

Engaging RWHAP Consumers in Planning and Needs Assessment

#6746

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Disclosures

Presenters have no financial interest to disclose.

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Learning Objectives

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

- To describe at least 1 challenge experienced and 1 strategy from their Planning Council/Planning Body (PC/PB) that can be used for enhancing consumer engagement in planning bodies, committees, and needs assessment activities
- To identify at least 2 strategies and models used to enhance the involvement of RWHAP consumers as members of PCs/PBs and consumer committees that may be appropriate for use in their program
- To describe at least 3 innovative strategies for obtaining input on consumer service needs, gaps, and barriers that do not involve typical consumer surveys or focus groups



Obtaining CME/CE Credit

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Introduction of Panel and Resource People

Workshop Background

- EGMC just completing for the Division of Metropolitan HIV/AIDS Programs (DMHAP) an assessment of “the perceived successes, key structural issues, abilities, challenges, and technical assistance (TA) needs of Part A Planning Councils/Planning Bodies (PCs/PBs)”
- A major topic: PLWH and especially consumer engagement, and how it has been affected by factors such as the changing HIV/AIDS service environment and the health and employment status of PLWH
- Findings indicate a wide range of experiences – including challenges and effective strategies for consumer engagement as planning body and committee members and sources of information about service needs and gaps
- Many of the findings are applicable to other planning bodies

Workshop Purpose

To engage participants in:

- **Sharing and exploring promising initiatives and strategies for engaging consumers** of Ryan White HIV/AIDS Program (RWHAP) services at a time of change
- **Discussing ways to strengthen community planning activities** through ongoing, active consumer input and participation as planning body members and leaders
- **Presenting new/innovative models** for improving consumer response to needs assessment and obtaining information needed for decision making about service priorities, allocations, and strategies

Workshop Objectives

- To share at least 1 challenge or 1 strategy experienced by your Planning Council/Planning Body (PC/PB) related to enhancing consumer engagement in planning bodies, committees, and needs assessment activities
- To identify at least 2 strategies and models used to enhance the involvement of RWHAP consumers as members of PCs/PBs and consumer committees that may be appropriate for use in your program
- To describe at least 3 innovative strategies for obtaining input on consumer service needs, gaps, and barriers that do not involve typical consumer surveys or focus groups

Key Findings from the PC/PB Assessment and Discussion of Key Issues

Defining “Consumer”

- For RWHAP, consumers are PLWH who receive Ryan White-funded core and/or support services (or their caretakers)
- For Part A, focus on “unaligned consumers” – PLWH who receive services from a Part A-funded provider and do not have a financial or governance interest in a Part A-funded provider as paid staff, paid consultant, or Board member
- When PLWH receive most medical-related services through public or private insurance, sometimes challenging for Part A to decide who is a consumer – especially if Part B pays insurance premiums and cost-sharing
- Some integrated prevention-care bodies want a new definition for consumers of *prevention* services

Consumer Engagement

- **Consumers as decision makers**
 - Voting members of a planning body – full decision-making power
 - Active participants in the work of a planning body through committee or caucus or members of a service provider's Consumer Advisory Board (CAB) – possible limited decision-making power
- **Consumers as contributors without decision-making power**
 - Providing input to needs assessment or Quality Management (QM) efforts
 - Participating in activities/events
 - Speaking during public input periods

