Florida Comprehensive Planning Network 2025 Needs Assessment Toolkit

A Letter from the Needs Assessment Committee Co-Chairs:

Dear Members of the HIV Community across Florida,

The Florida Comprehensive Planning Network (FCPN) is an advisory council to the Florida Department of Health, HIV/AIDS Section, and serves as a statewide planning body. Its needs assessment process is a 3-year cycle, designed to assist providers with identifying client needs *based on meaningful input from people with HIV (PWH)*.

According to current policy, the planning body shall participate in the Statewide Coordinated Statement of Need (SCSN) every three years. With the local area planning body taking the lead role for survey distribution and collection, the statewide needs assessment is a partnership activity of state and local planning bodies, recipient, lead agency, and community.

The FCPN Needs Assessment Committee has developed this Toolkit as to provide guidance on the needs assessment process while sharing best practices and providing available resources. We have worked hard to develop a new statewide client survey for 2025, which is attached to this Toolkit.

To People with HIV:

We want to hear from you! In today’s rapidly changing landscape of public health, it is more important than ever that our work reflects and supports your needs. This confidential and anonymous survey will help us improve our programs, outreach, and overall impact. Your valuable input will shape our next steps and how we serve the HIV community. We will share our findings with you and our communities, continuously partnering every step of the way.

To Providers:

You have valuable first-hand insights on the needs of the HIV communities you serve. Your active participation in the needs assessment process within your area and facilitating various methods of data collection from the clients you serve *is critical*.

In an effort to reduce client survey fatigue, we hope more agencies and consumer advisory boards will integrate this questionnaire along with any client surveys already in effect while collaborating and strategically implementing needs assessment.

Given current developments impacting HIV health care across the nation, many of our efforts at the state level may not provide a complete picture of what PWH needs are in Florida. We encourage local planning bodies, service organizations, community-based organizations, care teams, case managers, and medical providers to *increase and maximize needs assessment efforts at the local level* in order to ascertain the most accurate assessment of needs for PWH.

This toolkit is designed to help implement effective information collection methods, including surveys, focus groups, key informant interviews, and town halls. We hope you find this information useful. *Your opinions matter, every voice is important, and we thank you for your time and feedback.*

Travis Neff and Brad Barnes
Co-Chairs, FCPN Needs Assessment Committee

This toolkit provides useful information aimed at increasing meaningful, active community engagement and involvement in needs assessment processes and assisting individuals with little or no prior experience in community planning or community-based research.

Learning Objectives

Readers of this toolkit and participants in Toolkit presentations will gain increased knowledge about:

- Section 1: Definitions of Common Terms Used in the HIV Continuum of Care
- Section 2: The Importance of a Needs Assessment
- Section 3: Needs Assessment Policy and Procedures
- Section 4: Key Components
- Section 5: Means and Best Practices of Collecting Data
- Section 6: Methodology for Estimating Community Unmet Need

SECTION 1

HIV Care Continuum

The HIV care continuum is a public health model that maps the steps that individuals should go through from HIV diagnosis to viral suppression. This can help health care providers make sure persons with HIV (PWH) are getting the care they need. In addition, each step in the HIV care continuum is tracked to provide a population-level view of progress in addressing the HIV epidemic. Activities done to reach the first Continuum step are commonly called ‘linking to care.’ The ultimate goal is ‘Suppressed Viral Load,’ which is key to lowering the overall number of PWH who require care and resources.

In Care: PWH with at least one documented viral load (VL) or CD4 lab, medical visit, or prescription in the measurement year.

Retained in Care: PWH with multiple documented medical visits, prescriptions, or VL/CD4 tests at least three months apart during the measurement period.

Suppressed Viral Load: PWH with a suppressed VL (<200 copies/mL) on the last test in the measurement year.

SECTION 2

What Is a Needs Assessment?

A needs assessment is a systematic evaluation of the way things are, why they are that way, and the way they should be. Needs assessments are essential for local planning bodies to decide service priorities and resource allocation. They are used by the Department and local area lead agencies to create an action plan that helps its stakeholders receive desired services or meet specific needs.

A needs assessment can cover the entire scope of audience and stakeholder needs, including factors such as environment, economic conditions, regional needs, access to resources, and government policies and practices.

A needs assessment is a partnership activity of local and state planning bodies, service providers and administrators, lead agency, and the community. All the information ascertained within the context of a needs assessment should be recorded in a formal report, which should be written in clear, direct language formatted in such a way that information can be easily located and extracted in the future when planning strategies or allocation proposals.

SECTION 3

Needs Assessment Procedure

The Planning Body must participate in the SCSN based on a 3-year cycle schedule from the Florida Department of Health, HIV/AIDS Section.

