



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

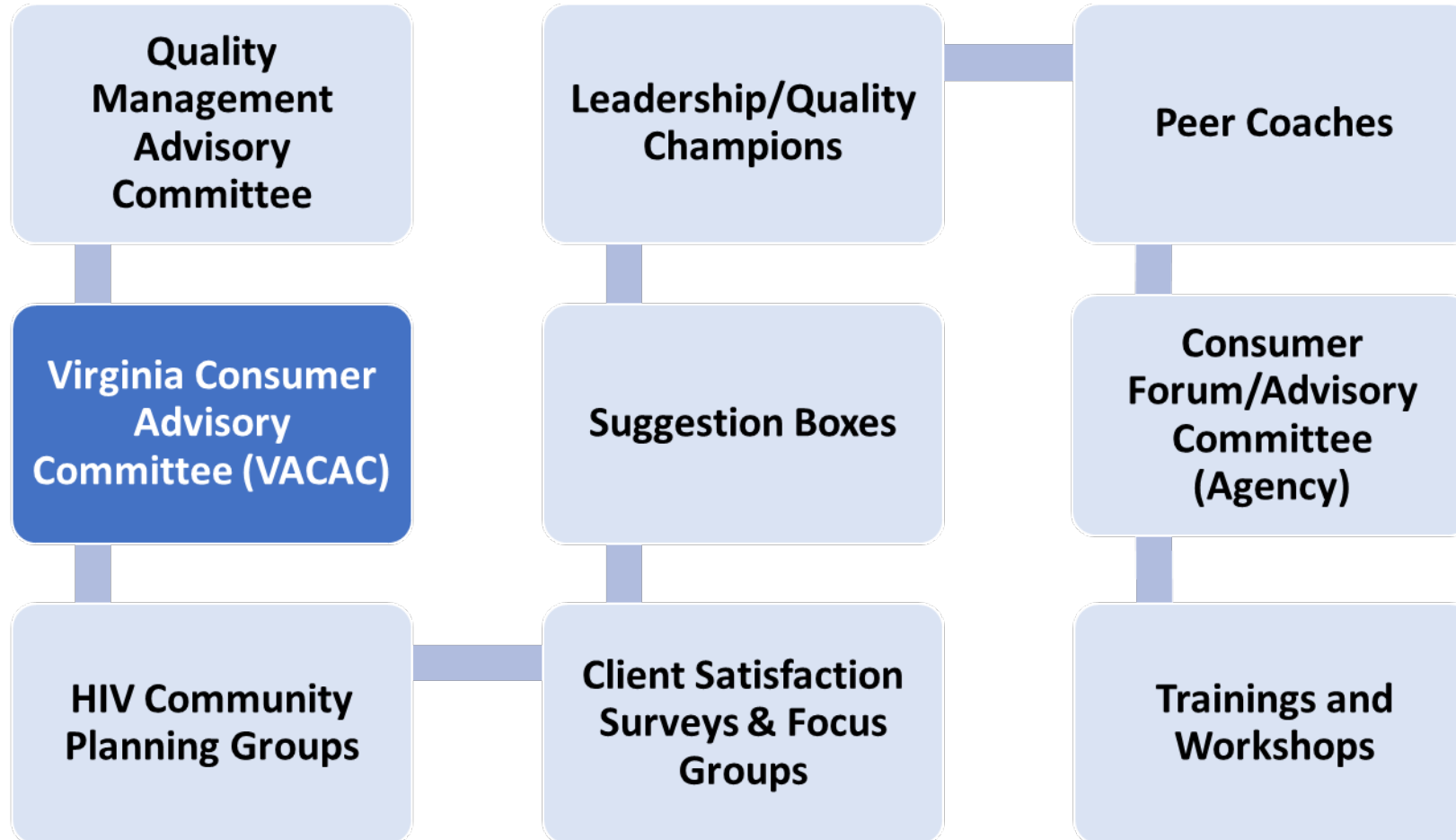
Virginia's Response

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



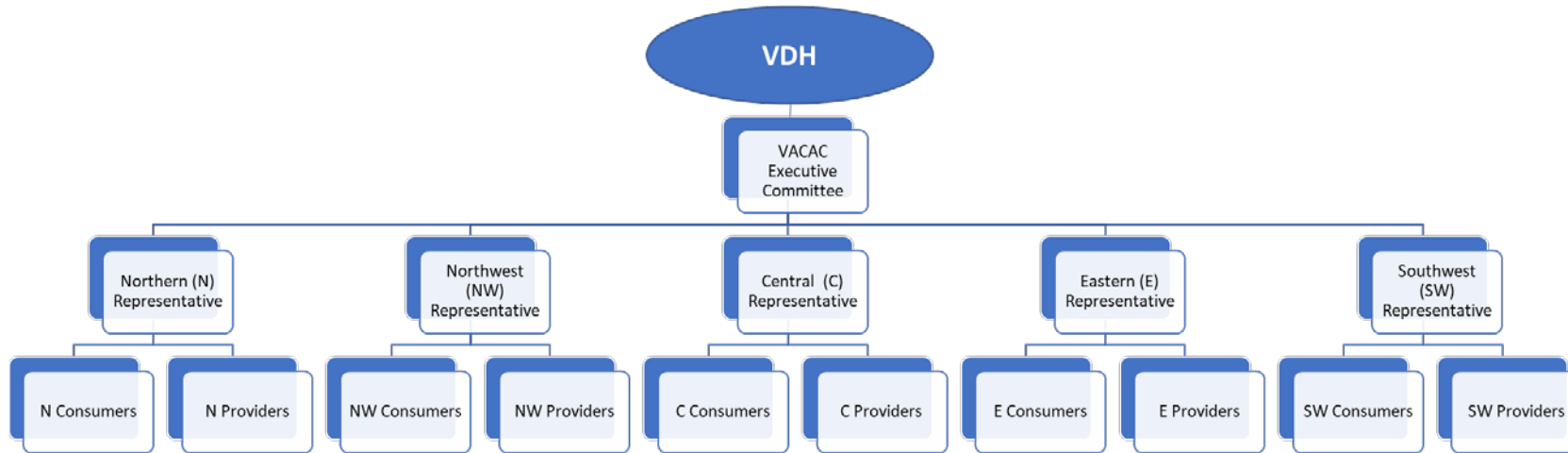
1. To act as liaison between consumers, Virginia Department of Health (VDH) and service providers.
2. To engage, educate, and bring together consumers through a variety of activities that support health promotion and quality of life.
3. Assess challenges with linkage to care and identify quality of care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



VDH

- VACAC Executive Committee
