



VIRTUAL  
**2020 NATIONAL**  
**RYAN WHITE**  
**CONFERENCE ON**  
HIV CARE & TREATMENT

# 2020 National Ryan White Conference on HIV Care and Treatment

Virginia Department of Health



# People Living With HIV/Consumer Involvement Leading the Way to End the Epidemic

# Disclosures



- Presenters have no financial interest to disclose.
- Commercial Support was not received for this activity.

# Meet the Presenters!



- VACAC Presenters
  - Juan Pierce, Central Region Representative and Executive Director Minority Health Consortium, Inc
  - Lynea Hogan, Interim VACAC Co-Chair and Eastern Region Representative
- VDH Presenters
  - Safere Diawara, MPH, HIV Care Services Clinical Quality Management Coordinator
  - Jonathan Albright Williams, BAS, HIV Care Services Quality Management Specialist
- Support Staff
  - Michael Hager, MPH MA, Organizational Ideas, LLC

# Learning Objectives



- Understand challenges and barriers involved with engaging PLWH.
- Develop effective ways to engage PLWH in short term and long-term opportunities.
- Gain insight from lessons learned that can be applied in other regions/localities.

# Obtaining CME/CE Credit



- If you would like to receive continuing education credit for this activity, please visit:
- <http://ryanwhite.cds.pesgce.com>