In the first year of each cycle, data is collected via a statewide survey, analyzed, and made available to the Planning Body and the community. In the second and third years of the SCSN cycle, lead agencies in all areas are encouraged to collect additional data using other collection methods, such as an assessment of all unmet needs and/or identified service gaps.

Population needs can be identified and provided, along with any other data from the needs assessment process to the Planning Body during its annual priority setting and resource allocation processes. All the raw data must be submitted to the Florida Department of Health, HIV/AIDS Section.

SECTION 4

Components of Needs Assessment

In an effort to draft a thorough assessment of PWH unmet needs, barriers, and/or service gaps, areas should look to collect as much (current and relevant) data as possible as frequently as possible. Components of data collection may include, but are not limited, to the following:

1. Area epidemiological profile
2. Provider and resource inventory
3. Profile of provider capability and capacity
4. Assessment of PWH unmet needs (relevant to medical care), barriers to care, as well as gaps in services
5. Assessment of the characteristics of PWH with unmet need and individuals with HIV who do not yet know their status

(1) Area Epidemiological Profile

A state of Florida epidemiological profile is published annually by the Florida Department of Health. The epidemiological profile offers a clear picture of the HIV epidemic among groups at risk of acquiring HIV, which helps planning bodies set goals and identify objectives and strategies that prevent the spread of HIV, plan activities to improve services for people with HIV, and inform the community on policies and programmatic developments as they pertain to HIV prevention and treatment.

The most recent available statewide epidemiological profile can be found at Florida CHARTS.

(2) Provider Inventory

A provider inventory reflects up-to-date information on organizations throughout an area that are providing prevention, care, and support services for PWH or people at risk for acquiring HIV. This inventory should include not only Ryan White Program-funded providers (sub-recipients), but also community providers (i.e., non-Ryan White Program-funded entities). It should list the provider name, contact person, address, telephone number, and any eligibility requirements for accessing patient care services.

(3) Profile of Provider Capacity and Capability

The purpose of conducting a provider capacity and capability assessment is to identify the extent to which HIV-related services, specifically patient care and prevention services, are accessible, available, and appropriate for PWH in a given service area. Profiles of provider capacity and capability assist planning bodies in making informed, data-based decisions about improving the system of care for PWH. This may be accomplished through the development of a separate provider survey.

Information gathered from current providers of HIV-related services may include:

- Types of services provided
- Geographic location(s) of services
- Hours of operation
- Current caseloads per service provided
- Maximum caseloads per service provided
- Current resources, including funding and personnel
- Ability to increase caseloads and resources required

(4) Assessment of PWH Service Needs and Barriers

Ultimately, the goal of the needs assessment process is to collect a wide variety of data based on stakeholder feedback in an effort to:

- Identify and describe HIV prevention and care services that currently exist
- Identify and describe HIV prevention and care services that are needed
- Identify ways to enhance the quality of services for PWH as well as persons at higher risk of acquiring HIV
- Identify barriers that impede access to existing services

SECTION 5

Methods of Data Collection

Common methods for collecting data may include, but are not limited to, the following:

(1) Surveys
(2) Focus Groups
(3) Key Informant Interviews
(4) Town Hall Meetings

(1) SURVEYS

A survey is a type of data-gathering method used to collect, analyze, and interpret the different views of a group or community. FCPN has developed a list of core questions for PWH, which must be incorporated into each local area’s client-level HIV care needs survey questionnaire.

Each local area should target a minimum response benchmark equal to 10% of the total number of PWH (i.e., HIV prevalence) in their area. Results from surveys can help provide lead agencies with a clearer picture as to whether their services are meeting or not meeting their clients' needs and reflect any barriers to services clients may be experiencing in their area.

See Appendix 1 for the paper version of the 2025 Needs Assessment Survey Core Questions. An electronic version of the survey can be found at https://www.theaidsinstitute.org/florida-integrated-hiv-prevention-and-care-plan/2025-hiv-care-needs-survey. Local areas requiring technical assistance with creating an online survey can contact the AIDS Institute.

Best Practices

- Engage peers in survey development, recruiting participants, and any opportunities to offer guidance to participants needing interpretation of the questions and responses.
- Test the survey with some people located within targeted populations prior to distribution to ensure survey participants understand the survey.
- Review the survey questions with any front desk or medical staff, medical case managers, or peers who may be facilitating the distribution and collection of surveys.
- Target survey participants in rural and urban communities to best reflect the diverse demographics and geographic makeup of the HIV population within an area, group, or community.
- Develop relationships with private providers and any case managers making referrals within the private sector.
- Develop relationships with agencies providing intervention services to assist in survey distribution and data collection.
- Leverage relationships with local providers and ally agencies that have staffing, tools, and resources to assist in survey distribution and data collection.
- Provide various methods for PWH to complete surveys digitally, including computers or tablets that are available in HIV service provider offices.
- Offer surveys in multiple formats (online, paper) and multiple languages.
- Have dedicated staff available who are bilingual or multilingual who can assist with completing surveys if required.

