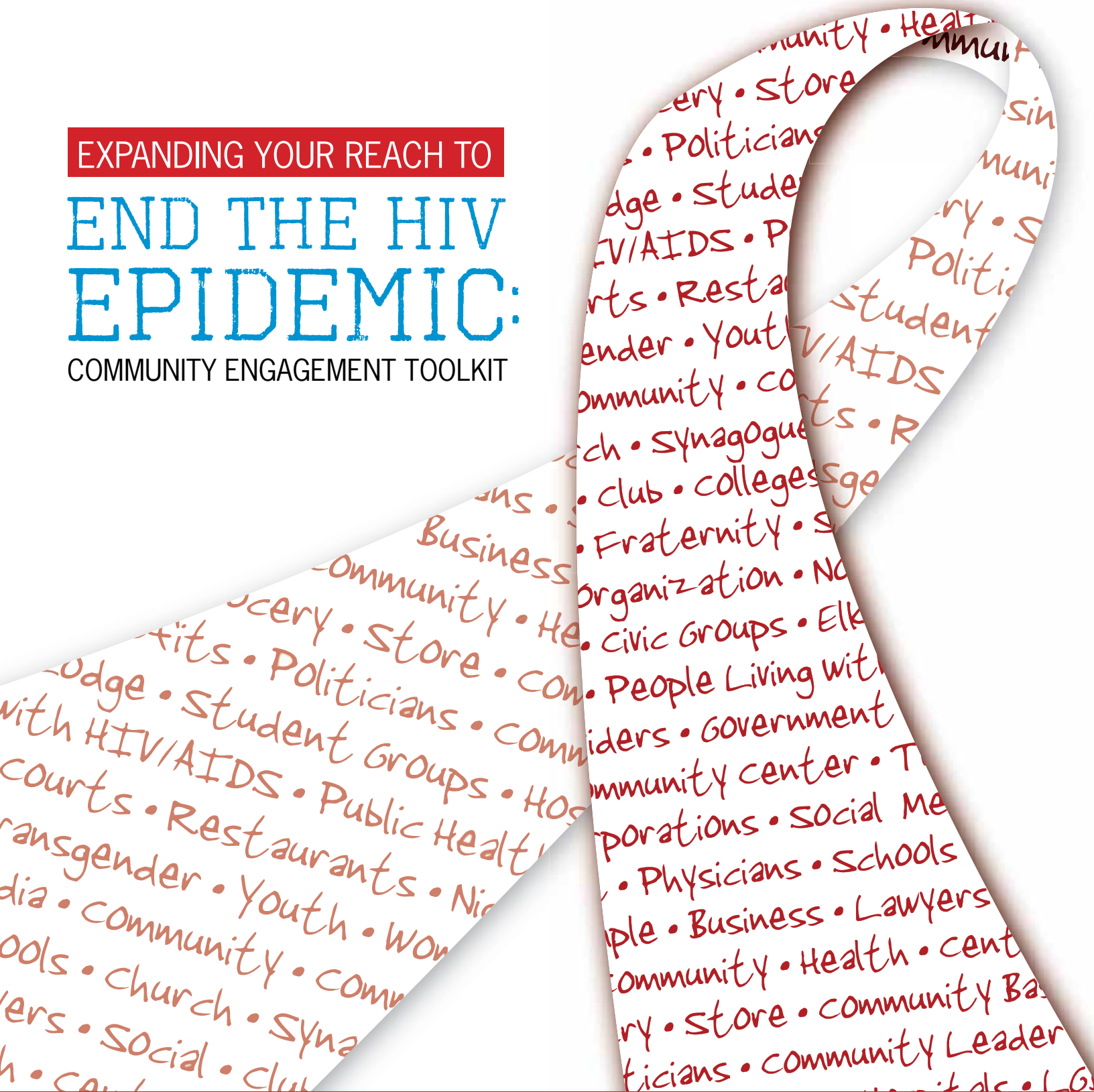


EXPANDING YOUR REACH TO

END THE HIV EPIDEMIC:

COMMUNITY ENGAGEMENT TOOLKIT



About NMAC

The National Minority AIDS Council (NMAC) was founded in 1987 by a small group of minority leaders alarmed by the fast-growing incidence of AIDS in communities of color. Today, NMAC is an experienced coalition of more than 4,000 community-based organizations, health departments, and community planning groups across the U.S. and its territories. NMAC's formal mission is "to develop leadership in communities of color to END the HIV/AIDS epidemic." To achieve this goal, NMAC provides education, training, technical assistance, and other capacity building services to thousands of our constituents.

