

# Engaging People Living with HIV/AIDS to Effect Positive Change in Ending the HIV/AIDS Epidemic

## Presenters

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# Disclosures

Presenters have no financial interest to disclose.

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Commercial Support was not received for this activity.

# Learning Objectives

At the conclusion of this activity, the participant will be able to:

1. Understand challenges and barriers involved with engaging PLWHA<fill in>
2. Develop effective ways to engage PLWHA in short term and long-term opportunities
3. Gain insight from lessons learned

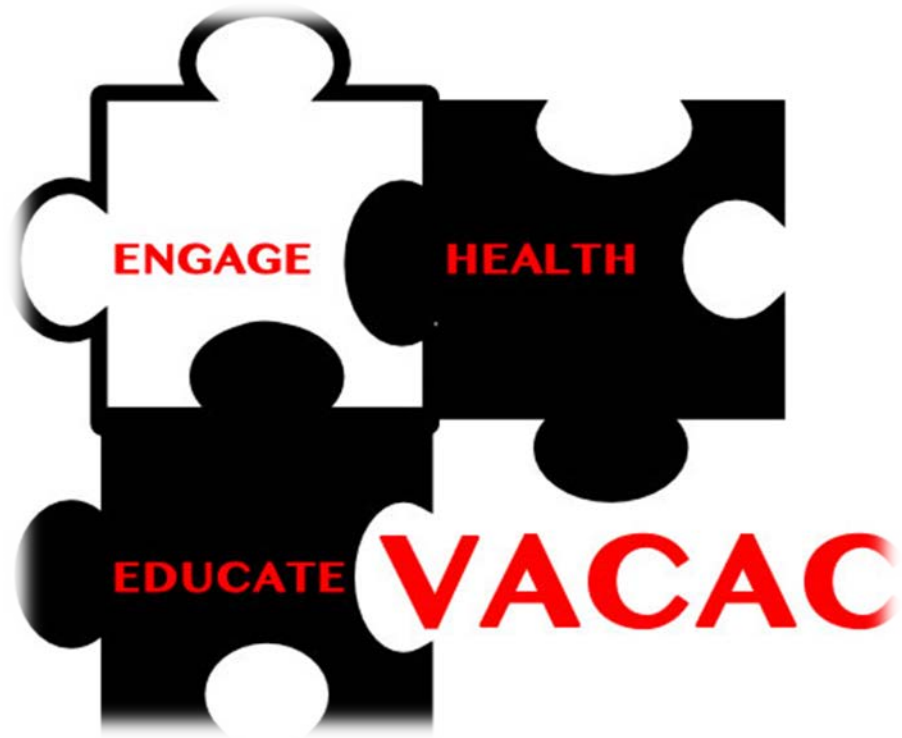
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# Virginia Quality of Care Consumer Advisory Committee (VACAC)

# Virginia Consumers in Quality of Care



## Who we are:

We are the VACAC, an advisory committee of consumers in the commonwealth of Virginia that ensures people living with HIV/AIDS have input into the creation, development, and implementation of all HIV services in Virginia's five health regions.

## Our Mission:

The **mission** of the VACAC is to establish a unique and sustainable partnership with providers to incorporate the experiential perspectives of people living with HIV/AIDS into the quality improvement process.

# Our Goals

1. To act as liaison between consumers, Virginia Department of Health (VDH) and service providers.
2. To engage, educate, and bring together consumers through a variety of activities that support health promotion and quality of life.
3. Assess challenges with linkage to care and identify quality of care best practices for implementation locally, regionally, and/or statewide.

# VACAC Membership

The VACAC membership is unlimited and comprised of members representing each of the five health regions of the Virginia Commonwealth (*Central, Eastern, Northern, Southwest, and Northwest*), and members representing special targeted groups.

Committee composition reflects diverse communities impacted by the HIV epidemic in Virginia.

The Executive Committee includes 15 members



# Consumer Involvement: *Why?*

Health Resources & Services Administration legislation mandates that all Ryan White HIV/AIDS Programs, planning bodies and consortia include people living with HIV/AIDS (PLWHA) be included in the following activities:

- Ryan White Programs and the Planning process
- Needs assessment activities
- Planning for services
- Helping to identify and set service priorities
- In some cases, assist with making allocation recommendations for funding opportunities

# Consumer Participation: *The Value of Consumers*

**Consumer Perspective.** Consumers provide a critical perspective on Ryan White Program service planning, delivery, and evaluation. This occurs within a diverse consortium membership that provides a forum for participants to interact.

**Reality Check.** Consumers help keep programs and systems focused and on track by providing a first-hand perspective on issues facing them and their families. They can discuss their actual experiences in seeking and obtaining services.

**Help in Needs Assessment.** Consumers can help ensure that needs assessments consider the needs of consumers from differing populations and geographic locations.

# Barriers to Consumer Involvement:

- Lack of awareness of Care Act programs and planning bodies
- Lack of knowledge about how to get involved, including criteria for membership
- Unclear roles, responsibilities, and expectations
- Belief that PLWHA are not taken seriously
- Fear of disclosure of HIV status, sexual orientation, stigmas
- Financial cost to participate (transportation issues)
- Distrust of public programs and providers
- Discomfort or lack of understanding of the complexity and formality of planning body procedures

# Consumer Engagement Infrastructure: *Multiple Avenues for PLWHA*

- **Quality Management Advisory Committee**
- **HIV Community Planning Groups**
- **Client Satisfaction Surveys**
- **Focus Groups**
- **Suggestion Boxes**
- **Leadership/Quality Champions**
- **Peer Coaches**
- **Consumer Forum/Advisory Committee**
- **Trainings and Workshops**

# Successful Consumer Involvement in Virginia

## Institute continuous processes that help maintain consumer participation statewide

- Develop VACAC infrastructure: EC, regional reps and QMAC subcommittee
- Orientation: Orientation and mentorship
- Training: Regional trainings, QMAC meetings, QM summit
- Relationship building and National events:
  - CQII trainings
    - Training of Consumers on Quality Plus (TCQPlus) – **100 consumers** trained in 2 days in Virginia
    - Training of Consumers on Quality Plus (TCQPlus) – **1 consumer** sent to training in San Diego, California
    - Center for Quality Improvement and Innovation Training of Trainers (TOT) – **2 consumers** trained in Kansas City, Missouri
  - ADAP Advocacy Association 2018 Annual Conference – **4 consumer** sent to represent in Washington, DC
  - 2018 National Ryan White Conference on HIV Care and Treatment – **2 consumers** presenters in Washington, DC
  - PrEP Ambassadors & REVIVE Training! – more than **25 consumers** trained in Virginia
  - Access to Information: Glasscubes via the Center for Quality Improvement and Innovation
- Financial Support or Incentives through approved funding for hotel, travel, foods, and per diems

# Other Notable Successes & Achievements

- Consistency in PLWHA Involvement statewide
- Increased PLWHA capacity to improve quality
- Different methods of successful engagement
- Recognition for leadership
- Consumer Forum/training in quality
- Consumer Advisory Committee
- Peer education training program
- Culinary Education Pilot Program

# LESSONS LEARNED

- Provide transportation, employment, and incentives as needed
- Develop and administer ongoing, brief consumer satisfaction survey
- Report all survey results to all stakeholders
- Ability and willingness to make operational changes
- Ensure assessments reflect the needs of consumers
- Ensure PLWHA are aware of involvement opportunities
- Ensure PLWHA see positive effects of their involvement

# Questions?