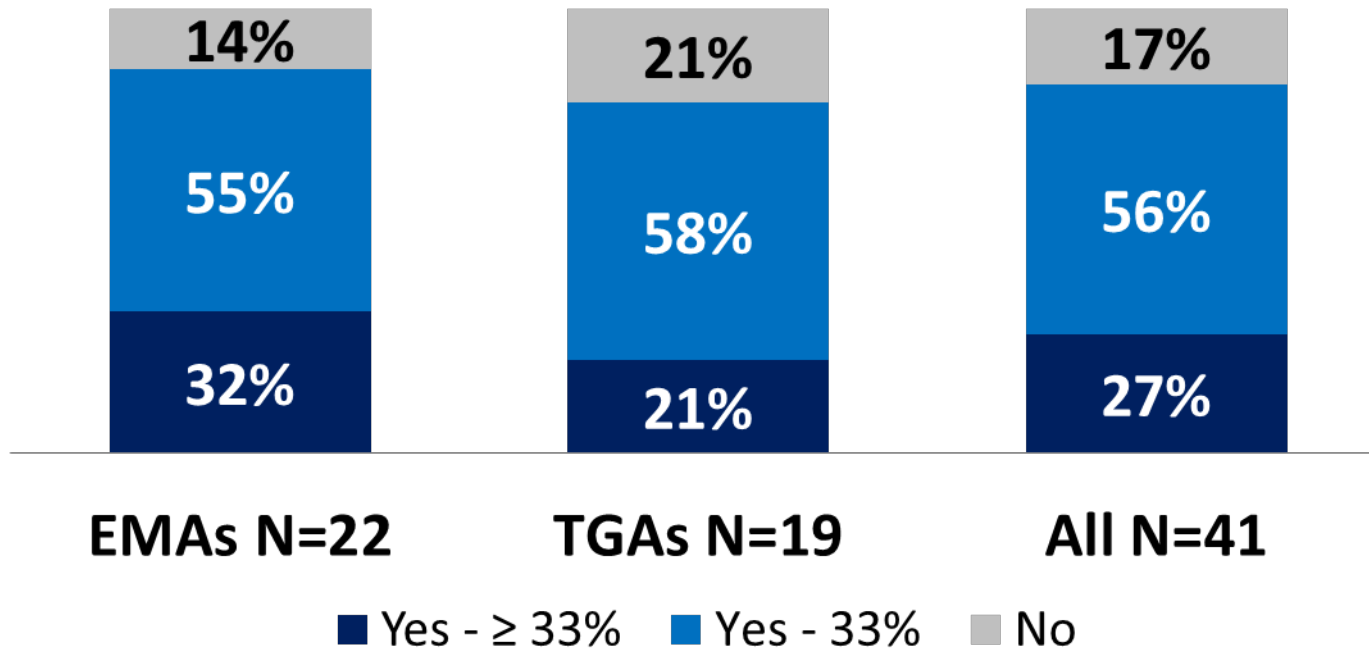
Importance of Consumer Engagement

- **Consumer engagement & empowerment** was the 3rd most often identified recent accomplishment of Planning Councils – after enhanced PC structure & operations and new service models & an improved system of care
- **Consumer voice & decision-making role** was the 2nd most often identified “most important value or benefit of having a Planning Council,” after community involvement

Discussion

Why do you see consumer engagement as important?

Reported Part A Planning Council Ability to Maintain Active Engagement of Unaligned Consumer Members [N=41]



Most Part A Planning Councils (PCs) are maintaining active engagement of unaligned consumers as at least 33% of voting members – but many find this challenging

Maintaining Engagement of Unaligned Consumers

- 7 of 41 Part A programs responding to the VRI reported not being able to meet the 33% unaligned consumer requirement
- 8% of the more than 100 recommendations for legislative changes involved revising the 33% unaligned consumer requirement – 3rd most frequent recommendation after reducing mandated member categories (16%) and maintaining current PC requirements for EMAs & requiring TGAs to have PCs (12%)

Identified Challenges/Barriers to Consumer Engagement

- **Employment** – so consumers are less available for meetings
- **Perceived limitations on consumer capacity for decision making** in an increasingly complex HIV prevention and care environment
- **Unaligned consumers becoming aligned**
- **Stigma and disclosure issues**
- **Generational issues**
- **Transportation and other expenses**
- **Negative environment**
- **Personal and societal challenges**
- **Language and cultural differences**
- **Exclusion due to past legal problems**
- **Insufficient orientation, training, and support**

Discussion

- *What do you see as the most important challenges and barriers to ongoing consumer engagement in your planning body?*
- *What approaches have you used successfully to overcome them?*