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# Consumer Involvement

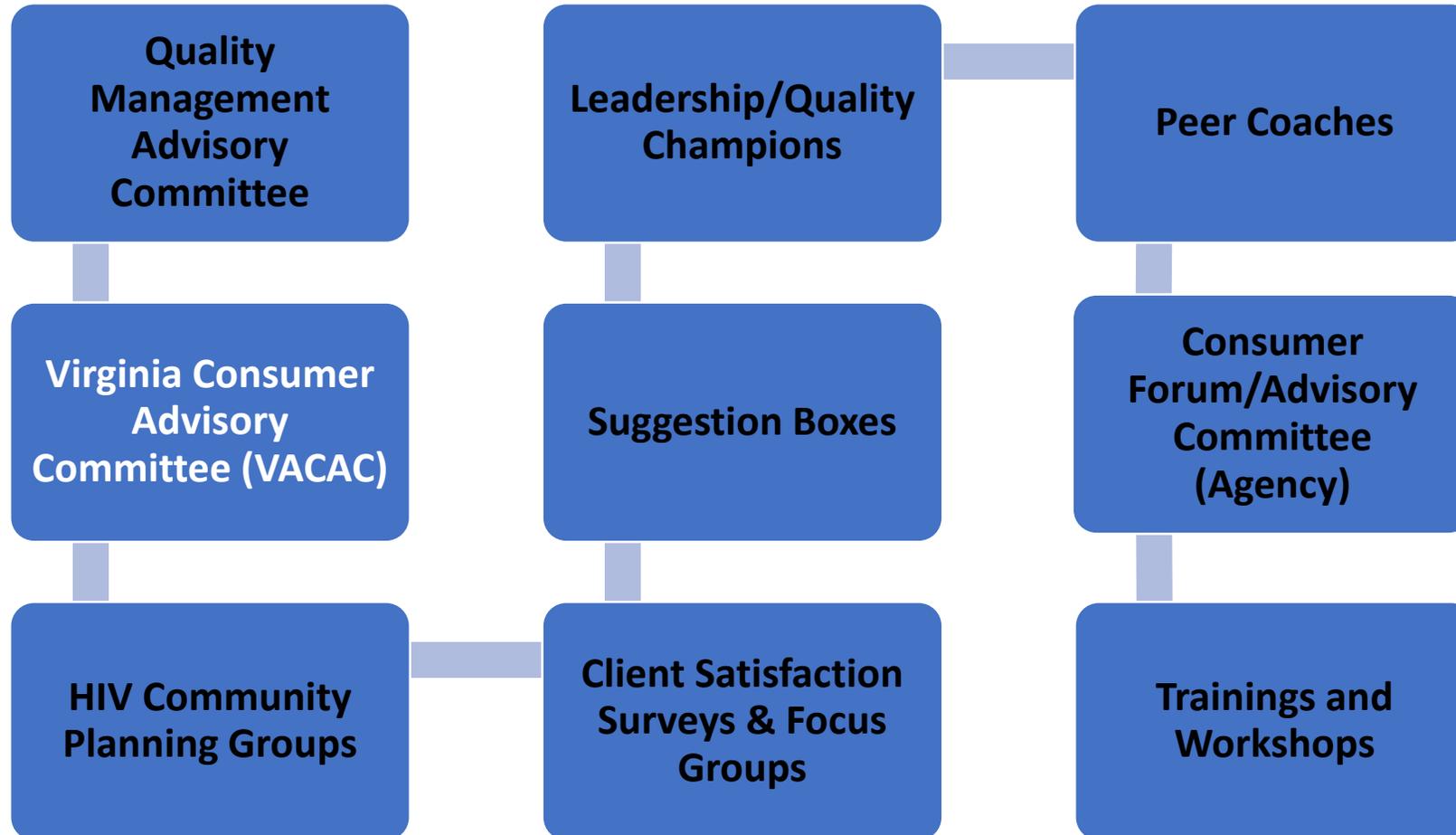
Virginia's Response

# 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

# Involving Consumers in Virginia



- Care and Prevention Integrated Plan (2017) – Statewide Comprehensive and Services Needs (SCSN)
- Training of Consumers on Quality (TCQ) - February 2017 (100 consumers)
  - Training
  - Needs assessment activities
- VACAC (May 2017) held the first Executive Committee meeting
  - What are your expectations?
  - What do you plan to bring to the group? and
  - What do you plan to give to the group?
  - What are your vision?
  - What will be the VACAC mission?
  - **First group of VACAC Peer-to-Peer Trainers put together**



# What is VACAC?

Developing consumer leadership across the Old Dominion

# VA Consumer Advisory Committee (VACAC)



## 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.

# VACAC Goals



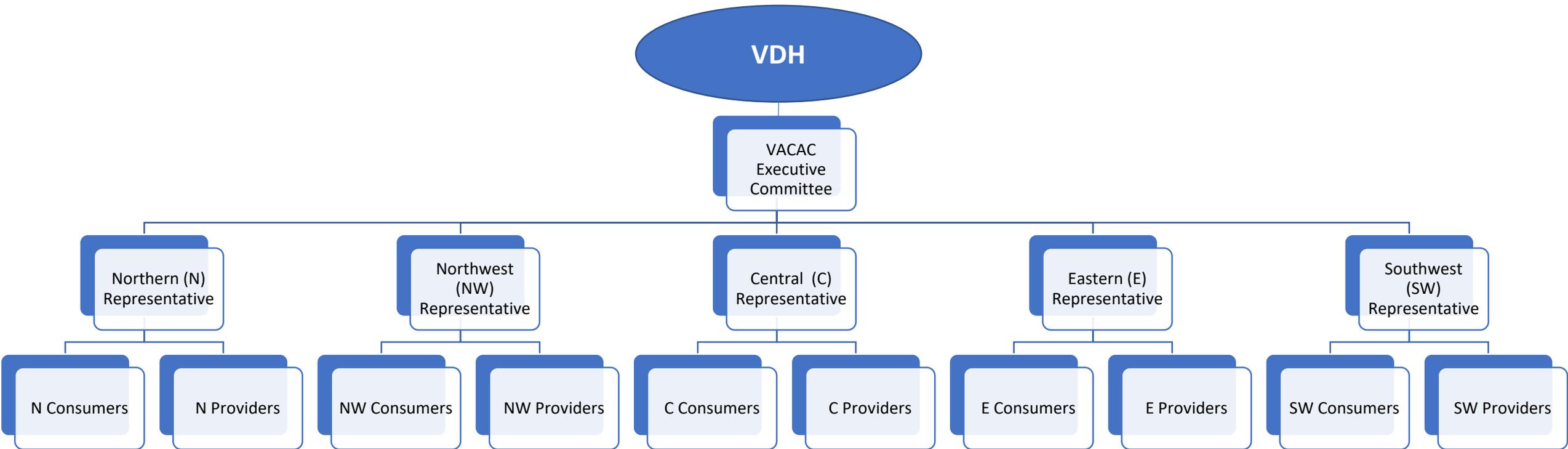
1. To act as liaison between consumers, Virginia Department of Health (VDH) and service providers.
2. To engage, educate, and bring together consumers through a variety of activities that support health promotion and quality of life.
3. Assess challenges with linkage to care and identify quality of care 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.
- VACAC is steered by an Executive Committee, which includes 15-20 members (VACAC chairs, regional reps, and alternates for chairs and reps).
- VDH provides formal guidance and support to VACAC leadership.

