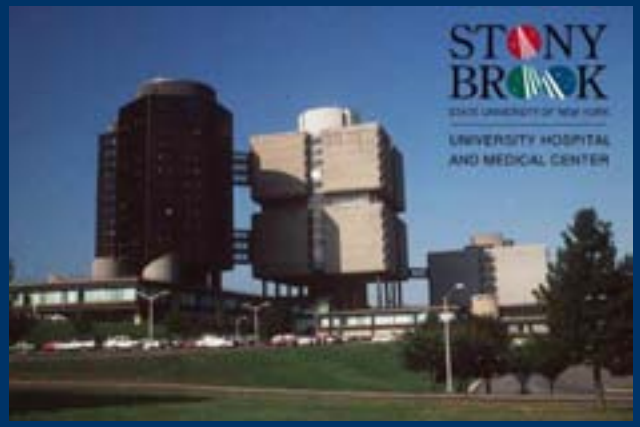
Many Hands Make Light Work:
A Network-wide Approach to Addressing Health Literacy



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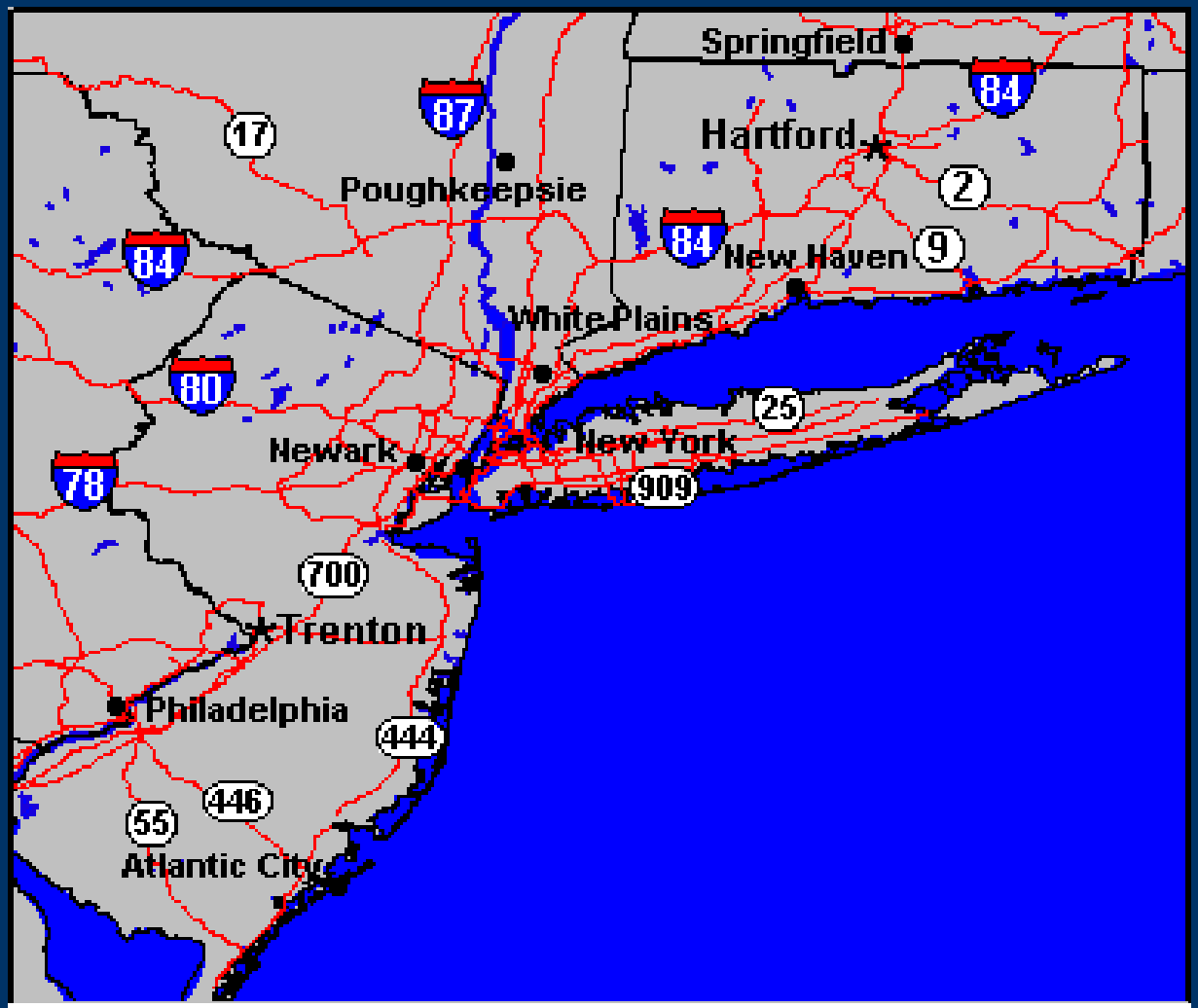
Ryan White Part D

20 Years of Leadership
A LEGACY OF CARE

Where in the world is Stony Brook?

