

Consumer Committees and Caucuses: Elevating Consumer Voices

This document addresses common questions about Consumer (or People with HIV) Committees and Caucuses as part of Ryan White HIV/AIDS Program (RWHAP) Part A Planning Councils/Planning Bodies (PC/PBs).

WHAT IS A CONSUMER OR PEOPLE WITH HIV (PWH) COMMITTEE OR CAUCUS?

A Consumer or PWH Committee or Caucus is a body associated with a RWHAP Part A PC/PB that is designed to provide input from Part A consumers and other people with HIV (PWH) to all PC/PB activities, and to serve as a link between the PC/PB and the PWH community. A Consumer Committee or Caucus usually has flexible or open membership, including both members of the PC/PB and other consumers and PWH from the community and their caregivers. The focus is often on unaligned consumers, since the RWHAP legislation requires that at least 33% of voting members of a PC be individuals receiving RWHAP Part A services who are not affiliated with a Part A subrecipient as board members, employees, or paid consultants.¹ A Consumer or PWH Committee or Caucus typically provides information and training to members and the community, engages PWH including community residents in the work of the PC/PB, and creates a pool of potential PC/PB consumer members. As with other standing committees or PC/PB caucuses, the PC/PB may reimburse Consumer Committee or Caucus members' expenses for attending meetings, based on established policies.²

Why "Consumer" rather than "People with HIV"?

PC/PBs have many names for these committees. Most avoid using "people with HIV" in the committee's name because of stigma – and many use terms like "community" instead of either "PWH" or "consumer." For example, a look at PC/PB Bylaws for 48 of the 52 PC/PBs shows that 35 – nearly three-fourths – have committees or caucuses of RWHAP consumers and other PWH.³ Their names are extremely varied:

- 12 have "consumer" in their names – e.g., Consumer, Consumer Advocacy, Consumer Access, Consumer Involvement, Consumer Liaison.
- 13 have "community" in their name – e.g., Affected Communities, Community Access, Community Empowerment, Community Engagement, Community Involvement, Community Voices.
- 3 are called PLWH Committees.
- 7 have other names unique to them – e.g., Community Meetings, Empowerment, Our Voices, Client, + Plus, People Who Care, People's, Positive Voices.
- Town hall meetings can also be used to hear from service providers instead of or in addition to people with HIV.

Who are the members of Consumer Committees and Caucuses?

Most of these committees and caucuses have members that include both unaligned RWHAP Part A consumers and other people with HIV, regardless of where they are receiving care, as well as their caregivers. Some committees have clearly defined membership eligibility – e.g., only unaligned consumers, or in a few cases, only PC/PB members who are consumers or other PWH – but many are open to anyone with HIV, and some are open to anyone from the community who wishes to attend. However, only consumers utilizing Ryan Whites services count toward the legislative expectation that 33% of PC/PB members are consumers.



Consumers utilizing RWHAP services must represent 33% of a PC/PB's members

What is the difference between a Consumer Committee and a Consumer Caucus?

Sometimes the difference between a Consumer Committee and a Consumer/PWH Caucus is only the name. For example, five PCs have groups called caucuses. Three of these are listed in the Bylaws of their PC as standing committees, one is in the Bylaws as a named caucus, and one is not named in the Bylaws, but the Bylaws do provide specifically for the formation of caucuses of PWH or specific subpopulations. A few PC/PBs that are official boards or commissions sometimes prefer to call the group a caucus because using this term makes it easier for the group to have different membership requirements and procedures from other committees.

In cases where a caucus is not a standing committee, there are often other differences:

- **A Consumer Committee** is typically a standing committee of a RWHAP PC/PB, with its roles and membership described in the Bylaws. It typically ensures consumer input into the work of the PC/PB, both to the other committees and to the PC/PB as a whole. It also serves as the PC/PB's liaison to the community. As a standing committee, it can be the primary committee assignment for consumer members. A Consumer Committee generally has more flexible membership requirements and operational processes than other standing committees. Membership is often open to any person with HIV, though sometimes there are limitations on number or types of members, and sometimes voting rights require a certain level of attendance.
- **A Consumer Caucus** that is either included in the Bylaws as a caucus or not named in the Bylaws usually serves a similar function to a Consumer Committee: providing PWH input to the work of the PC/PB and enabling the PC/PB to serve as a link with the PWH community. However, it does not serve as a committee assignment for members of the PC/PB, and it may or may not be regularly asked for input by various committees as they do their work. A caucus may exist for a short period or be an ongoing body. The current caucuses all appear to have been established by the PC/PB, but some communities also have PWH caucuses that developed independently to serve as advocates for PWH and at some point established a formal relationship with the PC/PB.

What benefits does a Consumer Committee or Caucus bring to a PC/PB?