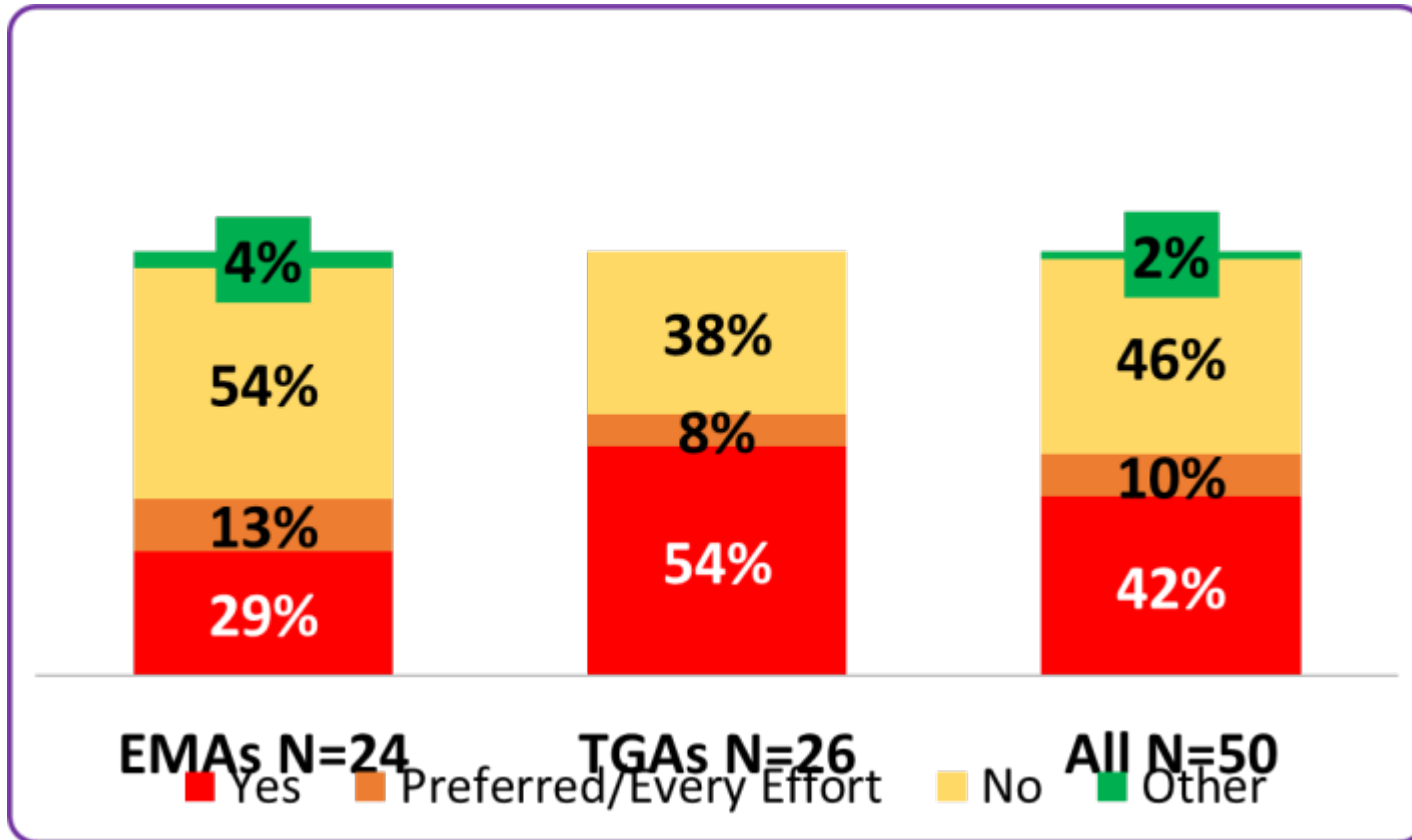
Factors that Contribute to Consumer Engagement

- Value placed on consumer participation – including support from the recipient
- Clearly defined roles, responsibilities, and expectations
- Adequate staffing and support
- Orientation, training, and opportunities for leadership
- A sense of accomplishment – “making a difference”
- Meeting times and locations that facilitate consumer participation