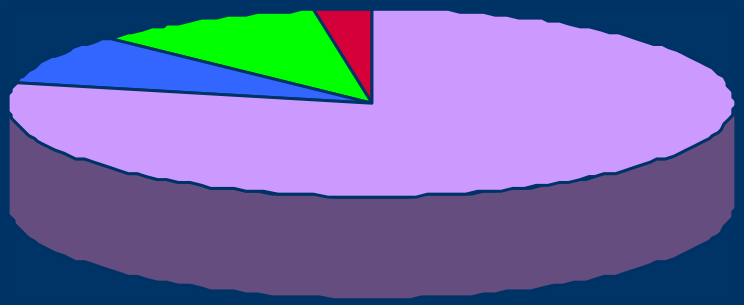


Suffolk County, New York

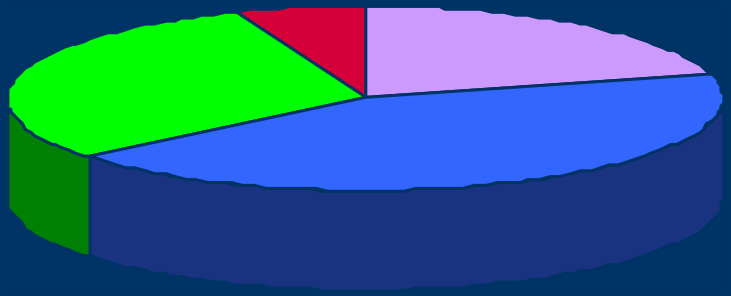
- Eastern Long Island, suburb of NYC
- 912 square miles, population 1.5 million
- >2,800 presumed living with HIV/AIDS (NYSDOH)

Disproportionate impact of HIV on women of color in Suffolk County

Long Island Population (US Census)



Female HIV Incidence 2004-2006 (NYSDOH)