# VACAC Structure



# VACAC Regional Representatives



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## VACAC CO-CHAIRS



Sylvester Askins



Mark Baker

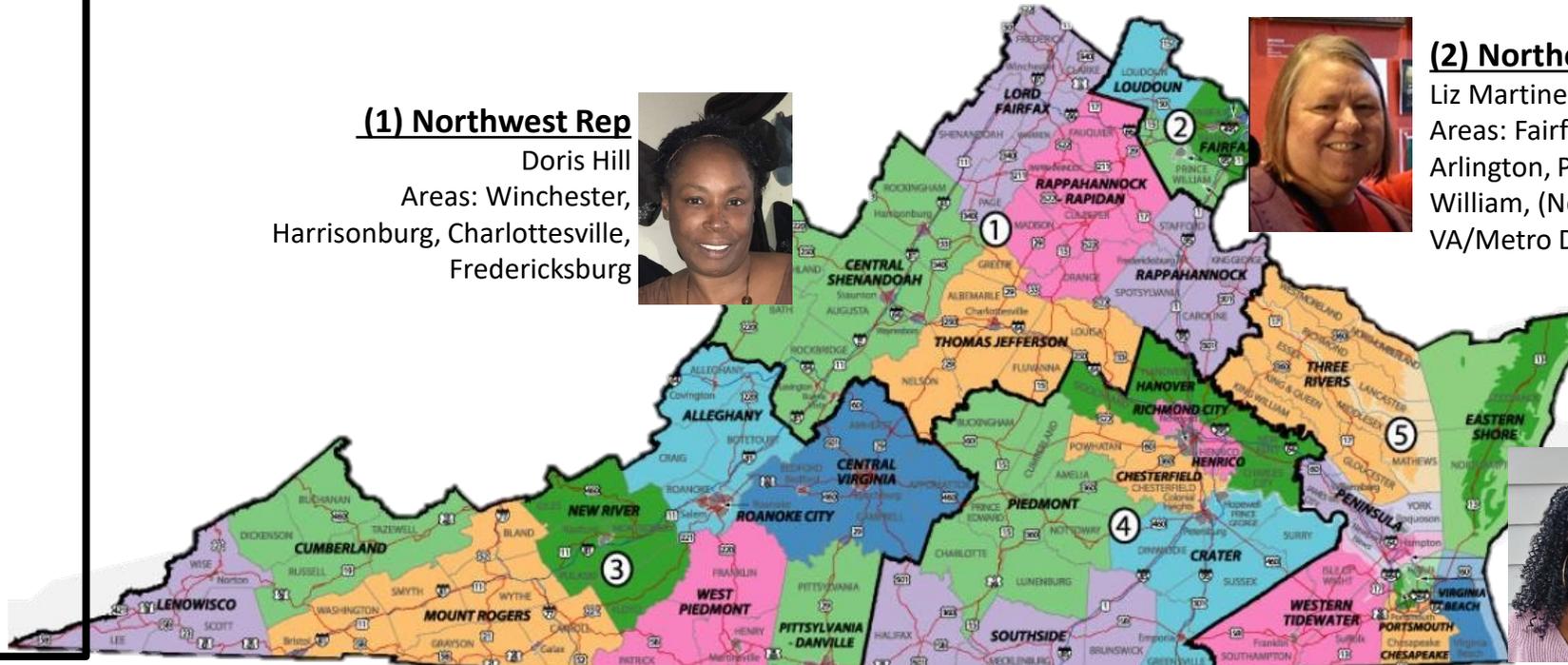
### (1) Northwest Rep

Doris Hill  
Areas: Winchester,  
Harrisonburg, Charlottesville,  
Fredericksburg