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1. Introduction

Purpose of the Toolkit

This toolkit is designed to provide practical information and tools to assist HIV Planning Groups and Health Departments in implementing the Community Engagement process described in the Centers for Disease Control and Prevention (CDC)'s 2012 *HIV Planning Guidance*. The toolkit:

- Describes CDC expectations for community engagement
- Summarizes community engagement theory, concepts, principles, and models, from public health and human service perspectives
- Presents a process for developing and implementing community engagement strategies, appropriate roles and responsibilities
- Presents examples of effective community engagement approaches and strategies
- Includes several practical tools to support the community engagement process
- Lists references and resources, with Internet links

CDC Expectations for Community Engagement

Community engagement has been a priority within the HIV prevention planning process since the CDC issued its first blueprint for community planning in December 1993. As noted in a 2005 orientation guide, the HIV community planning group itself has been the primary focus for community engagement. It works to accomplish and maintain PIR—parity, inclusion, and representation—so that the planning group understands and represents groups most affected by the epidemic and all members participate actively and have voices that are heard throughout the planning process.¹ Planning groups seek a diverse membership that represents the jurisdiction's prevention target populations, including individuals living with HIV and at high risk for infection and many other stakeholders, among them community and social services agencies, health care providers, public agencies with related roles and target groups, educators, researchers, and representatives from the private sector.

While diverse and active planning body membership remains a key priority, the 2012 *HIV Planning Guidance* provides a new focus on community engagement *beyond* planning body membership. Developing strategies for such community engagement is a new priority task that asks HIV planning groups (HPGs) to reach beyond the circle of planning group members, health department personnel, and HIV providers to engage a broader mix of stakeholders and deepen links to other planning bodies, agencies, and programs. Many of the activities that contribute to a diverse and active HPG also support broader community engagement, since they identify potential partners, some of whom are unable to serve on the planning group due to its size limitations and/or the required time commitment.

The 2012 *Guidance* specifies three major steps in the planning process

Step 1: Stakeholder Identification

Step 2: Results-oriented Engagement Process

Step 3: Jurisdictional Plan Development, Implementation, and Monitoring

Input from community stakeholders and partners should be obtained prior to development or updating of the jurisdictional plan, so it can influence the content of the plan. Ongoing engagement is needed to support plan implementation as well as program coordination and service integration. Because needs and opportunities change, outreach to identify and develop relationships with stakeholders should be ongoing, guided by data on the changing epidemic and on utilization of prevention and testing services.

The HPG has the primary responsibility for developing the community engagement process. The health department has primary responsibility for implementing the process, but the HPG—as a body, and through individual members—should also be involved. HPG members may be

particularly helpful in reaching out to populations or sectors they represent.

The *Guidance* calls for a new level of accountability, including documentation of activities, monitoring of progress, and assessment of the extent to which community engagement efforts contribute to a more coordinated and accessible system of HIV services, and ultimately to reduction in new HIV infections and HIV-related health disparities.

Importance and Value of Community Engagement

The 2012 *HIV Planning Guidance* emphasizes the importance and value of community engagement as an integral component of HIV planning. The *Guidance's* Background section explains that local planning is the best way to respond to local HIV prevention needs and priorities and that comprehensive participation is critical to the success of the HIV planning process. A successful HIV planning process contributing to the reduction of new infections and HIV-related health disparities requires significant community involvement that goes beyond HPG voting and non-voting members. According to the *Guidance*, “Some stakeholders may not be a part of the official HPG membership, but they are needed to develop and implement the Jurisdictional HIV Prevention Plan, the execution of HIV programs and activities, and the achievement of the goals of NHAS.”²

The U.S. Surgeon General affirmed the importance of community participation in public health efforts in 2011, in the introduction to *Principles of Community Engagement*³:

Americans need to live and work in environments where they can practice healthy behaviors and obtain quality medical care... Creating these healthy environments for people of all ages will require their active involvement in grassroots efforts. Private citizens, community leaders, health professionals, and researchers will need to work together to make the changes that will allow such environments to flourish.