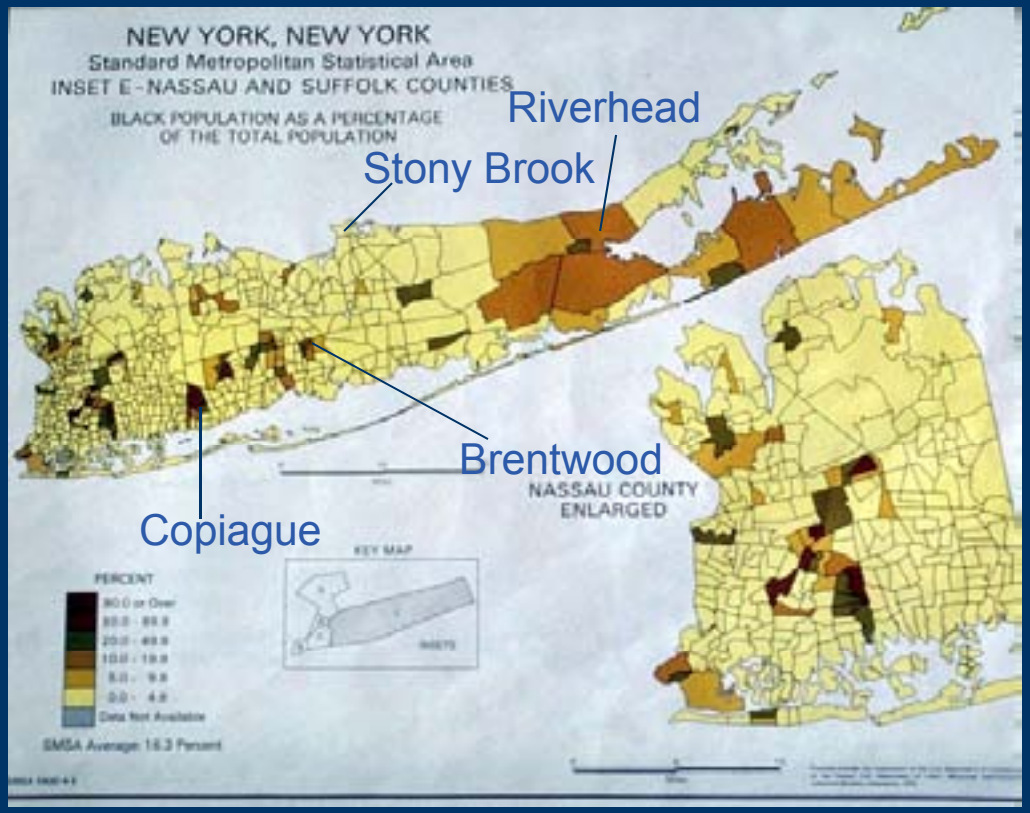
- white
- black
- Hispanic
- other

- white
- black
- Hispanic
- other

Stony Brook University Medical Center

- Suffolk County's Designated AIDS Center
- Multidisciplinary team approach to care
- In 2009, Part D program served >250 HIV+ women, children, youth and their families (404 clients total, approximately 70% African-American and/or Hispanic)

Suffolk County, Long Island locations of SPARC offices



20 Years of Leadership
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Suffolk Project for AIDS Resource Coordination (Part D program)

- Primary and specialty HIV care
- Linkage to care coordination
- Women's care coordination
- Access to care (transportation, child care)
- Youth clinic
- SPARC Consortium

"Poor health literacy is a stronger predictor of a person's health status than age, income, employment status, education level or race."

American Medical Association

What is health literacy?

- The degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions
- Fundamental literacy, scientific literacy, civic literacy and cultural literacy all play a role in health literacy

Our two-pronged approach:

- Increase the capacity of providers to serve clients with low levels of health literacy
- Increase the level of health literacy among HIV+ women and youth in our community

What did we hope to accomplish?

- Enhance skills of providers
- Increase knowledge of clients
- Increase retention in care
- Improve health status
- Reduce health disparities
- Evaluate effectiveness

Why use a network?

- To broaden our reach
- To increase our odds of success
- To strengthen relationships between providers
- It just seemed like the right thing to do

Who did we partner with?

- Medical providers (3)
- Case management agencies (3)
- Mental health provider (1)

Why stop there?

- Most HIV+ women and youth in Suffolk County receive care from one or more of these providers
- Needed to limit pool to obtain collaboration agreements in advance of grant deadline and effectively manage provider training and data collection

How was this funded?

- One-time expansion grant - Ryan White Part D - $71,000

Cost/benefit

- Benefit for the client: 5-13 additional years of life due to optimally managed HIV
- Benefit for society: $60,000 per quality of life year gained
- By comparison, costs of implementing the program are minimal

What did partners agree to do?

- Send at least 2 medical and/or care coordination/social work providers to attend training and share information with other staff
- Provide health literacy education to at least 15-20 HIV+ women and/or youth
- Gather data to assess impact of initiative
- Provide feedback throughout initiative

What did Stony Brook commit to do?

- Convene meetings with network partners to plan implementation and data collection activities
- Develop and conduct provider training for network partners
- Develop consumer training curriculum for use by network partners
- Facilitate ability of network partners to offer the program to their clients by providing reimbursement to clients for their costs associated with participating
- Maintain regular contact with network partners to obtain feedback, etc.

What data did we collect?

- Numbers of providers educated
- Numbers of clients educated by each network partner
- Client pre and post test scores to assess changes in knowledge
- Baseline and post-initiative data on appointment attendance, CD4 and viral load to assess impact on retention in care and health status
- Qualitative feedback from providers and clients

Provider training components

- HRSA's Unified Health Communication 101: Addressing Health Literacy, Cultural Competency and Limited English Proficiency
- free interactive on-line course available at www.train.org
- fee to receive continuing education credits (CEU/CE, CHES, CME, CNE)
- 5 modules, takes approximately 5 hours to complete (does not have to be completed all at once)

Provider training components continued

- Skills practice specific to HIV
- Review of consumer training curriculum
- Discussion of data collection procedures
- Review resources for additional training/materials

Provider trainings

- 2 full day trainings were held for network partners (each individual attended only one)
- At 1 training site, each participant could use a computer to complete the on-line portion of the training and receive continuing education credits
- Additional full day trainings were held later for other staff at 2 network partner agencies

