

# Incorporating Client Focus Groups in Improving HIV Care

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HIV ACCESS & The Family Care Network



# Location of Clinics

The Title III & IV clinics span Alameda and Contra Costa Counties, located in or around:

- Berkeley
- Oakland
- San Leandro
- Richmond
- Fremont





# Why Was This Necessary?

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- As a Ryan White program, HRSA requires consumer involvement.
- We believe that our program will benefit greatly from consumer feedback.
- A majority of our consumers are undereducated and are not knowledgeable about the quality of their health care.
- Previous attempts to have an on-going consumer group failed due to the geographical barriers, stigma and the amount of staff time that needed to be dedicated to facilitate the group (.25 FTE).



# The Pilot Project

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- Developed consumer a Quality Management input meeting that was **interactive** and took place in a **single session**.
- Provided concentrated education to consumers so they could in turn provide explicit feedback about the program.
- Created a safe environment and kept consumers engaged throughout the session.
- Rotated the focus group between clinics.



# Hypothesis

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- Patients would be more likely to come to a session at their own care site.
- Clinic specific feedback from clients would be more helpful to each site than network-wide feedback.
- Enough network-wide themes would emerge from site specific sessions to make it useful for the network as a whole.
- Presence of senior program leaders at the session will facilitate response to the consumer feedback.



# Outcomes

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## Patient Learning Empowerment

- Patients are engaged and give ideas
- Patients rate the session highly
- Patients' knowledge increase as shown on post-test

## Program Learning Improvement

- Program generates improvement ideas
- Program's priorities are confirmed or changed
- Program implements service delivery change



# Focus Group Logistics

## Pre-session

- Ask clinic to invite 7-9 clients and arrange a location in the clinic where focus group can be held away from clinic staff.
- Ask site to identify a pharmaceutical company to provide lunch for the consumers.\*
- Schedule 95 minutes for the focus group.
- Arrange for interpreter services (by HIV positive peer if possible). Invite Medical Director, Program Director and QM coordinator.

\*If clinic cannot find a sponsor for the lunch, program can provide affordable, healthy meal.

## During and After Session

- Record consumer feedback.
- Have consumers fill out an evaluation of focus group.
- Present focus group feedback to clinicians and line staff.
- Help clinic develop action plans to address feedback.
- Provide action plan information back to consumers who participated in the focus group.



# Sample agenda

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- Consumers sign-in/Facilitators introduce purpose and goals of session (5 minutes).
- **Activity 1:** *The HIV Care Satisfaction Continuum- Consumers stand along a wall and rate their care from 1-5 (5= excellent care). Consumers discuss reasons in small groups then report to the whole group (30 minutes).*
- **Activity 2:** *Personal Assessment Worksheet- Consumers are given a list of clinical indicators and are asked to fill out if they have had labs within 4 months, annual tests such as PPDs and Paps, and education about ARV's. If consumers don't know about a test or don't know if they have had a test, this is an opportunity to educate patients (20 minutes).*

\*Note it is important to modify focus group curriculum to fit program needs

Our focus group included activities from "**Making Sure Your HIV Care Is the Best It Can Be: A Consumer Quality of Care Training Workshop Curriculum Guide for Workshop Facilitators**" (New York State Department of Health AIDS Institute)



# Sample agenda

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- **Activity 3:** *Scenarios- Consumers are asked what they would do if they were in one of the scenarios described. Again this is an opportunity to educate patients (20 minutes). An example of a scenario is:*