A large body of documented experience and a more limited body of research show the link between community engagement/partnerships and population-based public health outcomes and community-level behavior change, so that “community engagement is increasingly recognized as a vital component of efforts to expand access to quality care, prevent disease, and achieve health equity for all Americans.”⁴

Studies and observations in the U.S.,⁵ the United Kingdom,⁶ and other countries⁷ have documented specific outcomes of community engagement and partnerships in public health and human services, among them the following benefits for individuals and communities. While these examples are borrowed from other areas, they transfer easily to HIV:

- Creating health-enhancing attitude and behavior changes, such as safer sex practices and increased physical activity
- Reducing negative behaviors related to tobacco use, alcohol use, and illicit drug use
- Changing priorities and the public health agenda, including the use of local health funds
- Improving health literacy
- Supporting the empowerment of community residents and increasing their confidence, self-esteem, and self-efficacy (belief in their own ability to succeed)
- Making services more “appropriate, effective, cost-effective, and sustainable”⁸ for targeted populations
- Increasing the use of services in particular geographic communities or by specific populations
- Strengthening research by improving the framing of questions for cultural appropriateness and increasing participation by target populations
- Increasing trust in government agencies

Community engagement in health and human services and community development has evolved and expanded in the U.S. over the past five decades. In the 1960s, it became a primary strategy in anti-poverty efforts.⁹ The importance of community participation in health programs gained international attention and recognition at the International Conference on Primary Health Care held in Alma-Ata, Kazakhstan, in September 1978, when the Alma-Ata Declaration on the urgent need for the implementation of primary health care worldwide included this statement as one of its ten provisions:

IV. The people have a right and duty to participate individually and collectively in the planning and implementation of their health care.¹⁰

In the past two decades, HIV prevention and care programs have required and supported community engagement, with community planning groups committed to Parity, Inclusion, and Representation, and Ryan White Part B programs having a participatory planning process. Part A Planning Councils

are required to ensure that consumers of services make up at least one-third of their voting members.

Today, community engagement is widely accepted as valuable and necessary: “Involving the community and collaborating with its members are cornerstones of efforts to improve public health.”¹¹

Other countries also place strong emphasis on community engagement. Scotland has a Ministry of Communities. The Minister describes the importance of community engagement:

The Scottish Executive is committed to people in Scotland having a greater say in how local services are planned and delivered. Only by genuinely engaging with local people can we develop services which meet local needs and aspirations. In particular the effective engagement of local people is critical to the regeneration of our most disadvantaged communities by local partnerships.

It is only by listening to the experiences and ideas of the people who live in these communities that we can find solutions which will make a lasting difference.¹²

“The Centers for Disease Control and Prevention (CDC) and the Health Resources and Services Administration (HRSA) are pleased to support integrated HIV prevention and care planning groups and activities. Integrated planning, reports, and activities will help further progress in reaching the goals of the National HIV/AIDS Strategy....

Community involvement is an essential component for planning comprehensive, effective HIV prevention and care programs in this country.”

– CDC-HRSA Integrated Planning “Dear Colleague” Letter,
May 22, 2013

Community Engagement for Integrated Prevention and Care Planning

Many states and an increasing number of cities/metropolitan areas have developed integrated HIV prevention and care planning bodies, and others collaborate on some aspects of HIV planning, such as conducting needs assessments and developing joint comprehensive plans. Both The CDC and the Health Resources and Services Administration (HRSA) support joint planning and merged planning bodies.¹³

Integrated prevention and care planning bodies are most effective when both efforts receive equal attention and when community engagement strategies reflect both the CDC’s *Guidance* and Ryan White legislative requirements and expectations. HRSA expectations are described in the *Part A Manual* (which covers metropolitan area grantees that receive direct funding) and the *Part B Manual* (which covers state and territorial grantees).¹⁴