Provider trainings and participants

Location	#	Disciplines represented
Riverhead	5	CSW, case management, health education
Stony Brook	14	CSW, care coordination, case management, RD, health education
Southampton	6	NP, CSW, interpreter
Copiague	4	CSW, care coordination

Consumer curriculum components

- 10 modules (2 basic, 8 general)
- Each module contains content, exercise to demonstrate understanding and resources
- Sample brochures included
- Spanish language materials included if available
- Data collection forms

Consumer training module topics

1. What to expect at a doctor's visit
2. Understanding basic medical terminology
3. Understanding your immune system and how HIV affects it
4. Treatment of HIV
5. HIV-specific medical terminology

Consumer training module topics continued

6. Reading a medication bottle
7. Getting the most out of your medical visit/ becoming a partner in your own health care
8. Taking other medications
9. Understanding resistance and resistance testing
10. Where to go for more information

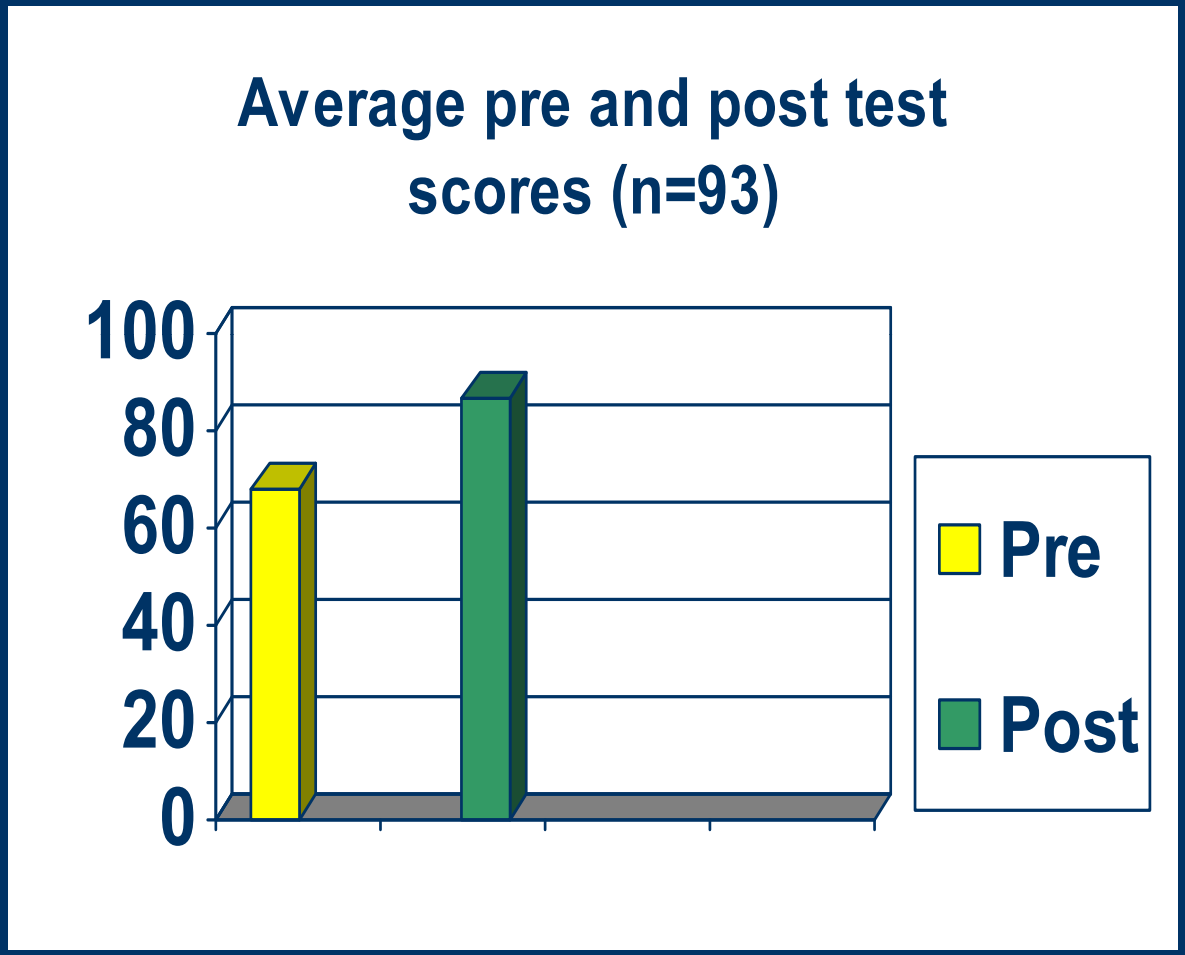
Consumer training implementation models

- Individual
- Group

How many clients were educated?

