Strategies to Improve Patient Retention: Experiences from Grantees

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Panel: Tammy Derden, MBA,BS Ed, CHES, Jeff Curtis, MS
Overview

• Introduction
• Measurement
• Quality improvement and retention
• Strategies and conclusions
Why is Retention Important?

• Medical Care
  ▪ The heart of the patient-provider relationship; “medical home”

• The Primary Care Model
  ▪ Access
  ▪ Coordination
  ▪ Continuity
  ▪ Comprehensiveness
  ▪ Quality
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
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.
Continuum
Engagement in Care

- Unaware of HIV Status (not tested or never received results)
- Know HIV Status (not referred to care; didn’t keep referral)
- May Be Receiving Other Medical Care But Not HIV Care
- Entered HIV Primary Medical Care But Dropped Out (lost to follow-up)
- In and Out of HIV Care or Infrequent User
- Fully Engaged in HIV Primary Medical Care

Non-engager
Sporadic User
Fully Engaged

Health Resources Service Administration (HRSA)
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
Measurement

• What is the extent of the problem?
  ▪ No-shows
  ▪ Retention rates
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?
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
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
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
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
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?
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
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 Bucellato
Keep the Balance…
Quality Improvement and Retention
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
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)
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
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
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
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
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
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?”
Way Forward

• Coordination of clinical and non-clinical service agencies

• Collaboration between city and state initiatives
Acknowledgements

• Bruce Agins, MD, MPH

• The New York City Health and Hospitals Corporation HIV Quality Learning Network

• Margaret Palumbo

• Elizabeth Horstmann

• Phoebe Arde-Acquah
Grantee Example 1:

Using Quality Improvement to Improve Patient Retention in HIV Care

A Tri-State Regional Quality Group Approach (Ohio, WV, PA)
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.
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
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
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
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
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
Retention in Care – Baseline Data

Retention in Care - Baseline Individual Site Data

% Pts Seen for Trimester Visit

SITE

A  B  C  D  E  F  G  H  I  J

86  80  90  68  79  81  87  87  74  88

1/1/05 - 4/30/05
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)
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
Follow-up Results

Retention in Care - Individual Site Data 3 trimesters 2005

SITE

MEDIAN: 82.5%, AVERAGE: 82, LOW: 64, HIGH: 95
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
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
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
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
Grantee Example 2:

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

Tammy Derden, MBA, BS Ed, CHES
Quality Management Coordinator/Database Manager
Tammy.Derden@nationwidechildrens.org
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 an Consumer Advocate

FACES Program Quality Management Program 2008
FACES Program Retention Project

HIV Positive Retention Rate

Improvement Percentages

1st Visit = 33% Improvement
2nd Visit = 31% Improvement
# FACES Program Retention Project

## Action Plan to Improve Retention

<table>
<thead>
<tr>
<th>Year</th>
<th>Action</th>
<th>Effectiveness</th>
<th>Challenges</th>
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<tbody>
<tr>
<td>2005</td>
<td>Phone calls Reminder, Postcards Reminders</td>
<td>Not Effective 47% Average Retention Rate.</td>
<td>Disconnected Phone, Return Mail, Pts. Didn’t want phone calls and/or mail going to the home</td>
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<tr>
<td>2006</td>
<td>Incentives Plan: Bus, cab, gas cards, food card</td>
<td>Somewhat Effective 47% Average Retention Rate.</td>
<td>Patients come only for the incentives.</td>
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<tr>
<td>2007</td>
<td>Consumer Advocate, Incentive Plan</td>
<td>Very Effective 76.5% Average Retention Rate</td>
<td>Consumer Advocate is out sick at times.</td>
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</tbody>
</table>

*The FACES Program also provide childcare services.*
Grantee Example 3:

Northwest Rural AIDS Alliance - Clarion University
Jeffrey A. Curtis, M.S., Executive Director
Pennsylvania’s Seven Part B Regions
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.
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
Northwest Pennsylvania Rural AIDS Alliance