### (2) Northern Rep

Liz Martinez  
Areas: Fairfax,  
Arlington, Prince  
William, (Northern  
VA/Metro DC)



### (3) Southwest Rep

Thomas Salyer  
Areas: Lynchburg, Roanoke,  
Danville, Martinsville, Far SW



### (4) Central Rep

Amp Hayden  
Areas: Richmond, Petersburg,  
Hopewell, Emporia, Southside



### (5) Eastern Rep

Lynea Hogan  
Areas: Hampton Roads,  
Williamsburg, Eastern Shore,  
Three Rivers





# Improving Access to Care and Other Care Processes

Consumer roles in shaping statewide, local, and organizational HIV program design

# The Value Consumers Bring



- **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.

# Teach One, Reach One



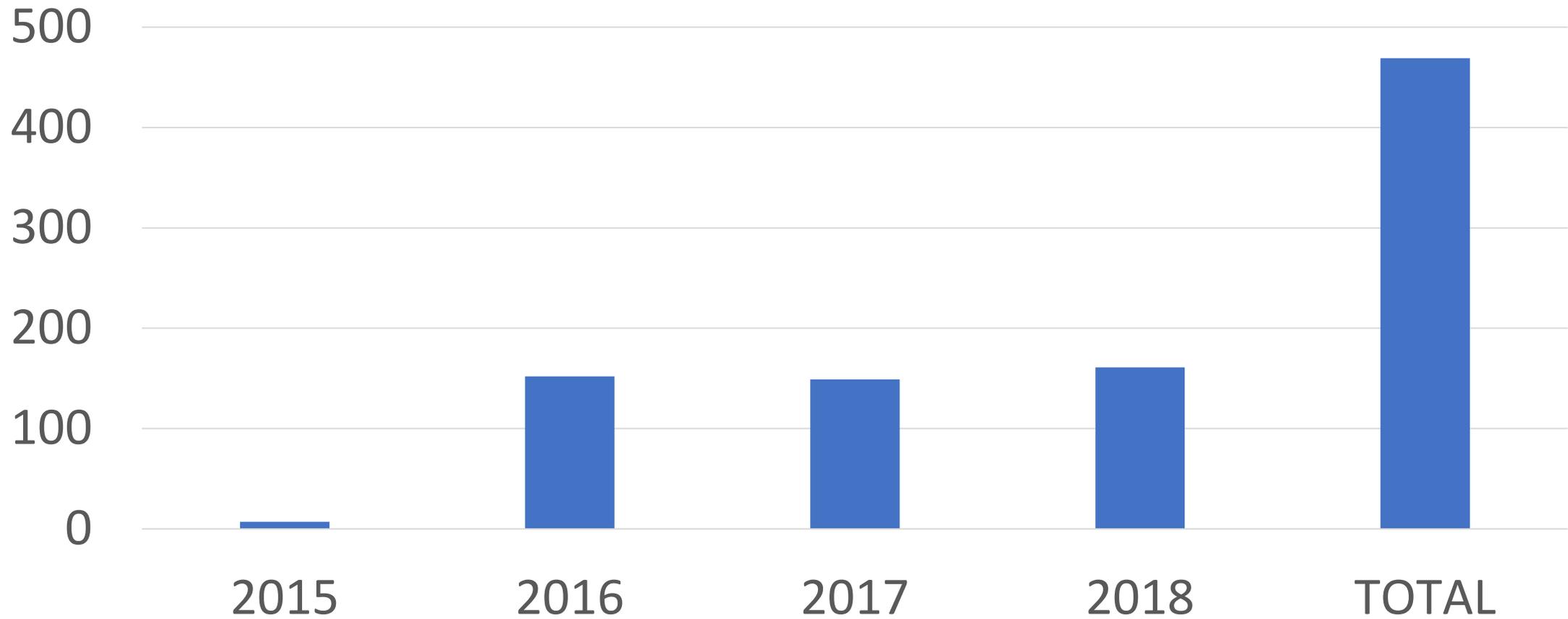
- VACAC is an opportunity for ALL consumers of RWHAP services to have a voice in planning and evaluating Virginia’s HIV services
- Capacity-building approaches encourage bringing on new members
- Regional representatives are responsible for shepherding the consumers in their regions through training and regional-level discussions
- VACAC highly values personal growth of its members related to their individual HIV and CQM journeys
- VACAC ensures there is at least 1 trained consumer involved in quality processes at each RWHAP-funded entity in the state