Ryan White legislation and HRSA guidance require community input to planning and decision-making about development and improvement of the continuum of care, setting of service priorities, and allocation of resources. Community planning bodies are required for most Part A metropolitan area grantees and are strongly encouraged for Part B state and territorial grantees. In Part A, these planning groups are decision-making bodies; in Part B, as in HIV prevention, they are advisory. Like CDC, HRSA calls for community input beyond planning body members for specific tasks and products, including needs assessment, development of a Statewide Coordinated Statement of Need (SCSN), priority setting, and resource allocation. (Integrated community engagement efforts for joint HIV prevention and care planning are discussed in more detail in Section 3.)

2. Community Engagement Concepts

Community engagement is a priority for many government-funded programs and services in the U.S. and elsewhere, including health, a wide range of human services, and community development. It has been a priority for CDC for many years. In 1994, CDC identified “Ten Essential Services of Public Health” that describe “the public health activities that should be undertaken in all communities”; two address community engagement. Today, these standards provide the framework for the National Public Health Performance Standards Program.¹⁵

As indicated in *Principles of Community Engagement*, a widely used document developed for CDC in 1997 and updated and expanded with support from the National Institutes of Health (NIH) in 2011, “community engagement is increasingly recognized as a vital component of efforts to expand access to quality care, prevent disease, and achieve health equity for all Americans.”¹⁶ A considerable body of literature provides definitions, concepts, theoretical frameworks, principles, and models that guide community engagement efforts. This section summarizes some of these concepts, with the hope that they will help HPGs and health departments to:

Community Engagement-related “Essential Services of Public Health”

- **Inform, educate, and empower people about health issues.**
- **Mobilize community partnerships and action to identify and solve health problems.**

- Develop a shared understanding of what community engagement is and how it can be used to support and strengthen HIV prevention, care, and treatment.
- Agree on what you want to accomplish through community engagement and how to go about it – your goals, assumptions, strategies, and processes.
- Use community engagement successfully, to create and maintain partnerships and collaboration that will ultimately contribute to reducing HIV transmission, improving treatment outcomes, and eliminating HIV-related health disparities.

Definitions and Descriptions

One important success factor for community engagement is a shared understanding of critical terms and definitions. There is no single “correct” definition for any of these terms, but the HPG and health department should agree on what is meant by terms like *community*, *stakeholder*, and *community engagement*.

Community: The word *community* is widely used and has multiple meanings, some of which focus on a shared geographic location, others on characteristics. The following are definitions of *community* from public health entities in the U.S. and the United Kingdom:

- “A group of people with diverse characteristics who are linked by social ties, share common perspectives, and engage in joint action in geographical locations or settings.”¹⁷
- “A group of people who have common characteristics. Communities can be defined by location, race, ethnicity, age, occupation, a shared interest (such as using the same service) or affinity (such as religion and faith), or other common bonds. A community can also be defined as a group of individuals living within the same geographical location (such as a hostel, a street, a ward, town or region).”¹⁸

Definitions differ on whether community members necessarily have common characteristics, but agree that there are *communities of place or geography* as well as *communities defined by culture or other shared characteristics or interests*.

In HIV planning, you need to define your target communities in order to decide how best to reach and engage them. For example, as discussed in *Principles of Community Engagement*, use of *community* to refer to the people “who are affected by the health issues being addressed” helps in recognizing that this community may have “historically been left out of health improvement efforts even though it is supposed to be the beneficiary of those efforts.” *Community* can also be “used in a more general way, illustrated by referring to stakeholders such as academics,

public health professionals, and policy makers as communities. This use has the advantage of recognizing that every group has its own particular culture and norms and that anyone can take the lead in engagement efforts” —including consumers of services and other community residents who are not trained professionals—and “that all who are involved in engaging a community must be responsive to the needs of that community as defined by the community itself.”¹⁹

Stakeholder: This term was first used to describe the person entrusted with the bets or stakes in a betting game or contest. It is now used more broadly to refer to “a person who has a share or interest” (a stake) “in an enterprise and is involved in or affected by a course of action,”²⁰ including someone who influences the decision.²¹

There can be many categories of stakeholders—among them members of geographic, cultural, and other types of communities, policy makers, government agencies, service providers, community-based organizations, private-sector entities, researchers, and others. Not surprisingly, broad and varied groups of stakeholders often have different value systems, cultural backgrounds, and interests—and differing views regarding what a program or a community engagement effort should look like.