Key
- Offices
- Clinic Sites
- Physician Locations

Northwest Alliance
“Have Bag, Will Travel” Model

- **Staff:**
  - 1 physician
  - 2 nurses
  - 1 medical service coordinator

- **Equipment:**
  - Blood draw supplies
  - Patient Files
  - BIA equipment
  - Computers/Printer
  - Supplements & OTC supplies
  - Medical waste supplies
  - Exam table (1 site only)
Patient Retention Data

<table>
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<tr>
<th>Date</th>
<th>Patient</th>
<th>Clinic</th>
<th>New Patient</th>
<th>Return of Old Patient</th>
<th>DOH</th>
<th>PCP</th>
<th>PHC</th>
<th>SMC</th>
<th>PHN</th>
<th>Self</th>
<th>Patient</th>
<th>Jail</th>
<th>CHN</th>
<th>OM</th>
<th>Meeting in Action</th>
<th>Transfer to Other HIV Care in Region</th>
<th>Moved in Region without HIV Care</th>
<th>Moved out of Region without HIV Care</th>
<th>Reused Care</th>
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<th>Never came to first visit (explanation required)</th>
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<td>Total number of patients at the beginning of the month is</td>
<td>New Patients</td>
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<td>Total number of inactive patients at the beginning of the month is</td>
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<td>Total number of dead patients at the beginning of the month is</td>
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If a patient never came to the first visit please also select another reason to explain why.

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## Why Patients No Show

### Visit Disposition

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<th>Time</th>
<th>Patient</th>
<th>Next Appt.</th>
<th>SBP/Bp.</th>
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<th>Lab draw at clinic (R or S)</th>
<th>Case Manager</th>
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<td></td>
</tr>
<tr>
<td>4:15 PM</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Space below this line is reserved for cancellations

- xxx move to March 2008
- xxx has a lab slip
- xxx squire lab slip sent
- xxx lab slip sent
- xxx arrived inebriated to at clinic - did not see
- xxx had to work
- xxx said no babysitter
- xxx said car trouble - MCM says NV/I

Need to fit a new patient in this month
Need to fit if she needs come in

### Totals

<table>
<thead>
<tr>
<th></th>
<th>R</th>
<th>S</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total</td>
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<tr>
<td></td>
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<td>6</td>
</tr>
<tr>
<td></td>
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</tbody>
</table>
Fishbone Diagram

Access
- No Clinic in my area
- No Insurance
- No Transportation

Facility
- No Clinic in my Area
- Poor Parking
- Don't like the location

Patient / Support system
- I don't trust the staff, I heard them talking about other patients
- Didn't want to get 00B
- I didn't want to go
- I forgot
- Don't like needles
- Anxiety

Procedures
- Didn't get Labs done
- I don't want to know the results
- I might see someone I know

Staff
- Hate the Doctor
- Don't like Needles
- the staff doesn't really care about me

Lack of Retention of Care
## Aggregate Data for Analysis and Management

<table>
<thead>
<tr>
<th>Erie</th>
<th>1/1/07-3/31/07</th>
<th>4/1/07-6/30/07</th>
<th>7/1/07-9/30/07</th>
<th>10/1/07-12/31/07</th>
<th>1/1/07-12/31/07</th>
</tr>
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<tbody>
<tr>
<td># of clinics per above date</td>
<td>3.5</td>
<td>4</td>
<td>4</td>
<td>3.5</td>
<td>15</td>
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<tr>
<td>Total Patients Scheduled</td>
<td>38</td>
<td>40</td>
<td>43</td>
<td>36</td>
<td>157</td>
</tr>
<tr>
<td>Total Patients Seen</td>
<td>26</td>
<td>35</td>
<td>33</td>
<td>35</td>
<td>129</td>
</tr>
<tr>
<td>Average patients per clinic</td>
<td>7.43</td>
<td>8.75</td>
<td>8.25</td>
<td>10.00</td>
<td>8.60</td>
</tr>
<tr>
<td>Number of No Shows</td>
<td>11</td>
<td>4</td>
<td>10</td>
<td>0</td>
<td>25</td>
</tr>
<tr>
<td>Number of Cancellations</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Percent No Show</td>
<td>29%</td>
<td>10%</td>
<td>23%</td>
<td>0%</td>
<td>16%</td>
</tr>
<tr>
<td>Percent Cancelled</td>
<td>3%</td>
<td>3%</td>
<td>0%</td>
<td>3%</td>
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<table>
<thead>
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<th>7/1/07-9/30/07</th>
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<td>12.5</td>
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<td>10.5</td>
<td>43</td>
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<td>Total Patients Scheduled</td>
<td>83</td>
<td>113</td>
<td>110</td>
<td>105</td>
<td>411</td>
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<td>Total Patients Seen</td>
<td>65</td>
<td>94</td>
<td>77</td>
<td>87</td>
<td>323</td>
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<td>Average patients per clinic</td>
<td>7.65</td>
<td>7.52</td>
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<td>13</td>
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<td>19%</td>
<td>12%</td>
<td>19%</td>
<td>12%</td>
<td>16%</td>
</tr>
<tr>
<td>Percent Cancelled</td>
<td>2%</td>
<td>5%</td>
<td>4%</td>
<td>5%</td>
<td>4%</td>
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## Interventions and Outcomes