 - Northern (N) Representative
 - N Consumers
 - N Providers
 - Northwest (NW) Representative
 - NW Consumers
 - NW Providers
 - Central (C) Representative
 - C Consumers
 - C Providers
 - Eastern (E) Representative
 - E Consumers
 - E Providers
 - Southwest (SW) Representative
 - SW Consumers
 - SW Providers

VACAC Regional Representatives



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VACAC CO-CHAIRS



Sylvester Askins



Mark Baker

(1) Northwest Rep

Doris Hill

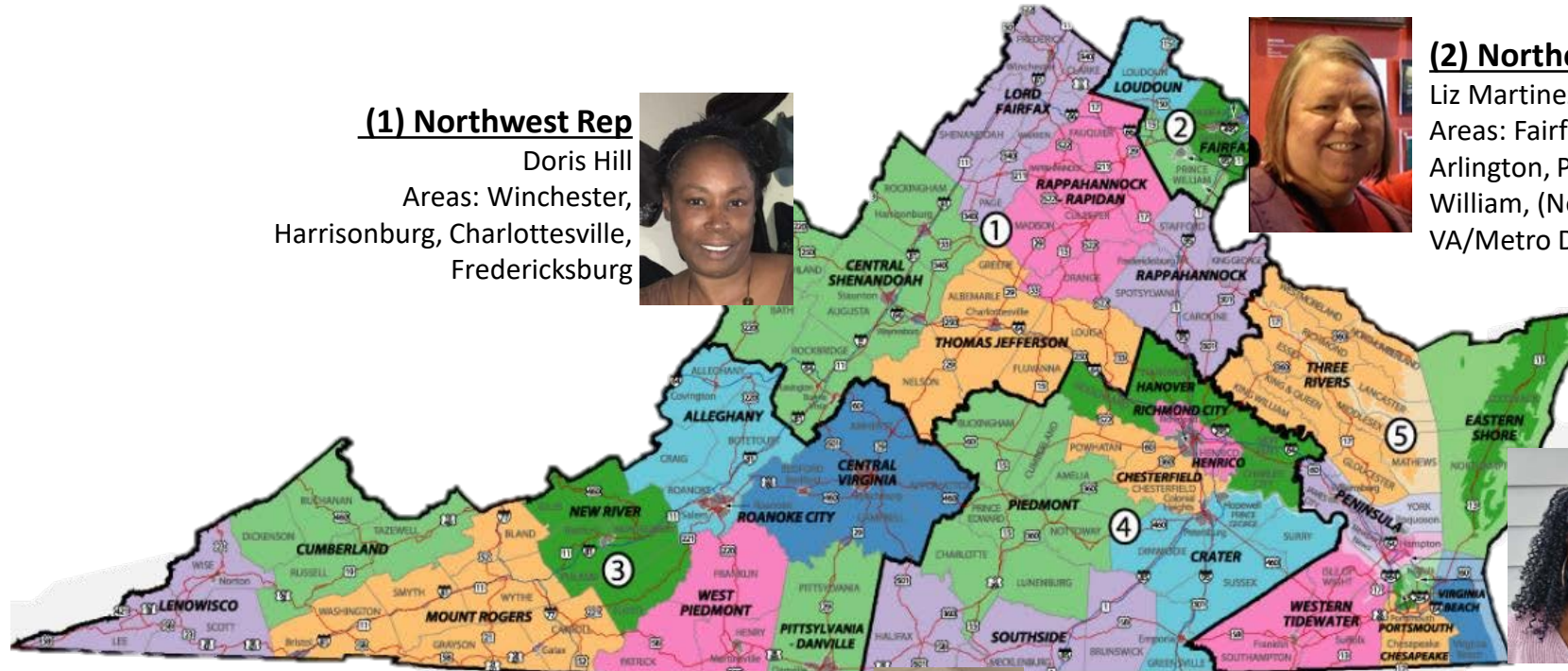
Areas: Winchester,
Harrisonburg, Charlottesville,
Fredericksburg