- Network partners educated a combined total of 97 clients
- Total included 2 duplicates (possibly 3) and 4 affected family members

Results: improvements in knowledge



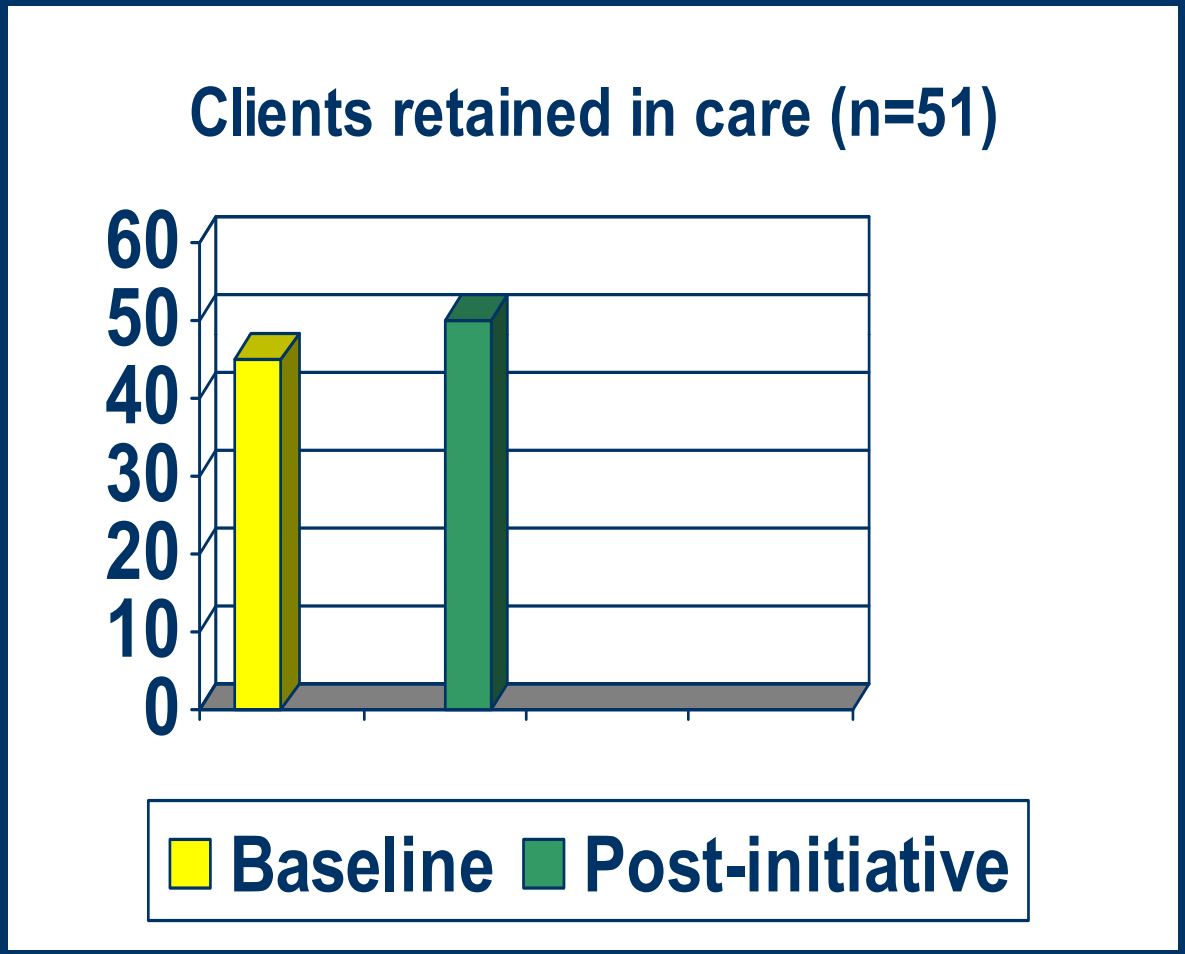
Results: improvements in knowledge continued

- 72 clients (77%) showed improvement in knowledge from pre to post test

Results: improvements in retention

- Dates of last two outpatient medical appointments for the routine management of HIV were recorded at baseline and post-initiative
- Clients with two appointments within 6 months were considered to be retained in care