A Consumer Committee or Caucus, with its ability to involve PWH who are both PC/PB members and non-members, has many benefits, for example:

- **Ensuring that the PC/PB and its committees receive regular input from consumers**
 - Assisting the committee responsible for needs assessment to develop survey questions and appropriate response categories
 - Helping with other PWH-focused needs assessment activities
 - Helping to review and update Service Standards, and ensure that they are both appropriate and written in language useful for consumers
 - Offering consumer input at data presentations and discussions
 - Providing a consumer perspective at roundtables and other discussions about services
- **Serving as a liaison between the PC/PB and the PWH community**
 - Making community presentations on behalf of the PC/PB
 - Encouraging consumers and other PWH to attend PC/PB events
 - Taking the lead on planning and managing town halls and other community meetings
- **Engaging consumers and recruiting consumer members for the PC/PB**
 - Helping to recruit unaligned consumers and other potential PC/PB members from the community, often with emphasis on disproportionately affected and underserved communities
 - Providing a place for consumers and other PWH to learn about available services and other topics of interest to them in a safe and comfortable setting
 - Offering unaligned consumers and other PWH an opportunity to become involved with the PC/PB and to learn about and contribute to its work, and perhaps decide to become members
 - Providing ongoing leadership training for consumers
- **Supporting retention of consumer members of the PC/PB, to maintain consumer membership at 33% or more**
 - Providing calendar-based training important to consumer members, on topics related to PC/PB responsibilities, such as Needs Assessment and Priority Setting and Resource Allocation
 - Offering sessions on how to review and use data, with a focus on data-based decision making
 - Reviewing key materials related to upcoming PC/PB agenda topics prior to meetings, so the consumer members feel fully prepared for active participation
 - Providing leadership training on such topics as planning and chairing meetings, developing committee work plans, and building high-performing teams
 - Providing leadership opportunities for consumer members by having an elected Chair and Vice Chair, with the Chair serving as a member of the Executive Committee and the Vice Chair gaining experience in committee leadership
 - Offering consumer members the opportunity to represent the PC/PB in the community, making presentations and informing the community about the work of the PC/PB
 - Enabling consumer members to serve as mentors for other committee/caucus members

What do Bylaws typically say about a Consumer Committee or Caucus?

Here are several slightly edited samples of Bylaws provisions from Part A PC/PBs.

CONSUMER COMMITTEE THAT IS A STANDING COMMITTEE AND LIMITS MEMBERSHIP TO UNALIGNED CONSUMERS:

IV. Consumers Committee

Section 1. Duties. The Consumers Committee is charged with the following duties:

- a. Oversee efforts to ensure meaningful and substantial involvement of people living with HIV/AIDS in all Planning Council activities.
- b. Collaborate with the Rules and Membership Committee in recruitment measures, such as outreach efforts, to secure appropriate consumer representation on the Planning Council.
- c. Collaborate with the Rules and Membership Committee in retention measures, including orientation, training, and mentoring, to help consumer members stay engaged and participate fully.
- d. Work with staff to see that issues of financial support for consumer involvement are addressed appropriately and follow local and federal guidelines.

Section 2. Composition. Membership is limited to no more than 30 in number. In composition, it must meet the following conditions:

- a. Committee membership includes Planning Council members who are unaligned consumers.
- b. The remainder are unaligned consumers who are not voting members of the Planning Council.



CONSUMER COMMITTEE THAT IS A STANDING COMMITTEE AND HAS OPEN MEMBERSHIP:

These Bylaws provide information on roles, responsibilities, membership, leadership, and voting.

Section 5.1 Standing Committees

(B) CONSUMER ADVOCACY COMMITTEE



(i) Mission: The mission of the Consumer Advocacy Committee is to recruit, advocate for, and empower people living with HIV/AIDS in the TGA for participation in Planning Council activities. This is done in conjunction with the Planning Council Support Staff by:

1. Creating a safe place for open discussion and education about the problems and possibilities facing the HIV/AIDS community;
2. Developing and providing leadership and training for the infected and affected community; and
3. Educating the community at large about the purpose of the Planning Council and its relationship with the continuum of HIV Care in the TGA.

The Consumer Advocacy Committee supports PLWHA involvement with the Planning Council by providing outreach to and serving as liaison with consumers. The Committee helps ensure ongoing consumer input to Planning Council activities, with special emphasis on needs assessment and the identification of individuals who know their HIV status but are not receiving regular primary medical care and/or case management. Providing the Planning Council with advice about issues affecting consumers is a major responsibility of this Committee.