(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



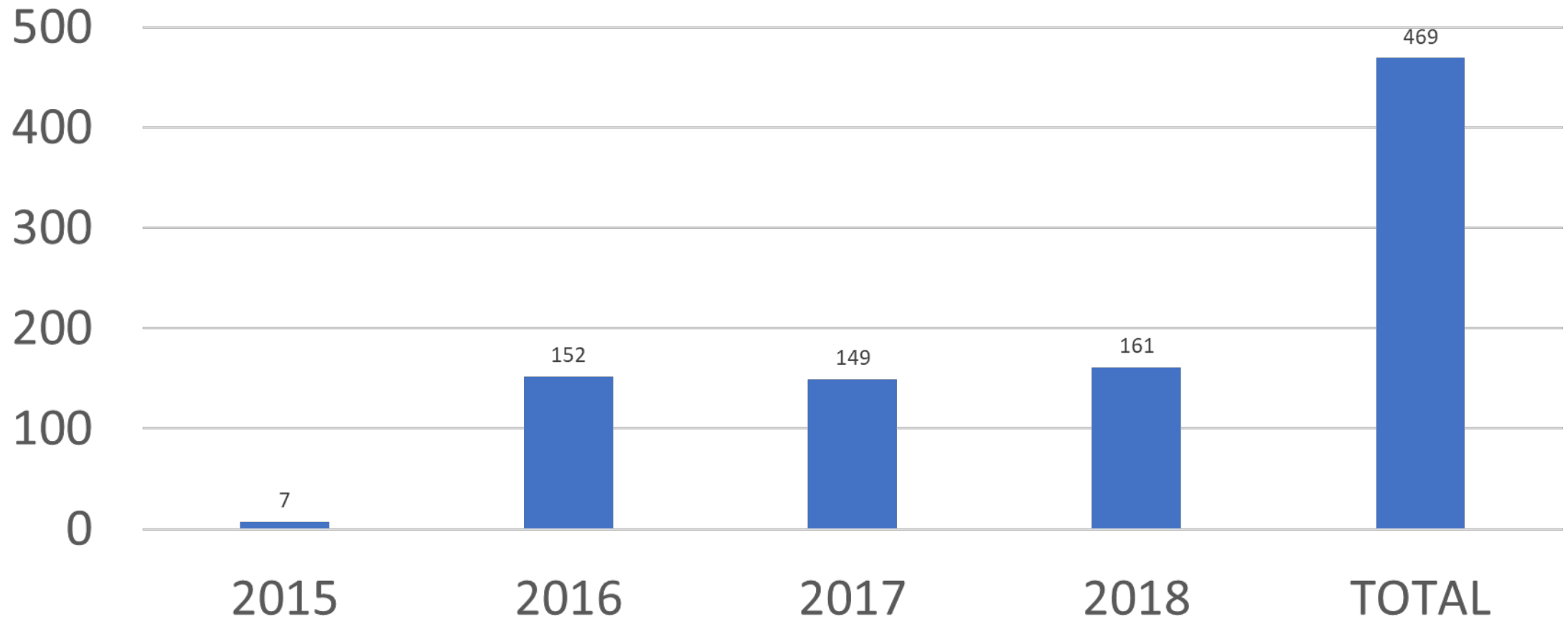
- VACAC is an opportunity for ALL consumers of RWHAP services to have a voice in planning and evaluating Virginia’s HIV services
- Capacity-building approaches encourage bringing on new members
- Regional representatives are responsible for shepherding the consumers in their regions through training 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 1



- 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 2



- **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 3



- 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



- 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
- VACAC has shown that consumers are critical in the success of any healthcare programming and service delivery improvement process.
- Our VACAC members are able to assist in a variety of ways (training, meeting) to help get consumer involvement and engagement.
- The VACAC emphasizes the need to include value of consumers time and expertise through incentive programs that encourage appreciation and sustained participation.

Thank You





Proposal to be discussed in group

1-5 slides to Michael (Xmin)

6-8 slides to Safere (Xmin)

9-15 slides to Juan (Xmin)

16-20 slides to Lynea (Xmin)

21-23 slides to Michael (Xmin)

24-30 slides to Jonathan (Xmin)

31-33 slides are discussion questions (Xmin)