- Create a QR code that directs a participant to the stakeholder to an electronic survey. Share survey results with all participating stakeholders to build trust and reflect transparency while supporting the needs assessment process.

Advantages

- Surveys can determine the frequency of similar perceptions, attitudes, and experiences of a group or community.
- Data results from different areas or populations are easier to compare than with other data collection methods.
- Through surveys, people with lived experience with HIV feel heard, and there is documentation of what they say they need or are experiencing in regard to barriers to their care or service gaps.
- Data gathered from surveys can be used to make area-specific decisions about the service delivery system.
- Surveys provide opportunities to provide anonymous feedback on HIV-related care and provided services

Disadvantages

- Questionnaires are challenging for people who are visually or hearing impaired.
- Survey distribution and data collection methods are limited in some areas.
- Many community members are experiencing “survey fatigue.”
- Unlike focus groups or key informant interviews, which allow for follow-up questions to ensure participants are comprehending the topic or question, survey results may be misleading if respondents do not understand the questions.
- Little to no incentives (compensation, gift card, etc.) are available to survey respondents due to the volume of respondents and responses needed and the limited resources in each area.

(2) FOCUS GROUPS

A focus group is a small-group discussion used to gather in-depth information about a community’s thoughts and opinions on a designated topic. The group's composition and overall discussion should be carefully planned to create a non-threatening environment. It is essential to prioritize confidentiality throughout the process to protect the privacy of participants, especially in a focus group involving PWH. Participants should be encouraged to talk openly, give honest opinions, and respond to other members in the group. Directed by a trained leader, focus groups offer depth, nuance, and variety to the discussion that would not be typically available through surveys and questionnaires.

A focus group usually consists of 5–12 individuals who all possess certain characteristics relevant to the group’s topic. A moderator (or leader) facilitates the discussion and creates an environment that promotes the communication of different perceptions and points of view. Focus groups usually last for about 1–2 hours, during which group members are usually asked 5–6 general questions. The discussion is then carefully analyzed to provide insights as to how a product, service, or opportunity might be perceived by the group.

Best Practices

- Ensure to record the entire session or assign someone to write down the key points.
- The leader's job is to elicit opinion and not judge it; all opinions should be respected.
- Consider asking questions again in a different way.
- Throughout the session, summarize what you think you have heard and ask if the group agrees.
- Be aware of how much time you are spending on each individual topic or group of topics.
- As much as possible, devise and use a coding system to "score" the data and count the number of times a particular theme is expressed.
- Before the focus group ends, ask if anyone has any other comments to make. This can be an effective way of gathering new opinions that have not been voiced or planned for.
- Don't forget to thank everyone in the group for coming and for sharing their experiences and suggestions!
- Share survey results with all participating stakeholders to build trust and reflect transparency while supporting the needs assessment process.

Advantages

- Focus groups are cost-effective as compared to individual interviews.
- Compared to a quantitative survey, focus groups can gather more information about perceptions, attitudes, and experiences.

- Participants can listen to and respond to each other's answers during the discussion.
- Because they are structured, directed, and expressive, focus groups can yield a lot of information in a relatively short time.

Disadvantages

- Focus groups present an opportunity for groupthink to occur. Groupthink is a phenomenon which puts the need for consensus and harmony before the value of critical thinking and healthy conflict to make a decision, which can lead to faulty decisions made by a group due to peer pressure.
- A group culture may intimidate or fail to energize participants, resulting in weaker data collection.
- If a group is too large, it may be difficult to manage and control.
- Shy participants or introverts may feel overpowered and intimidated by more assertive or dominant participants, which could limit their involvement, introduce bias, and impact the overall outcome.
- Analysis of data may be time-consuming and challenging.

(3) KEY INFORMANT INTERVIEWS

Key informant interviews resemble a conversation among acquaintances, allowing for a free flow of ideas and information. These involve qualitative, in-depth interviews of 5–15 selected key individuals who have first-hand knowledge of the information that is needed.

A "key informant" is someone who can provide detailed information and a unique perspective of a particular issue based on their expert knowledge. These in-depth interviews are used to gather qualitative information that can provide an enhanced understanding of the quantitative data gathered.

Key Informant Interviews are designed specifically to use in the following situations:

- When qualitative, descriptive information is sufficient for decision-making.
- When there is a need to understand motivation, behavior, and perspectives of clients or providers.
- When a main purpose of the process is to generate recommendations.
- When data collected through other methods need to be interpreted.

