



NATIONAL QUALITY CENTER *Improving HIV Care.*

How Can We Engage Consumers in Our Quality Management Program?

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Panel: Lennie Green, Michelle Lopez, Anselmo Fonseca

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HIV/AIDS Bureau

Agenda for the Session

- **Short slide presentation:**
 - Importance of engaging consumers
 - Potential roles of consumers in quality improvement
 - Barriers to participation
 - A Consumer Involvement Plan
 - Special considerations for a successful CAB
- **Open discussion:** what has and hasn't worked in your programs
 - Comments from panel of grantees and consumers
- **Resources and ideas** to take away and try....

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Perspective

- Providers of services want and need client input in order to meet high standards and develop excellence in HIV program design and service delivery.
- Consumers want to provide client input to:
 - feel valued and appreciated,
 - be part of something important,
 - connect with the community,
 - network and meet people, and
 - learn new skills.
- Partnerships are bonded through shared responsibilities.
- Sharing in the responsibility creates a win-win situation.



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Take Home Points: Lennie Green

Training for both consumers and providers is critical. This is a cultural proficiency challenge.

- Training for consumers should include:
- Definitions/acronyms
 - Processes
 - Roles
 - Basics of how clinical culture works
 - Consensus building

- Training for providers should include:
- Roles and importance of consumers
 - Consumer priorities
 - Understanding and appreciating different communication

Take Home Points: Michelle Lopez

Consumers should be included as decision makers, not just advisors.

- Consumers should be able to participate as:
Members of Board of Directors
Other decision-making bodies
Level playing field so consumers aren't in a lesser position than providers

Take Home Points: Anselmo Fonseca

Solving practical barriers and recognizing people's contributions keeps them engaged.

- Pay attention to:
 - Transportation
 - What hours your meetings happen
- Respectfully recognize peoples' contributions
 - Letters of appointment to panels and committees
 - Highlight contributions in newsletters, announcements and verbal reports

Consumer Involvement Can Take on Many Forms

- Focus Groups
- Needs Assessments
- Key Informant Interviews
- Client Satisfaction Surveys
- PLWHA representation at all levels within the agency:
 - Board of Directors
 - Staff (representative of the client population being served by the agency)
 - Client/Consumer Advisory Committee (CAC) or Consumer Advisory Board (CAB)
 - Agency's Quality Committee

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Lessons Learned: Consumer Involvement

- Make sure consumers are **aware of opportunities to participate**
- **Address consumer needs/barriers** for participation
- Consumers get involved and stay involved when they see their **input and recommendations implemented**
- Consumer involvement should have **written standards** and a **written plan** (or a section in the Quality Management Plan)
- **Dedicated training** on quality for consumers is critical
- Emphasize **equal partnership** in improving quality
- **Highlight consumer contributions** in newsletters, report outs, and conference calls on quality

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Consumers on the Quality Committee: Barriers

Consumers may experience:

- Unaware of opportunities to participate
- Feeling that their input isn't being used
- Lack of orientation and training
- Acronym angst
- Fear of disclosure
- Burnout (reliance on only a few consumers for activities)
- Practical barriers: Transportation, childcare, \$\$, work, time, illness or poor health

Grantees may worry about:

- Consumers slowing down the process
- Consumers may pass on unflattering info
- Just can't get consumers to come!

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Plan for Consumer Involvement

A written plan for consumer involvement describes structures that are in place to ensure active participation of People Living with HIV/AIDS (PLWHA) in the continuous development and improvement of HIV/AIDS programs. This can be included in the overall Quality Management Plan.

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Consumer Advisory Board (CAB) Selection Process

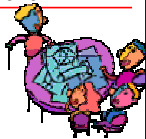
- The CAB should reflect the diversity of the client population of the HIV program
- To avoid burn-out, length of service should be set
- Some methods of selecting CAB members include soliciting volunteers, holding elections, establishing a nominations process or using recommendations by clients, current advisory board members, staff and the Board of Directors
- Consider using an interview process for membership, to allow mutual information and clarify expectations

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Once established, the CAB should:

- Provide orientation to new members
- Develop operating policies and procedures
- Meet on a regular basis (monthly/quarterly)
- Document minutes for all meetings
- Submit progress reports and issues of concern to the HIV Program Director and the Board of Directors
- Work with appropriate agency staff to evaluate the CAB's effectiveness



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**New York State Quality of Care
Consumer Advisory Committee Structure**