# Consumer Training



- Health Literacy – what is the care we receive and how does it theoretically affect our overall health and well-being?
- Health Numeracy – what is the data associated with our healthcare and how do we interact with data as consumers?
- HIV101 – keeping abreast of the latest scientific and social innovation
- Virginia Ryan White Systems – how does Virginia’s HIV care system work for people living with HIV served by it?
- Special Topics – driven by annual needs assessments that identify statewide consumer training needs and interest in these topics

# VACAC Training Reach





# Building Consumer Capacity and Efficacy in System Co-Design

Overcoming challenges to consumer participation

# Barriers to Consumer Involvement



- Fear of disclosure of HIV status, sexual orientation, stigmas
- Financial cost for consumers to participate (transportation issues)
- Consumer distrust of public programs and providers
- Consumer discomfort or lack of understanding of the complexity and formality of planning body procedures
- Lack of awareness of RWHAP programs and planning bodies
- Lack of knowledge about how to get involved in quality of care activities at various levels – what does it mean to be a VACAC member
- Unclear roles, responsibilities, and expectations (VDH, VACAC, providers)
- PLWHA are not taken seriously by all provider organizations

# Provider Participation and Partnership



## **BARRIERS & CHALLENGES**

- Confidentiality & HIPAA
- Staff changes
- Utilization without compensation

## **SUCCESSSES**

- Assigned RWB agencies in their area
- Use of CAB meetings
- Liaison between agency and consumer
- Reimbursement system



# Celebrating Success

What have we been able to accomplish in Virginia?

# Successful Consumer Involvement in Virginia



- Institute continuous processes that help maintain consumer participation statewide
- Develop VACAC infrastructure: Executive Committee, Regional reps, QMAC interface, Glasscubes folders
- Orientation: Orientation and mentorship
- Training: Regional trainings, QMAC meetings, QM summit
- Financial Support or Incentives through approved funding for hotel, travel, foods, and per diems

# Successful Consumer Involvement in Virginia



- **PrEP Ambassadors Program** – more than **25 consumers** trained in Virginia that promoted PrEP via social media campaign
- **REVIVE Training!** – more than **125 consumers** trained in Virginia to administer Naloxone for opioid overdoses. Medication was provided to consumers upon completion of training via Virginia’s Central Pharmacy
- **Building Leaders of Color (BLOC) Training** – **25 consumers** trained in Virginia by NMAC

# Successful Consumer Involvement in Virginia



- Relationship and Skills Building through National Trainings:
  - 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
    - 2019 Fireside Chat Retreat – **1 consumer** presented
  - **2019 SYNChronicity Conference – 2 consumers** represented VA on scholarships

# Other Notable Successes and Achievements



- Consistency in PLWH Involvement in system design statewide
- Increased PLWH capacity to improve quality at various levels
- Distinguishing between consumer involvement and engagement
- Helping VA RWHAP providers better engage their patients into care
- Recognition for VACAC leadership
- Consumer Forum for discussion of individual and group efforts
- Training in CQM, QI, Leadership, and more
- Peer education training program
- CHARLI Program (a funded project of VDH HIV prevention program)
  - Culinary education pilot program
  - Employment resilience pilot program

# VACAC Lessons Learned



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

# Summary



- VACAC provides consumer perspectives, regular reality checks, and value input that shows consumers are critical in the success of any healthcare programming and service delivery improvement.
- The VACAC helps further the mission and vision of Virginia Department of Health while putting the community's voice at the front end of the conversation
- The VACAC emphasizes the need to include value of consumers time and expertise through incentive programs that encourage appreciation and sustained participation.
- Our VACAC members are able to assist in a variety of ways (training, meeting) to help get consumer involvement and engagement.

# Thank You



**VDH** VIRGINIA  
DEPARTMENT  
OF HEALTH

*To protect the health and promote the well-being of all people in Virginia.*