Community engagement or community participation: These terms are often used interchangeably. Some international experts prefer the term *civil society engagement*,²² and community development programs sometimes use the term *public participation*. *Principles of Community Engagement* defines and describes community engagement as:

...the process of working collaboratively with and through groups of people affiliated by geographic proximity, special interest, or similar situations to address issues affecting the well-being of those people.²³ It is a powerful vehicle for bringing about environmental and behavioral changes that will improve the health of the community and its members. It often involves partnerships and coalitions that help mobilize resources and influence systems, change relationships among partners, and serve as catalysts for changing policies, programs, and practices.²⁴

Two other definitions offer related concepts in terms that include but are not limited to health:

- **From the World Health Organization (WHO):** “a process by which people are enabled to become actively and genuinely involved in defining the issues of concern to them, in making decisions about factors that affect their lives, in formulating and implementing policies, in planning, developing and delivering services, and in taking action to achieve change.”²⁵
- **From Health Consumers Queensland (HCQ), within the Queensland, Australia Department of Health and Aging:** “Community engagement refers to the connections between government, communities and citizens in the development and implementation of policies, programs, services and projects. It encompasses a wide variety of government-community interactions ranging from information sharing to community consultation and, in some instances, active participation in government decision-making. It incorporates public participation, with people being empowered to contribute to decisions affecting their lives, through the acquisition of skills, knowledge and experience.”²⁶

All these definitions and descriptions emphasize the involvement of individuals or groups of people in addressing issues that affect their lives or well-being. All describe a variety of types of engagement, from sharing information to influencing decision-making. The definitions indicate that community engagement should go beyond informing individuals and communities about issues and services of concern to them or asking them for input as part of needs assessment or research projects, and that it should include ongoing relationships and community involvement in the development and implementation of both services and policies.

In community development, stakeholders are “those who have an interest in a particular decision, either as individuals or representatives of a group. This includes people who influence a decision, or can influence it, as well as those affected by it.”

– Definition adopted at the 2002 World Summit on Sustainable Development

Theory and Assumptions

Underlying community engagement efforts is the belief that involving the community in designing and implementing policies, programs, and services will begin a chain of actions and outcomes that will ultimately lead to positive community outcomes. In the public health arena, the widely shared belief is that community engagement will create conditions that lead to better population health and reduced health disparities. As the Minnesota Department of Health puts it:²⁷

The public health community believes that by using our “collective intelligence” and working together, we will more accurately identify problems and develop more elegant and effective solutions. We also believe that conflict will be minimized if people have had a chance to “buy into” the process....

The most effective way to achieve public health goals, especially the elimination of disparities in health status, is to actively engage those experiencing the problems in every aspect of addressing them.

These views are consistent with a growing body of experience and some formal research indicating that community engagement can contribute to positive community and public health outcomes – and that the absence of meaningful community involvement may negatively affect such outcomes. *Principles of Community Engagement* provides an “ecological” rationale for community engagement that is based on both theory and research:

The rationale for community-engaged health promotion, policy making, and research is largely rooted in the recognition that lifestyles, behaviors, and the incidence of illness are all shaped by social and physical environments... This “ecological” view is consistent with the idea that health inequalities have their roots in larger socioeconomic conditions... If health is socially determined, then health issues are best addressed by engaging community partners who can bring their own perspectives and understandings of community life and health issues to a project. And if health inequalities are rooted in larger socioeconomic inequalities, then approaches to health improvement must take into account the concerns of communities and be able to benefit diverse populations.”²⁸

Goals: The ultimate goals often stated for community engagement in public health are to improve health outcomes and to eliminate health disparities—which closely parallel NHAS goals of reducing new infections, optimizing health outcomes, and reducing HIV-related health disparities. Shorter-term goals or outcomes are often stated as well, suggesting how community engagement contributes, step by step, to these long-term goals. For example:

- **Benefits for participants:** to provide participants with “networking opportunities, access to information and resources, personal recognition, skill enhancement, and a sense of contribution and helpfulness in solving community problems.”²⁹
- **Relationship building:** “to build trust, enlist new resources and allies, create better communication, and improve overall health outcomes as successful projects evolve into lasting collaborations.”³⁰
- **Partnerships:** “...engagement is a key mechanism to build partnerships that leverage resources and enable services, consumers and communities to work collaboratively to achieve desired health outcomes. It can also be used to empower consumers to work actively as partners in their healthcare, unlocking the potential available for consumer behaviour to contribute to more efficient and effective healthcare delivery.”³¹
- **Community conditions:** “to impact conditions that influence the health of communities and contribute to better health of the population.”³²
- **Ongoing engagement and advocacy:** “The goal of full community engagement is a collaborative partnership among the community, NGOs [non-governmental organizations], and government in which community members serve as champions and advocates for quality programs that take root and are sustained over time.”³³

These views of community participation involve the adoption of a “theory of change” that involves a set of assumptions and a chain of planned actions and events that over time lead to lasting community change. For example:

- Communities can be reached through media campaigns, representative leaders, or civil society and local community groups. When communities receive correct information, they are empowered to take appropriate action, which generally leads to long-lasting, positive health outcomes.”³⁴

Community engagement is viewed as a powerful strategy for positive community change, including improved public health.

Principles for Effective Community Engagement

Many groups in the U.S. and internationally have developed principles, standards, values, tips and other core concepts to guide community engagement efforts. Public health agencies have often been leaders in such efforts.

Several sets of principles, standards, values, and tips are provided below, each presenting a different perspective on keys to making community engagement effective. Note that the terminology varies; one of the international organizations uses the term *public participation*.

The first set of principles was developed in the U.S., with CDC support. They were presented in the 1997 *Principles of Community Engagement*, remained in the expanded 2011 Second Edition, and have been widely used both in the U.S. and internationally. These principles were developed by a task force whose members represented the National Institutes of Health, the Agency for Toxic Substances and Disease Registry, and the CDC. They were designed to provide “public health professionals, health care providers, researchers, and community-based leaders and organizations with both a science base and practical guidance for engaging partners in projects that may affect them.”

³⁵ A major focus in 1997 was on “health promotion, health protection, and disease prevention.” The principles were also designed to “help CDC programs and their partners guide community involvement in activities that affect or change health-related behaviors, including needs and asset assessment, planning, resource allocation, advocacy, outreach, program development, implementation, and evaluation.” ³⁶ The Second Edition also “provides tools for those who are leading efforts to improve population health through community engagement” including care and treatment services.³⁷

These principles have been adopted or refined for use by state and local health departments and other public agencies as well as nonprofit organizations and private-sector entities in the U.S. and internationally. Each of the nine principles covers an important component of community engagement; some principles address multiple issues. The principles are provided in Figure 1, grouped into three categories.

Figure 1: Principles for Community Engagement

Before starting a community engagement effort:

1. Be clear about the purposes or goals of the engagement effort and the populations and/or communities you want to engage.
2. Become knowledgeable about the community’s culture, economic conditions, social networks, political and power structures, norms and values, demographic trends, history, and experience with efforts by outside groups to engage it in various programs. Learn about the community’s perceptions of those initiating the engagement activities.

For engagement to occur, it is necessary to:

3. Go to the community, establish relationships, build trust, work with the formal and informal leadership, and seek commitment from community organizations and leaders to create processes for mobilizing the community.
4. Remember and accept that collective self-determination is the responsibility and right of all people in a community. No external entity should assume it can bestow on a community the power to act in its own self-interest.

