinics per above date	3.5	4	4	3.5	15
Total Patients Scheduled	38	40	43	36	157
Total Patients Seen	26	35	33	35	129
Average patients per clinic	7.43	8.75	8.25	10.00	8.60
Number of No Shows	11	4	10	0	25
Number of Cancellations	1	1	0	1	3
Percent No Show	29%	10%	23%	0%	16%
Percent Cancelled	3%	3%	0%	3%	2%
Totals	1/1/07-3/31/07	4/1/07-6/30/07	7/1/07-9/30/07	10/1/07-12/31/07	1/1/07-12/31/07
# of clinics per above date	8.5	12.5	11.5	10.5	43
Total Patients Scheduled	83	113	110	105	411
Total Patients Seen	65	94	77	87	323
Average patients per clinic	7.65	7.52	6.70	8.29	7.51
Number of No Shows	16	14	21	13	64
Number of Cancellations	2	6	4	5	17
Percent No Show	19%	12%	19%	12%	16%
Percent Cancelled	2%	5%	4%	5%	4%

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Interventions and Outcomes

Time Period	Intervention	Retention Rate	No Shows
Sep - Dec 2005		74%	
Jan - Apr 2006	Initiated post cards in January	88%	
May - Aug 2006		79%	
Sep - Dec 2006		80%	
{Jan - Dec 2006}		80%	103 = 21.8%
Jan - Apr 2007	Initiated more frequent follow-up calls January 2007	83%	
May - Aug 2007	Initiated more aggressive calls March 2007	84%	
Aug - Dec 2007		no data	
{Jan - Dec 2007}			64 = 15.6%

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Improvement No Show 2006 - 2007

Totals	1/1/07-12/31/07	1/1/06-12/31/06	Change	
# of clinics per above date	43	48	-5.00	
Total Patients Scheduled	411	472	-61.00	
Total Patients Seen	323	329	6.00	
Average patients per clinic	7.51	6.85	0.66	↑ Good
Number of No Shows	64	103	-39.00	↓ Good
Number of Cancellations	17	36	-19.00	↓ Good
Percent No Show	15.6%	21.8%	-6.25%	↓ Good
Percent Cancelled	4.1%	7.6%	-3.49%	↓ Good

Conservative estimate of reduction in "down time" is \$10,000

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Long Term Approach

- Large segment of no-shows because “not that important to them”
Therefore, must get patients to change attitude
- Will use “Stage-Based Behavioral Counseling”
- Designed to be integrated in clinic flow
- 10 Years of scientific study show effective
- CDC and NIH approve as an evidence based intervention
- Stage-Based Behavioral Counseling helps patients move from:
 - Pre-contemplative: “don’t care”
 - Contemplative: “want to, but...”
 - Ready for action: “ready to try”
 - Action: “doing it”
- This is long term approach – not a quick fix
- Staff have completed training
- Team has targeted small group to begin – will start this fall

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