Discussion

- *What are the most important factors in your jurisdiction that contribute to or support consumer engagement?*
- *What if anything have you been able to do to increase or build on these positive factors?*

Bylaws Requirement or Preference for a Chair/Vice Chair/Co-Chair to be HIV-Positive [N=50]



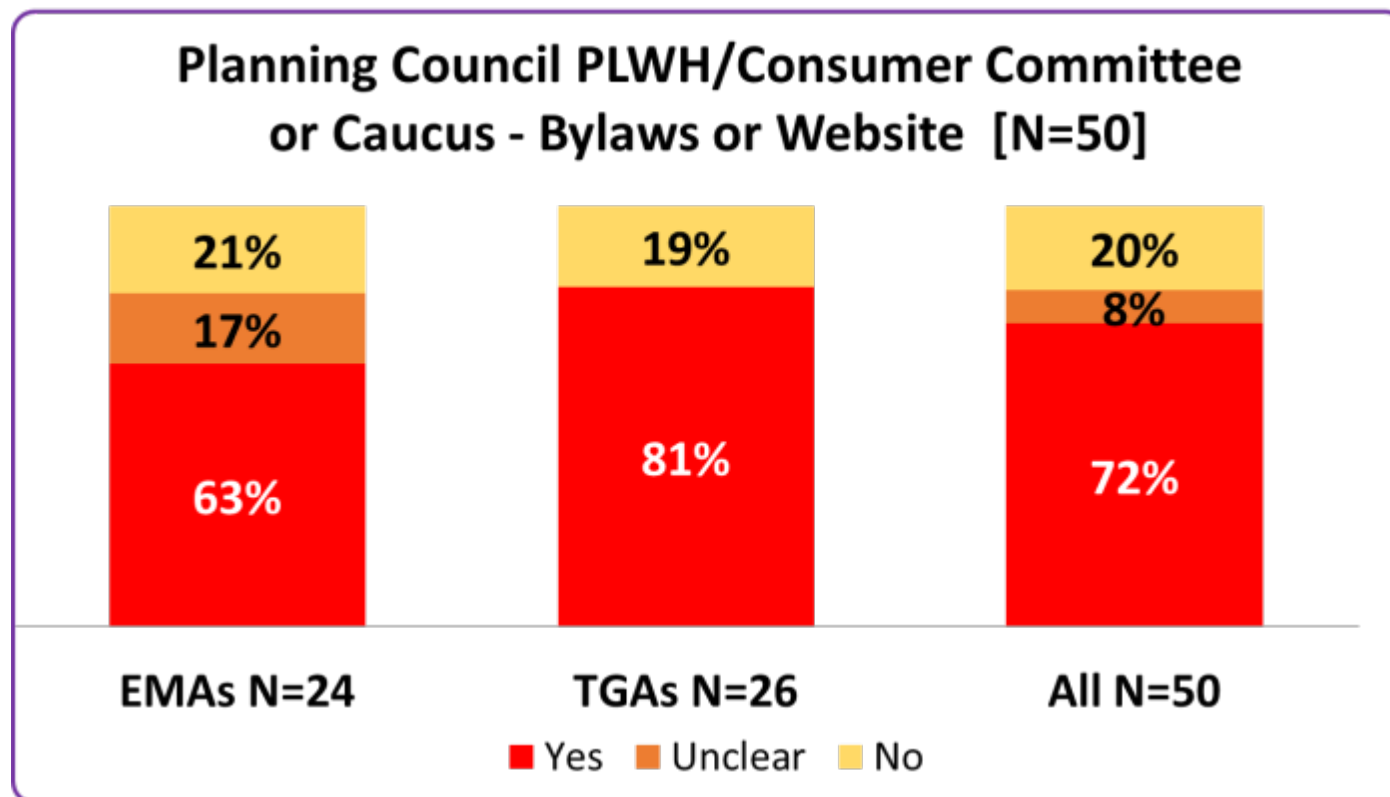
A majority of TGAs but a minority of EMAs have Bylaws requiring that at least one Chair/Co-Chair/Vice Chair be a PLWH