Results: improvements in retention



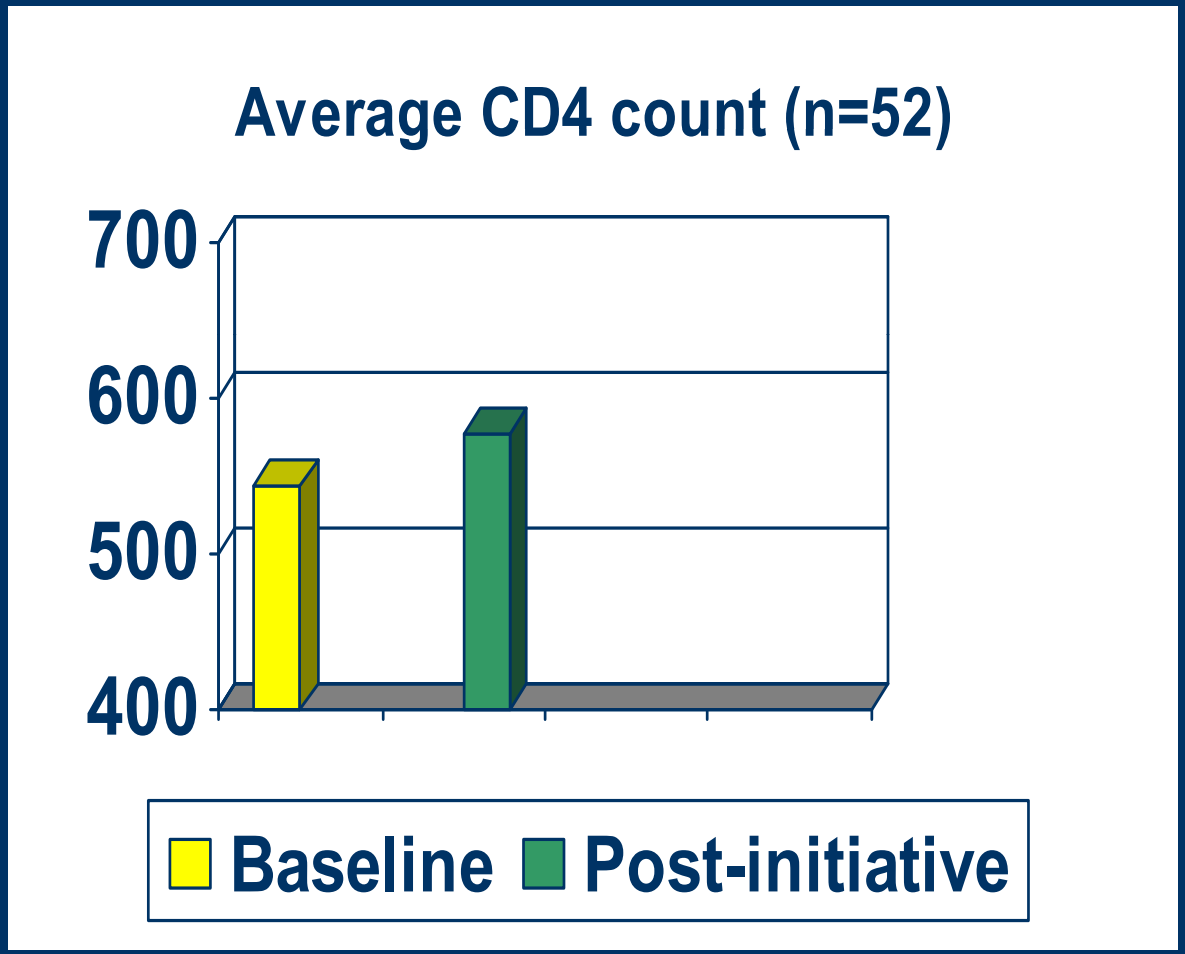
Results: improvements in retention continued

- Retention rates were high at baseline (88% of clients attended two or more medical appointments in prior 6 months)
- Post-initiative retention rate increased to 98%

Results: improvements in health status

- Most recent CD4 and viral load counts were measured at baseline and post-initiative

