Community Voice:

Lived Experience as Data



2026 Data Summit
October 30, 2026

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COMMISSION ON HIV

The Foundation for Consumer Voice

Consumer participation is a core component of the Ryan White HIV/AIDS Program. Health Resources & Services Administration legislation mandates that all planning councils:

- Must include at least 33% unaffiliated consumers receiving Part A services
- Priority Setting and Resource Allocation (PSRA) must consider community priorities
- Should use various methods to obtain consumer input (e.g., public meetings, surveys, listening sessions, etc.)
- Should reflect the demographics of the local HIV population

Value of Consumer Participation

Consumer participation has many benefits.

- Provides needed contact between the PC and the community it serves
- Helps ensure that services reflect client needs
- Provides a "user" perspective on service models, quality, and effectiveness
- Helps the PC & recipient understand the service needs of various populations

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Consumer Voice as Data

Community voice is qualitative data that adds context to the numbers. The strongest planning decisions happen when we integrate lived experience with quantitative data—valuing both equally.

Lived Experience

Direct accounts can reveal barriers and experiences that traditional quantitative measures may miss.

Local Knowledge

Community members help explain what is happening in real life and why.

Context + Numbers

When community voice is considered alongside quantitative data, planning decisions are grounded in local realities.

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Turning Community Voice into Data

Community voice becomes data when we intentionally collect, document, look for patterns, and use what we hear in planning.

LISTEN
Stories, needs, experiences

→

DOCUMENT
Capture what people say

→

IDENTIFY
Look for themes and patterns

→

USE
Bring findings into planning

The value is not one individual story alone . . . it is what we learn when stories are collected thoughtfully and considered alongside other data.

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Why Community Voice Matters

1

INCLUSIVITY

Brings perspectives into planning that may be underrepresented in traditional data.

2

BETTER PROGRAMS

Helps services respond to priorities, barriers, and solutions identified by consumers.

3

TRUST + ACCOUNTABILITY

Builds relationships, mutual respect, and shared responsibility.

4

EXPLAINS THE WHY

Adds context to quantitative data and helps us understand what may be driving the numbers.

Decisions are made with, not for, the community.

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Consumer Voice in the Data Cycle

Community voice should be present from planning through reporting.

Needs Assessments	Use input to identify needs, barriers, and gaps
Priority Setting & Resource Allocation	Use input to inform priority setting and resource allocation
Data Collection & Reporting	Use input to improve how data are collected, understood, and communicated

The result: a planning process that is more responsive to the people the system serves.

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Community Input Informs Planning

Planning decisions are strongest when community input is considered alongside other data.



PRIORITIES
What services are most important?

ALLOCATION
Where should resources go?

DIRECTIVES
What can be done to address barriers or gaps?

SERVICE STANDARDS
What should quality care look like?

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What Community Voice Reveals

The findings help explain the “why” behind patterns in quantitative data.

Limited engagement after initial diagnosis…	Community members described long waits, limited hours, distance, transportation, cost, paperwork, & insurance barriers.
Drop in retention…	Participants emphasized trust, respect, continuity, and feeling safe enough to stay connected to care.
Demand for mental health support…	Trauma, grief, depression, loneliness, social isolation, & stigma were repeatedly connected to HIV health and engagement.
Low service utilization…	People described difficulty finding services, understanding eligibility, navigating referrals, and connecting across systems.

Community voice helps us understand what the numbers may not explain on their own.

Practical Ways to Collect Consumer Input

There is no single right way to collect community input. Different methods helps broaden participation.

- Public comment at Commission sponsored meetings and events
- Surveys, polls, and/or suggestion cards
- Listening sessions & focus groups (with specific populations)
- Story circle or participatory video (clients record their own experiences)

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Community Voice Driving Change

The following are real-life examples of consumer input in Ryan White Planning within LA County over the past several years.

Women asked for PrEP messaging that reflects their experiences.	Black/African American consumers recommended cultural humility training for providers.	Consumers raised concerns about the DHSP grievance line and customer experience.
Outcome: A social media campaign was created that included women in biomedical prevention messaging.	**Outcome:** A cultural humility and implicit bias training was implemented reaching over 300 providers.	**Outcome:** Their feedback led to the development of the Customer Support Program to support service access issues.

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Community Voice in Action

The 2024–2026 Community Engagement Findings Report identified recurring themes across various listening sessions and community events.

SAFETY
People need to feel safe. Stigma & discrimination affect access.

NAVIGATION
Navigation lands on clients. System should take the lead.

TRUST
When people feel heard & safe, they stay connected.

MENTAL HEALTH
Emotional well-being impacts engagement in HIV care.

SERVICES
Finding services is hard. Strong need for clear, current info.

WHOLE-PERSON CARE
Housing, dental care & other needs matter.

COMMUNITY
Peer support & community partners help engagement.

ACCESS
System barriers (hours, waits, paperwork, etc.) limit use.

Findings are one part of the broader needs assessment and should be considered alongside epidemiologic, service utilization, and other data.

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Activity: Build Better Questions

Draft 5 plain-language questions you could use in a listening session.

Things to consider:

- ❑ What specific gap or barrier are you trying to identify?
- ❑ Does the question feel safe and non-judgmental?
- ❑ Is it easy to answer in a sentence or two?
- ❑ Use stigma-free, person-first language.
- ❑ Avoid medical jargon.
- ❑ Give people the option not to answer.