Consumers in Leadership Positions

- *How important is it to have a consumer in a leadership position in the planning body? Why?*
- *Does it matter whether the leader is a Part A consumer or not?*
- *What should a planning body do to prepare consumers for leadership positions?*
- *How should a planning body support them while in leadership positions?*

Planning Council/Consumer Committee

Planning Council PLWH/Consumer Committee or Caucus – Bylaws or Website [N=50]

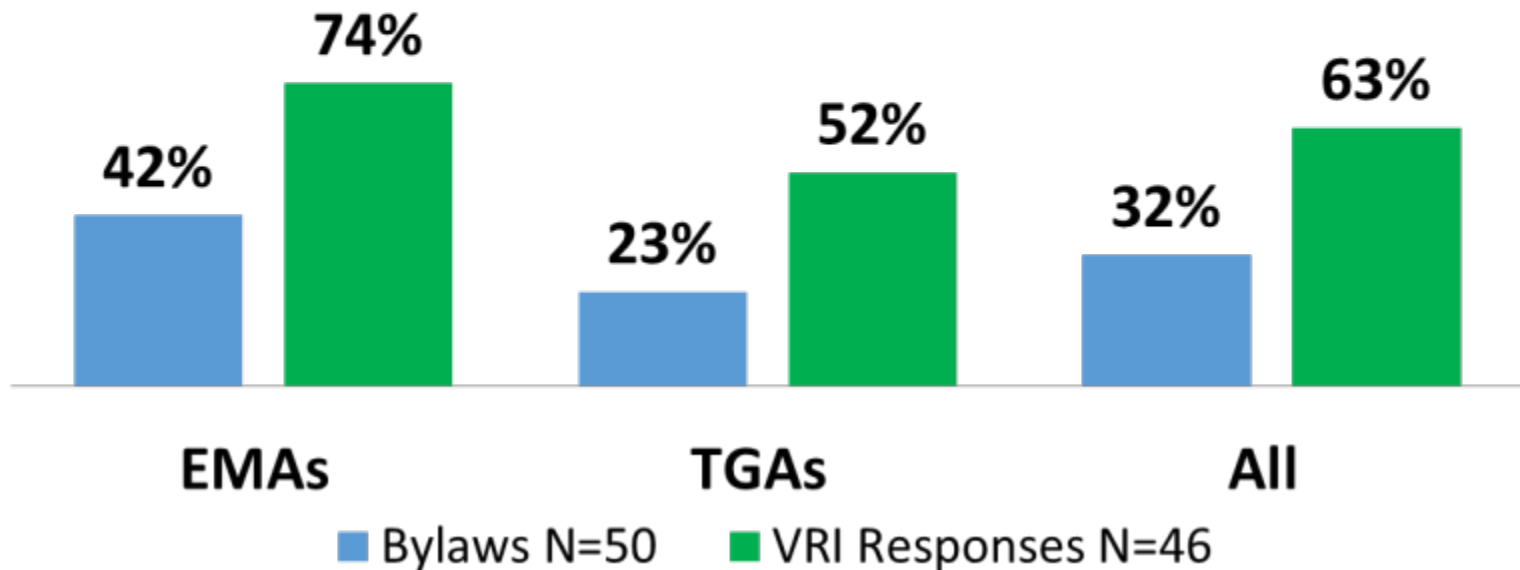


A majority of EMAs and a large majority of TGAs have a PLWH or Consumer committee or caucus – members generally need not be planning body members

Discussion

- *What are the roles & responsibilities of PLWH/Consumer committees and caucuses in your planning body?*
- *How do they help support involvement with the planning body?*

PLWH Involvement on Committees: Percent of Planning Councils that Have or Strive for PLWH or Consumers on All Committees: Bylaws and VRI Responses