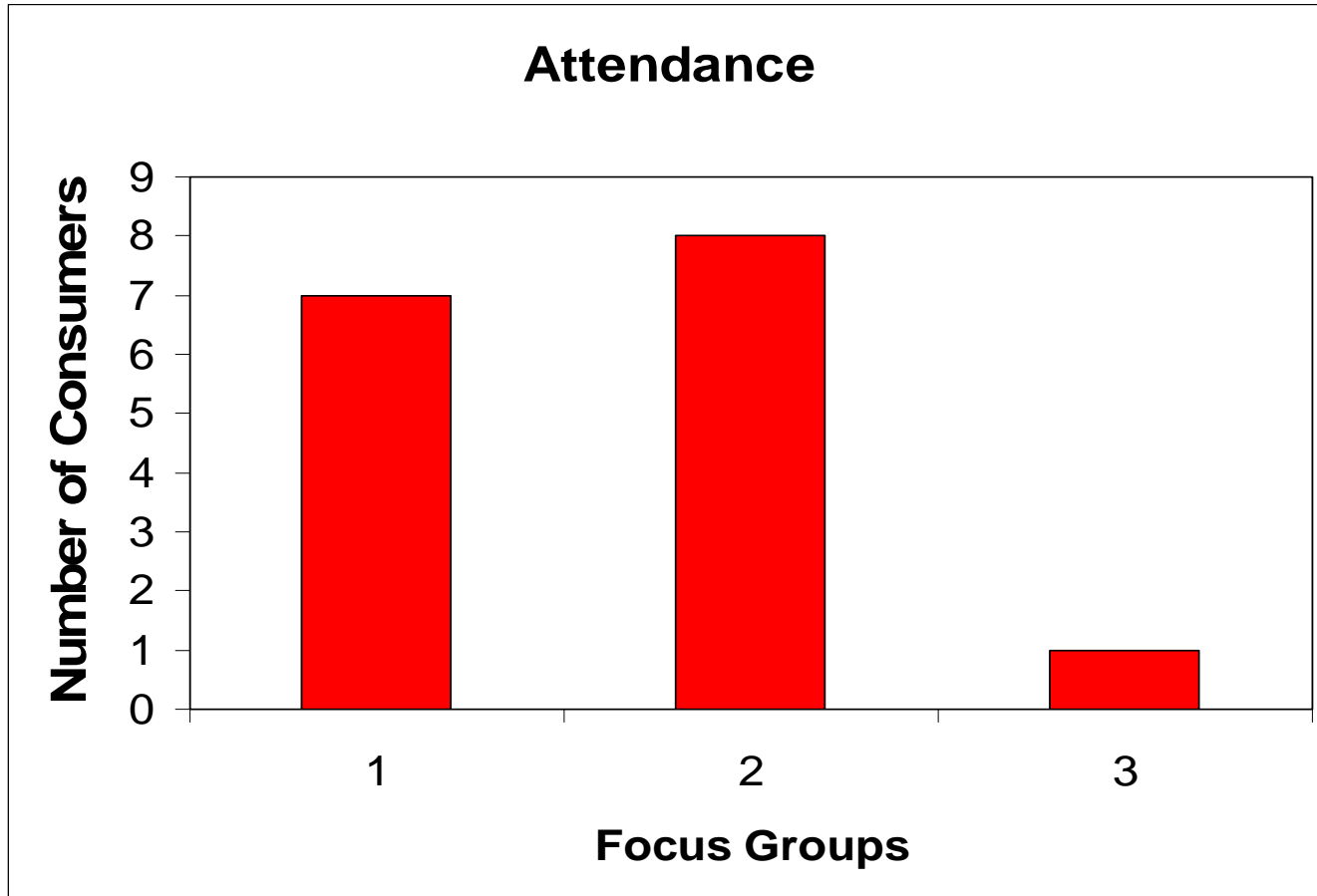
*You are attending a job-training program, but you have been arriving late because you can't wake up on time. The director of the program has told you that if you can't show up on time, you will be kicked out. You have told your doctor that your medication is making you sleepy, but your doctor has not changed your medication. What you haven't told your doctor is that because of oversleeping you have been missing some of your HIV medication.*

*What do you think you can do to advocate for yourself and improve the situation?*

- Questions and Answers (10 minutes)
- Evaluation/Thank consumers for their time (10 minutes)

# Results

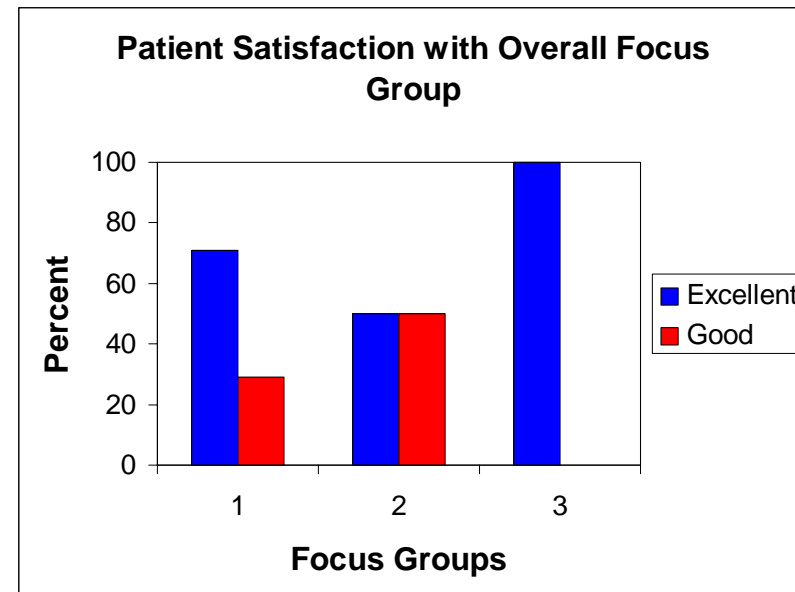
Of the 3 focus groups completed so far:



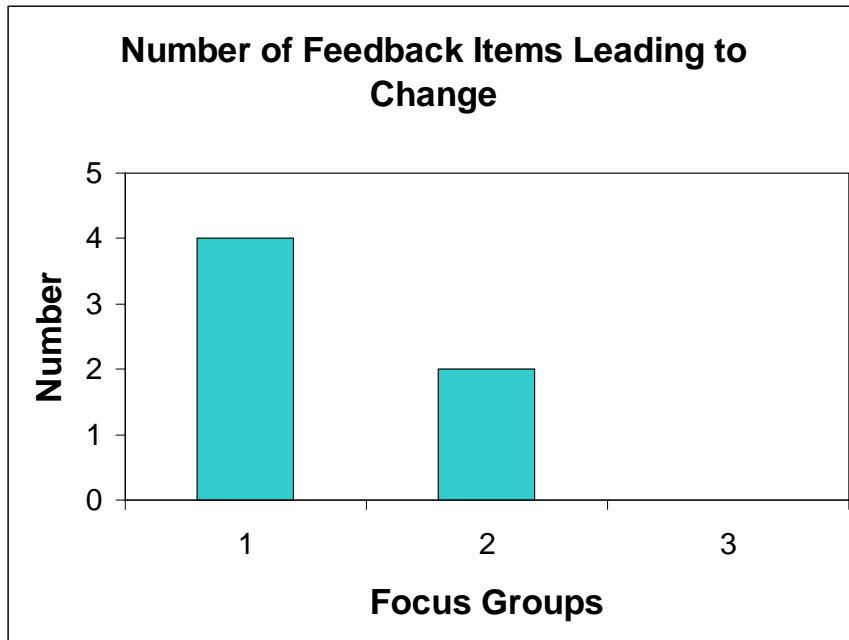
# Results (continued)

## Workshop Evaluation

	Poor	Fair	Good	Excellent
What is your overall rating of this workshop?	1	2	3	4
What is your overall rating of the workshop leaders?	1	2	3	4
Information was delivered in a way you could understand?	1	2	3	4
People were encouraged to express different opinions?	1	2	3	4
Did the workshop leaders provide opportunities for discussion?	1	2	3	4
Did the workshop leaders deliver the information clearly?	1	2	3	4



# Change Feedback



## Examples of feedback include:

- Changing voicemail message for clinic to be more personal
- Creating a quick information sheet that introduces new staff and has general FAQ's
- Developing an email system so that clients can ask clinicians general questions
- Updating patient educational materials in waiting area



# The Power of Consumers in Quality Work: An Anecdote

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**Problem:** Pap test rates are low in our program, but clinicians were resisting spending time on improvements, saying “No one is dying of cervical cancer, other issues are more critical to our patients’ health.”

**Consumer Input:** At an all-women’s consumer QM input session, consumers rated Pap tests as a high priority. When consumers were told that clinicians were saying Paps were not a high priority, they were surprised. One woman told us that since she had been diagnosed with HIV, she felt “dirty” and if she felt her clinician was reluctant to do a Pap test it would reinforce this sense of stigma.

**Follow-up:** This anecdote was reported back to the clinicians and was instrumental in their agreement to designate Pap rates as a priority for the year.



# Lessons and Next Steps

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## Lessons

- Consumers can give useable quality feedback in this **single session** interactive format
- Presence of the leadership is important and does not appear to stifle patient comment
- Follow-up to be sure that clinic implement consumer feedback is challenging but critical
- Anecdotes can be powerful. Even one person can give useful feedback

## Next Steps

- Create Pre-test and Post-test to evaluate consumer learning
- Measure how long it takes to make changes at clinic
- Add questions about culture competence of clinical sites to the session agenda

**If interested in collaborating on consumer feedback sessions or cultural competence please contact:**

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