(ii) Duties: The duties of the Consumer Advocacy Committee include but are not limited to:

1. Conducting PLWHA outreach and recruitment in collaboration with the Membership and Training Committee;
2. Ensuring PLWHA member and potential member orientation, training, and leadership development in collaboration with the Membership and Training Committee;
3. Providing input to needs assessment planning and reviewing needs assessment findings in collaboration with the Needs Assessment and Comprehensive Planning Committee;
4. Collaborating with Planning Council Support Staff to arrange and advertise consumer forums;
5. Providing input from the consumer perspective on the TGA's Standards of Care in collaboration with the Care Strategies Committee;
6. Providing input for Planning Council Directives to the Grantee on how to best meet service priorities in collaboration with the Priority Setting and Resource Allocation Committee and the Care Strategies Committee; and
7. Ensuring active PLWHA representation on all standing, special, and ad-hoc committees.

In addition, as all other Standing Committees could benefit from focused consumer input, the Consumer Advocacy Committee collaborates with all other Standing Committees to provide input from PLWHA.

(iii) Composition: The membership of the Consumer Advocacy Committee is open to anyone infected/affected by HIV disease, but must include at least one (1) Planning Council member who is a consumer.

(iv) Co-Chairs: The Consumer Advocacy Committee has two elected Co-Chairs, one of whom must be a Planning Council member. At least one Co-Chair must also be a PLWHA. Both Co-Chairs are expected to attend monthly Executive Committee meetings. Nominees for Co-Chair must have attended at least four Consumer Advocacy Committee meetings within the past 12 months to be eligible for election.

(v) Voting: All who attend may vote. Meetings are open to PLWHA and non-PLWHA (including the general public).

CONSUMER CAUCUS THAT IS A STANDING COMMITTEE:

ARTICLE VI - COMMITTEES

The Bylaws and the Council determine the work of committees. Committees develop recommendations which they present to the Executive Committee and full Council. The Council reviews and thoroughly discusses all committee recommendations. The full Council then either approves the recommendations or rejects them. If the recommendations are rejected, they are returned to the committee for modification, based on Planning Council feedback. The exception is for technical or copy-editing corrections. Each committee shall develop an annual work plan which will be reviewed, adjusted, and approved by the Executive Committee.

In rare circumstances, the normal flow of decision-making may be changed by both co-chairs in urgent situations.

Each committee shall have two co-chairs, with the Co-Chairs of the Council serving as the Executive Committee chairs. While having both chairs be Council members is preferable, the Standards of Care committee and +Caucus committee may each have one non-Council committee member serve in this role.

Standing Committees:

E. +Caucus: A committee comprised of HIV+ people including aligned and unaligned people, both Council members and non-Council members, will be responsible for:

- a. Increasing knowledge of issues brought before the Council;
- b. Training people living with HIV on leadership;
- c. Mentorship and education of people living with HIV in the TGA;
- d. Outreaching to other people living with HIV in the community.



CONSUMER CAUCUS THAT IS NOT A STANDING COMMITTEE:

ARTICLE VII. CAUCUSES

SECTION 1. Authority: The Chair may authorize the creation and define the power and duties of any Council Caucus which may be deemed appropriate to allow for the full and adequate representation of and participation by, certain communities in the EMA which have been particularly impacted by the HIV epidemic.

SECTION 2. Membership: Membership in any and all Caucuses shall not be limited to Members of the Planning Council, but shall be limited to the specific population for which the Caucus was established.

SECTION 3. Consumer Caucus. At a minimum, the Council shall have a Consumer Caucus made up of HIV-positive individuals who are consumers of Ryan White Part A-funded services. Consumers are defined as persons living with HIV disease who are recipients of Ryan White Part A-funded services.

SECTION 4. Meetings. The Caucuses shall meet when issues of interest have been brought to their attention and/or at regularly scheduled times.



What other materials are available to help a PC/PB develop or strengthen a Consumer or PWH Committee or Caucus?

Hila Berl, EGM Consulting, LLC, Building a Strong Consumer Committee – Tips for Non-Consumers, May 2020. Available at <https://egmc-dc.com/planning-council-support-resource/planning-council-support-materials/>; click on Consumer and Consumer Engagement. Provides principles and procedures that PC/PBs can use to build strong and engaged consumer committees. Builds on work done with the St. Louis Consumer Advocacy Committee.

Planning CHATT, Elevating Consumer Voices (webinar), January 2020. Available at <https://targethiv.org/planning-chatt/webinars>. This webinar featured presenters from the Atlanta and San Francisco EMAs sharing their strategies for engaging and elevating consumers' voices. Presenters discussed training approaches to build consumers' capacity to participate in and lead PC/PB activities.

REFERENCES

- 1 See Section 2602(b)(5)(C)(1).
- 2 The PC/PB should have policies and procedures that govern reimbursement of meeting-related expenses – primarily transportation but sometimes child care or other costs – for PC/PB members and for committee and caucus members, and those policies should be consistent with guidance from the HIV/AIDS Bureau.
- 3 All 35 are PCs; the 3 PBs do not appear to have such committees or caucuses.

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