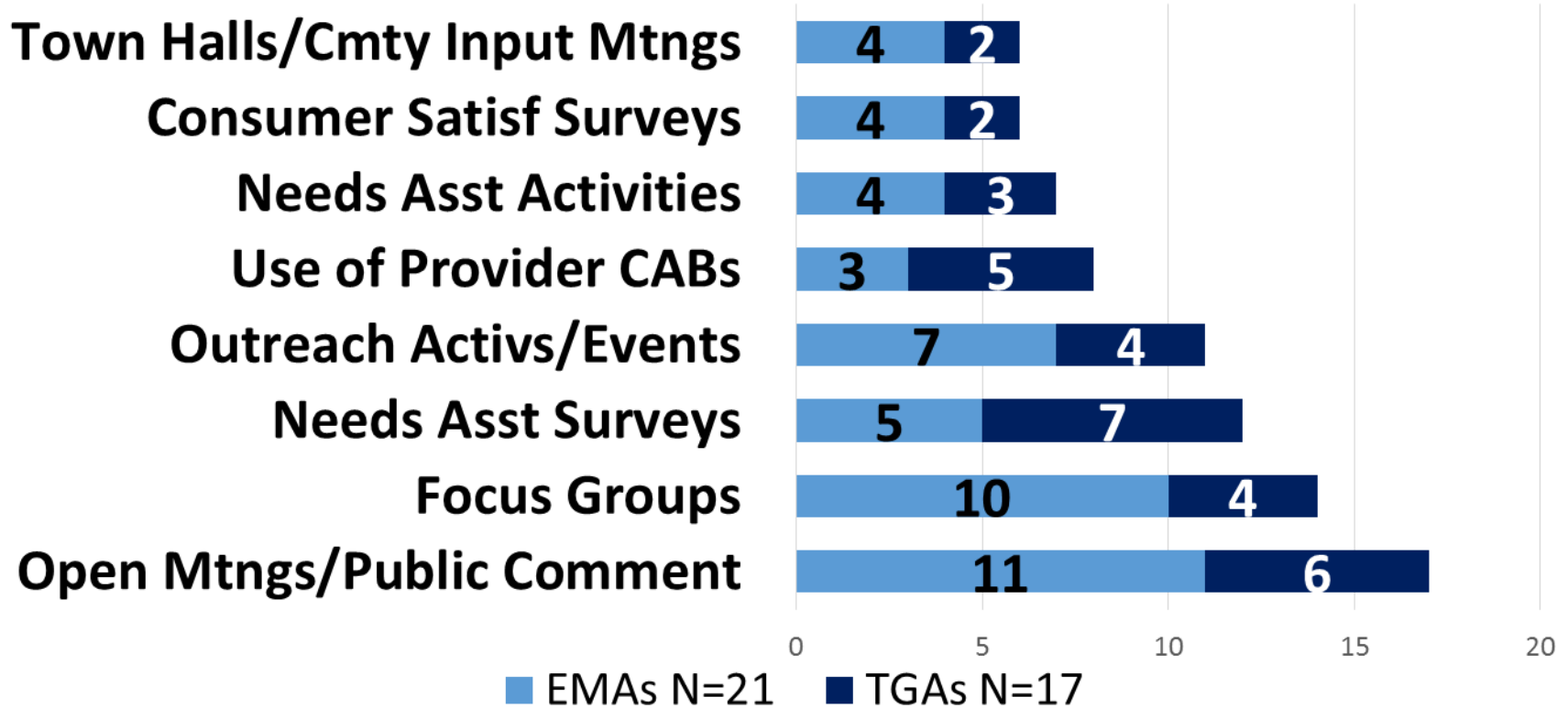


- Most Part A Planning Councils say they want PLWH or consumers on all committees, though only 1/3 have this in their Bylaws
- Several TGAs reported active consumer engagement on the PC but difficulties in retaining consumers on some committees – especially those viewed as “technical”

Discussion

- *How successful is your planning body in maintaining consumer involvement on all committees?*
- *What role does training play?*

Methods Used to Engage Consumers/PLWH Who are Not PC Members [N=38]



PCs report using many different strategies to engage consumers and other PLWH who are not PC members, most related to needs assessment or related input

Discussion

What strategies does your planning body use to engage consumers in ways other than planning body membership?

Sharing of Other Challenges and Successful Strategies

Final Thoughts on Innovative Models

- Houston
- Atlanta
- Other jurisdictions

Thank you so much!

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