Best Practices

- Key informants should be selected for their specialized knowledge and unique perspectives on a topic. It is important to select a group of informants who can provide various perspectives.
- Create a simple guide or handout that lists the specific topics and issues to be covered under each study question. The purpose is to explore a few issues in depth; guides are usually limited to 12 items.
- Questions are generally limited to 5 or fewer and should relate to *specific* concerns.
- Start with factual questions, then follow with questions needing opinions.
- Use probing techniques to encourage informants to detail the basis for their conclusions and recommendations.
- Share aggregated results and conclusions from the key informant interviews with all participating stakeholders to build trust and reflect transparency while supporting the needs assessment process.

Advantages

- The information provided is coming directly from knowledgeable people.
- There is the flexibility to explore new ideas and issues not anticipated during interview planning.
- They are inexpensive and simple to conduct.

Disadvantages

- They are an inappropriate method of collecting data if quantitative data is needed.
- They may be more susceptible to interviewer biases.
- Due to the small size of the group, the validity of findings may be difficult to prove.
- Since key informants are typically selected based on their expertise or position, their perspectives may not fully represent the broader population or diverse viewpoints, potentially limiting the richness and generalizability of the findings.

(4) TOWN HALL MEETINGS

Town hall meetings encourage public participation, which promotes sustainable decisions by recognizing and communicating the needs and interests of all participants, including decision makers. Town hall meetings generally touch on specific topics of discussion needed to gauge where a community stands, allowing community members to voice possible solutions to a problem. Such a gathering of community members is an opportunity to receive feedback from a potentially large, diverse population. The town hall format allows for back-and-forth exchanges to ensure opinions and insights are understood. Town hall meetings may provide access to individuals who may face challenges with filling out surveys or other written feedback tools. Typically, a moderator would brief the community, with a panel of three or four people leading the discussion and asking the questions.

Best Practices

- Form partnerships with a variety of organizations and other likely allies and work with them to plan your town hall meeting.
- Understand your community's unique characteristics, issues, challenges, and opportunities for positive change.
- Share ground rules with everyone in the beginning.
- More detailed information is obtained when participants hear open-ended questions.
- Set a time limit for each question; plan for the panel discussion to last 35–50 minutes.
- Allow for a question-and-answer period to last about 30 minutes.
- Consider splitting large groups into multiple groups for parts of the meeting to allow for more in-depth discussions.
- If possible, offer snacks/refreshments or raffle prizes to participants; such incentives attract more community participation.
- Ensure participants understand the significance and value of their contributions.

Advantages

- Town hall meetings offer opportunities to obtain input from a large group of people.
- There may be opportunities to ask participants follow-up questions about the feedback that they provide.
- As with focus groups, participants can listen to and respond to each other's answers during the discussion.

- Town hall meetings can be a relatively quick way to gather a lot of information.

Disadvantages

- There are often time and space limitations to accommodate such large groups, and some areas may have a lack of resources in certain jurisdictions to host and advertise town hall meetings.
- Town hall meetings lack anonymity. Participation may be low if there are not enough people who feel comfortable discussing their challenges and barriers in front of others they don't know.
- Some more vocal people can dominate the meeting, preventing a wide spectrum of perspectives to be expressed by others.
- Quiet people may not feel comfortable sharing their experience or needs in a large group setting. This can be somewhat mitigated by breaking the group into smaller groups for part of the meeting, allowing people to write down ideas or enter the ideas with smart phones and apps that are designed to collect information from groups.

SECTION 6

Methodology for Estimating Unmet Need

Assessment of the Characteristics of PWH with Unmet Need

In 2002, the Health Resources and Services Administration (HRSA) HIV/AIDS Bureau defined unmet need as: the need for HIV-related health services by individuals with HIV who are aware of their HIV status but are not receiving regular primary health care. To assist Ryan White HIV/AIDS Program (RWHAP) Part A and B recipients, HRSA created an Unmet Need Methodology Manual.

The Florida Department of Health (FDOH) focuses on using epidemiological profile information to evaluate populations out of care. Information can be found on the Care Continuum section on Florida CHARTS for all local areas. This information allows areas to focus efforts on needed prevention and care.

ll data related to unmet need are included in the epidemiological data received annually from the FDOH.

Assessment of the Characteristics of PWH Who Do Not Yet Know Their Status

Areas are encouraged to do a thorough calculation of the number and characteristics of PWH with unmet need, which should include an estimate of the number of PWH who do not yet know their HIV status.

Identifying PWH who are unaware of their status is calculated through a CD4 depletion model provided by the CDC that combines CD4 lab data, HIV diagnosis and prevalence data, and data on deaths among adults (aged 13 years and older) to create annual estimates. These estimates are available on a by-county basis from the FDOH HIV Surveillance Data Analysis Unit upon request. These estimates are calculated on a two-year lag. Some PWH estimates may lack statistical significance in counties with particularly low HIV prevalence. This limitation should be included in any discussions related to the calculation of unmet need.