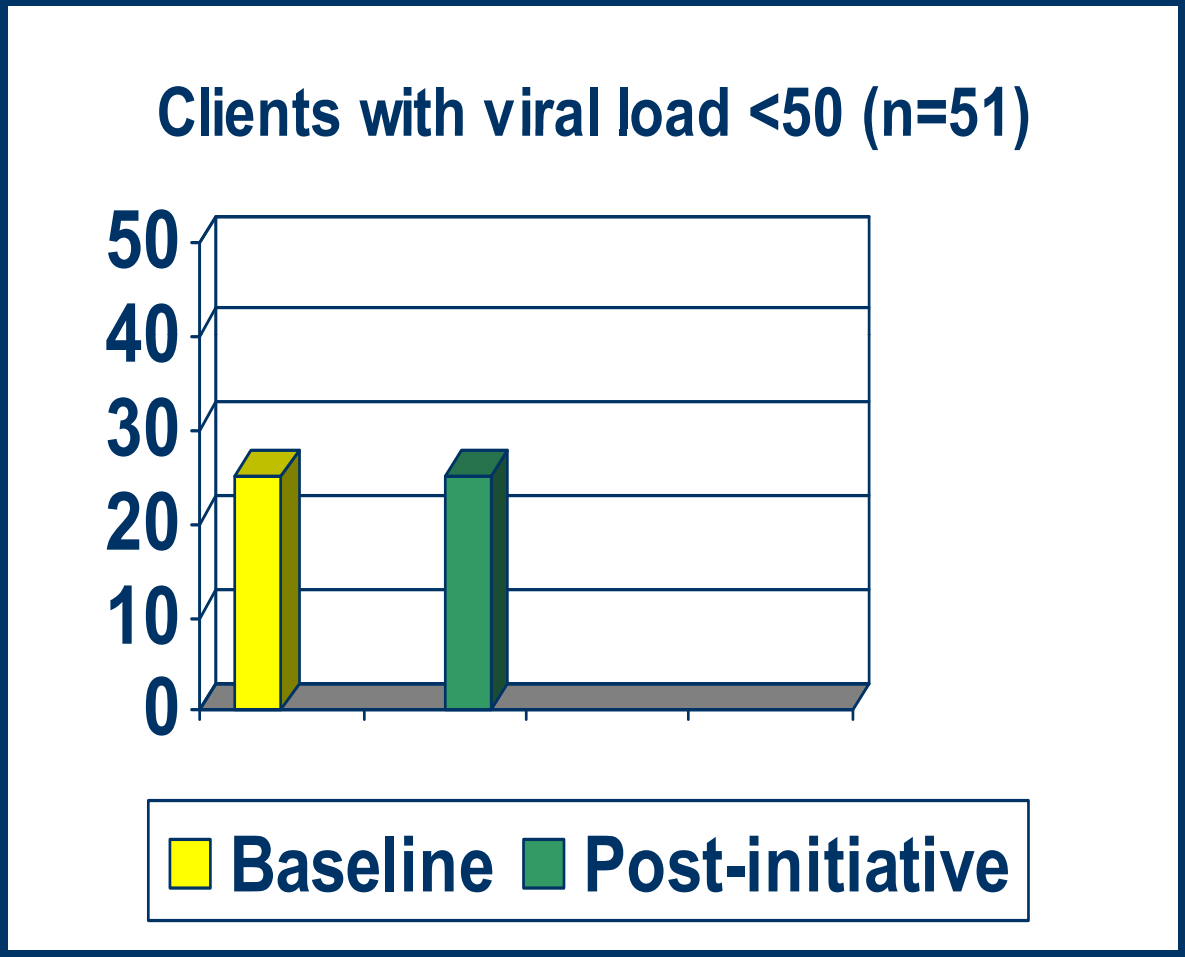
Results: improvements in health status



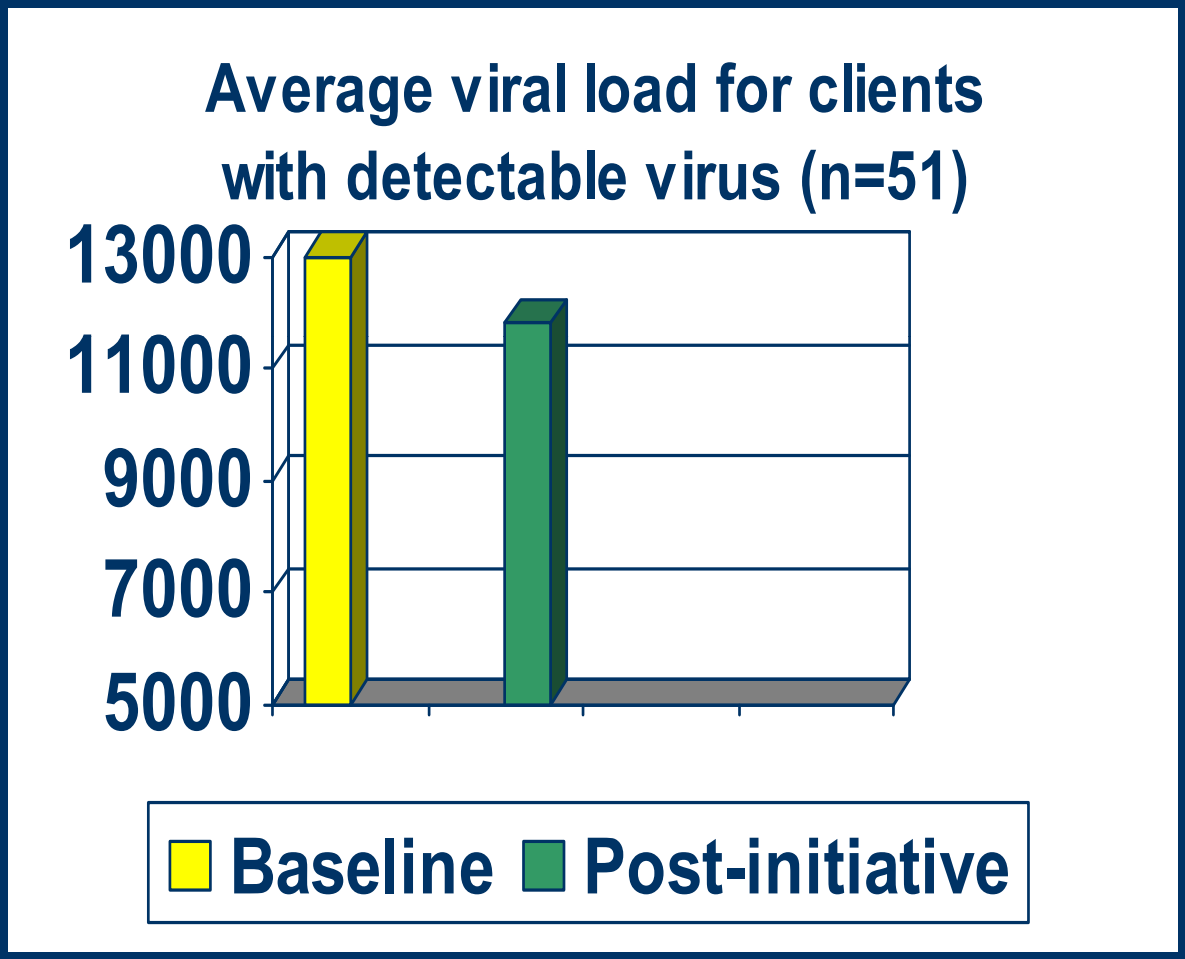
Results: improvements in health status continued

- 27 clients (52%) showed improvements in CD4 count from baseline to post-initiative

Results: improvements in health status



Results: improvements in health status



Results: improvements in health status continued

- 18 clients (35%) showed improvements in viral load from baseline to post-initiative
- 18 clients (35%) maintained undetectable viral loads from baseline to post-initiative
- 7 clients (14%) went from having a measurable viral load at baseline to an undetectable viral load post-initiative

Conclusions

- While we cannot claim that our health literacy initiative was solely responsible for the improvements in knowledge, retention and health status we observed; we are confident in concluding that our two-pronged approach to addressing health literacy in our community has been a success

Lessons learned

- Existing consumer health literacy curricula were inappropriate for many HIV+ clients who may have low levels of health literacy but have been in care for years

Lessons learned

- Working with a network increases the possibilities for success
- A variety of types of network partners works best
- Try to select partners with whom you have existing relationships (with both management and line staff)

Lessons learned

- It doesn't matter what the director commits the agency to do, it is the line staff who must buy-in
- It is hard to predict which partners will be most effective

Lessons learned

- If you want clinicians to participate in provider training, you need to clearly think through your strategy:
- Continuing education credits, food, scheduling training around clinic days, best interest of patient may not be enough
- Having agency administration mandate attendance and/or having clinician present/ co-present might be more effective

Lessons learned

- Incentives to network partners and/or clients can increase chances for success but may work best if they can be provided separately for each component of initiative

Lessons learned

- One year time frame is too short to complete post-initiative data collection

Lessons learned

- Small changes in understanding can result in big improvements in health status

Small group activity

Questions?

For more information

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