For engagement to succeed:

5. Partnering with the community is necessary to create change and improve health.
6. All aspects of community engagement must recognize and respect the diversity of the community. Awareness of the various cultures of a community and other factors affecting diversity must be paramount in planning, designing, and implementing approaches to engaging a community.
7. Community engagement can only be sustained by identifying and mobilizing community assets and strengths and by developing the community’s capacity and resources to make decisions and take action.
8. Organizations that wish to engage a community as well as individuals seeking to effect change must be prepared to release control of actions or interventions to the community and be flexible enough to meet its changing needs.
9. Community collaboration requires long-term commitment by the engaging organization and its partners.

Figure 2 provides another set of principles and related National Standards for Community Engagement, developed for the Scottish government for use whenever public entities—national, state, and local government agencies and commissions—engage with communities.³⁸ Each standard has a set of indicators for measuring success, and a user's guide, toolkit, case studies, and reference manual are available in several languages.

Figure 2: Principles and Standards for Community Engagement: Scotland

Principles for Community Engagement:

1. Fairness, equality and inclusion must underpin all aspects of community engagement, and should be reflected in both community engagement policies and the way that everyone involved participates.
2. Community engagement should have clear and agreed purposes, and methods that achieve these purposes.
3. Improving the quality of community engagement requires commitment to learning from experience.
4. Skill must be exercised in order to build communities, to ensure practise of equalities principles, to share ownership of the agenda, and to enable all viewpoints to be reflected.
5. As all parties to community engagement possess knowledge based on study, experience, observation and reflection, effective engagement processes will share and use that knowledge.
6. All participants should be given the opportunity to build on their knowledge and skills.
7. Accurate, timely information is crucial for effective engagement.

National Standards for Community Engagement:

1. **Involvement:** we will identify and involve the people and organisations who have an interest in the focus of the engagement
2. **Support:** we will identify and overcome any barriers to involvement
3. **Planning:** we will gather evidence of the needs and available resources and use this evidence to agree the purpose, scope and timescale of the engagement and the actions to be taken
4. **Methods:** we will agree and use methods of engagement that are fit for purpose
5. **Working Together:** we will agree and use clear procedures that enable the participants to work with one another effectively and efficiently
6. **Sharing Information:** we will ensure that necessary information is communicated between the participants
7. **Working With Others:** we will work effectively with others with an interest in the engagement
8. **Improvement:** we will develop actively the skills, knowledge and confidence of all the participants
9. **Feedback:** we will feed back the results of the engagement to the wider community and agencies affected
10. **Monitoring And Evaluation:** we will monitor and evaluate whether the engagement achieves its purposes and meets the national standards for community engagement

**Figure 3: Tips for Success
Contra Costa, CA Health Services**

- Honor and build on community interests, priorities, and assets
- Identify and leverage existing institutional relationships
- Define and communicate the parameters of joint health department and community efforts
- Provide support to maximize and maintain community participation
- Document and communicate the link between community engagement strategies and improved public health outcomes

At the state and local level, health departments and other entities sometimes use existing principles or standards, and sometimes revise them or develop principles focused specifically on meeting their community engagement needs. For example, the Minnesota Department of Health uses the Principles for Community Engagement and has both the principles and other resources on its website.³⁹ Contra Costa Health Services, the health department in Contra Costa County, CA developed its own conceptual framework for community engagement, including five specific “Tips for Success,”⁴⁰ as shown in Figure 3.

These are just a few samples of the principles, standards, values, and tips that have been developed to guide community engagement. They were prepared by very different entities, for somewhat different intended uses and users. However, they often include very similar concepts.