<table>
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<tr>
<th>Time Period</th>
<th>Intervention</th>
<th>Retention Rate</th>
<th>No Shows</th>
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<tbody>
<tr>
<td>Sep - Dec 2005</td>
<td></td>
<td>74%</td>
<td></td>
</tr>
<tr>
<td>Jan - Apr 2006</td>
<td>Initiated post cards in January</td>
<td>88%</td>
<td></td>
</tr>
<tr>
<td>May - Aug 2006</td>
<td></td>
<td>79%</td>
<td></td>
</tr>
<tr>
<td>Sep - Dec 2006</td>
<td></td>
<td>80%</td>
<td></td>
</tr>
<tr>
<td>[Jan - Dec 2006]</td>
<td></td>
<td><strong>80%</strong></td>
<td>103 = 21.8%</td>
</tr>
<tr>
<td>Jan - Apr 2007</td>
<td>Initiated more frequent follow-up calls January 2007</td>
<td>83%</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Initiated more aggressive calls March 2007</td>
<td></td>
<td></td>
</tr>
<tr>
<td>May - Aug 2007</td>
<td></td>
<td>84%</td>
<td></td>
</tr>
<tr>
<td>Aug - Dec 2007</td>
<td></td>
<td>no data</td>
<td></td>
</tr>
<tr>
<td>[Jan - Dec 2007]</td>
<td></td>
<td></td>
<td>64 = 15.6%</td>
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</table>
# Improvement No Show 2006 - 2007

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<th>Change</th>
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<tr>
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<tr>
<td>Total Patients Seen</td>
<td>323</td>
<td>329</td>
<td>6.00</td>
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<tr>
<td>Average patients per clinic</td>
<td>7.51</td>
<td>6.85</td>
<td>0.66</td>
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<tr>
<td>Good</td>
<td></td>
<td></td>
<td>Good</td>
</tr>
<tr>
<td>Number of No Shows</td>
<td>64</td>
<td>103</td>
<td>-39.00</td>
</tr>
<tr>
<td></td>
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<td></td>
<td>↓</td>
</tr>
<tr>
<td>Good</td>
<td></td>
<td></td>
<td>Good</td>
</tr>
<tr>
<td>Number of Cancellations</td>
<td>17</td>
<td>36</td>
<td>-19.00</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>↓</td>
</tr>
<tr>
<td>Good</td>
<td></td>
<td></td>
<td>Good</td>
</tr>
<tr>
<td>Percent No Show</td>
<td>15.6%</td>
<td>21.8%</td>
<td>-6.25%</td>
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<td>↓</td>
</tr>
<tr>
<td>Good</td>
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<td>Good</td>
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<tr>
<td>Percent Cancelled</td>
<td>4.1%</td>
<td>7.6%</td>
<td>-3.49%</td>
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</tr>
<tr>
<td>Good</td>
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</tbody>
</table>

Conservative estimate of reduction in “down time” is $10,000
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
Contact Information

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www.NationalQualityCenter.org