- The committee first met on July 24, 2002
- **Membership:** Up to 32 members representing various HIV communities in New York State (geographic region, gender, race, ethnicity and risk-groups)
- **Committee Member Selection:** Identification of PLWHA leaders with strong knowledge of HIV health care and the development of a structured nomination process
- **Meeting Structure:** Quarterly meetings (since July 2002) with frequent topic-specific sub-committees; by-laws have been written and approved by committee members.
- **Committee Co-Chairs:** Two consumer Co-Chairs; 1 appointed by NYSDOH and 1 elected by fellow committee members

**New York State Quality of Care
Consumer Advisory Committee
Accomplishments**

- A survey was developed, disseminated, collected, and used to assess consumer involvement in quality of care programs (63 out of 114 facilities in New York State responded)
- Brainstorm, recommend, and pilot testing of new performance indicators:
 1. prevention project for all ambulatory HIV facilities in NY State; and
 2. lab work to assess patient's awareness of essential lab results

**New York State Quality of Care
Consumer Advisory Committee
Accomplishments**

- Provide ongoing input into AIDS Institute Guidelines Committees Review and input in upcoming New York State HIV Guidelines
- Review and comment on upcoming publications and materials (ex: consumer materials, consumer satisfaction surveys, and performance data releases)
- Deliver "Making Sure your HIV Care is the Best It Can Be" within ambulatory care settings to both staff and consumers

New York State Quality of Care Consumer Advisory Committee Accomplishments

- Presentations at national and international HIV/AIDS conferences
- Share success stories related to consumer involvement in QOC
- Routine input into the development of AIDS Institute funding solicitations (RFAs/RFPs)
- Strategic Planning Meeting (March 9-10, 2007) to establish committee goals/objectives for FY 2007/2008
- Establishment of a Youth Discussion Group

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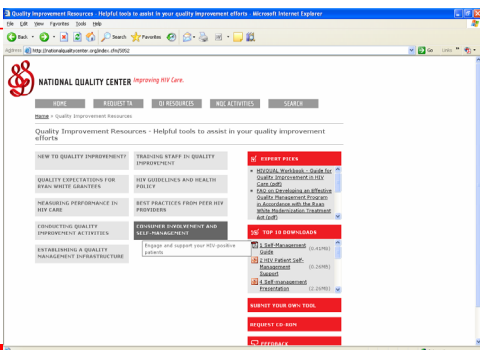
New York State Quality of Care Consumer Advisory Committee



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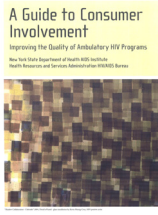
NQC Website: Consumer Resources



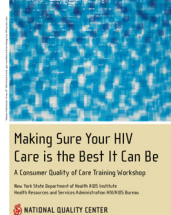
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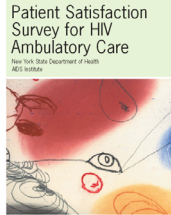
Consumer Involvement in Quality Management: Guides and Resources



Best practices gathered for involving consumers in QI. Pages 36-43 include RW standards for consumer involvement

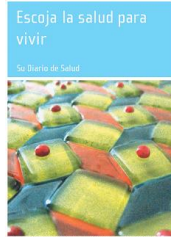


Extremely helpful consumer training resource



Validated HIV patient satisfaction survey

Product of Consumer Involvement: Patient Health Journal



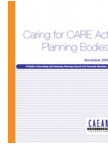
More Resources!



HAB resource for consumers focusing on involvement in Part A and B planning bodies



PLWH decisions on health care needs and the role of HIV+ peer advocates and mentors in self-management



Guide to recruiting and retaining Planning Council and Consortia members



AIDS Alliance resources in English and Spanish for developing CABs and a consumer guide for participating in planning bodies

Available Technical Assistance Resources

- National Quality Center (NQC) Resources and TA www.NationalQualityCenter.org, info@NationalQualityCenter.org
- HRSA HIV/AIDS Bureau (HAB) Resources www.hab.hrsa.gov
- HRSA/HAB TARGET Center: Training on Consumer Involvement and Leadership (Academy of Educational Development) www.careacttarget.org/links.htm#ConsumerInvolvement_PlanningLeadership
- AIDS Alliance Resources and Consumer Leadership Corp Training Program <http://www.aids-alliance.org>
- Communities Advocating Emergency AIDS Relief (CAEAR) Coalition Resources www.caeat.org

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