Figure 4:
Model Community Engagement Framework: Continuum of Engagement

Level of Community Engagement	Continuum of Engagement					
	Inform/Do Outreach	Consult	Involve	Collaborate	Empower/ Share Leadership	
	Goal or Outcome	To provide targeted stakeholders with balanced and objective information about the issue or program	To provide information and obtain input or feedback from the targeted stakeholders about the issue or program	To work actively with the targeted stakeholders on the issue or program, so they participate in planning or other processes	To partner with targeted stakeholders in developing and implementing the plan or program—including identification and assessment of alternatives	To place final decision making with targeted stakeholders in the community OR to give them a shared role in decision making
	Promise to Stakeholders	To keep them Informed	To keep them informed, listen to their input, acknowledge concerns, and provide feedback on how their input influenced the decision	To work with them to ensure that their concerns are directly reflected in alternatives considered and to provide feedback on how their input influenced the decision	To look to them for advice and innovative ideas in formulating alternatives and incorporate their advice and recommendations into the decisions to the maximum possible extent	To implement what they decide or what we jointly decide
	Sample Tools	<ul style="list-style-type: none">· Fact sheets· Websites· Open houses· Information forums· Education programs· Press releases· Webinars· Information sharing through Twitter, Facebook, and other social media	<ul style="list-style-type: none">· Focus groups· Surveys· Key informant interviews· Town halls or other public information-gathering meetings· Consultations at conferences· E-consulting· Information gathering through Twitter, Facebook, and other social media	<ul style="list-style-type: none">· Workshops· Roundtables· Conferences· Panels· Work sessions· Interactive webinars· Brainstorming Sessions· Online chats	<ul style="list-style-type: none">· Advisory committees· Caucuses· Planning committees or subcommittees· Task forces or work groups· Charrettes· Community networks· Online community forums and groups	<ul style="list-style-type: none">· Steering committees· Boards· Policy councils· Strategy groups· Standing committees· Community balloting

Types of Input and Engagement Models

There are many models and frameworks used to describe levels and types of community engagement. These models help in deciding what strategies to use with what groups of stakeholders. They also help in ensuring that community engagement is useful and meaningful, going beyond attendance at a meeting or event to involve active and ongoing engagement and shared responsibility for planning or programs.⁴¹

Such models are helpful in planning for community engagement, because they describe the types of activities and expected outcomes for different levels of engagement.

One of the most common models was developed by the International Association for Public Participation (IAP²), one of the best known organizations working internationally to encourage and support what it calls *public participation*. It has developed many practical tools and frameworks for use by all sectors, including a Public Participation Spectrum.⁴² This framework is often modified by other entities to fit their needs. Perhaps the most important

aspect of the spectrum is the continuum of levels of engagement, from *Informing*, the lowest level of community engagement, with one-way communication and limited commitments on both sides, to *Empowering*, which implies decision-making by the community partners or stakeholders. Some entities substitute *Outreach* for *Informing* and *Shared Leadership* for *Empowerment*. These different levels of engagement involve different goals or desired outcomes, communication flows, levels of commitment, and tools or strategies, which are often compared in such models. Figure 4 borrows from various versions of the Spectrum to provide a model framework for community engagement.

As the figure shows, all levels of community engagement can have positive outcomes. The more intensive levels lead to greater and longer-term involvement and also require more planning and ongoing effort.

Another useful model that focuses specifically on health is the ACE (Active Community Engagement) Continuum. It describes three levels of community engagement and how they differ in various characteristics, as shown in Figure 5. It was developed and used to guide community engagement for the ACQUIRE Project, a global reproductive health and HIV/AIDS.⁴³

Community • Community • Engagement • Physicians •
Church • Synagogue • Mosque • Temple • Business • La
cial • Club • Colleges • Universities • Community • Hea
nters • Fraternity • Sorority • Grocery • Store •
y Based Organization • Nonprofits • Politicians • C
ader • Civic Groups • Elk • Lodge • Student Groups
ls • LGBT • People Living with HIV/AIDS • Public He
FD • Providers • Government • Courts • Restaurant

* A charrette is an intensive, highly interactive planning session that brings together a group of stakeholders to work with designers or planners to develop a shared vision or plan for a specific development or project. It is often used for urban planning—for example, for agreeing on the design for a park or playground.

Figure 5:
Active Community Engagement (ACE) Continuum

Characteristics of community engagement	Level 1	Level 2	Level 3
Community involvement in assessment	General information from community meetings used to refine programs	As in Level 1, plus: Discussions with leaders regarding reproductive health and family planning issues	As in Levels 1 and 2, plus: Participatory exploration of community power relationships and social context
Access to information	Accurate RH/FP messages disseminated through media and government structures	As in Level 1, plus: Community agents disseminate messages with limited interpersonal interaction	As in Levels 1 and 2, plus: Community agents facilitate dialogue on RH/FP and its relevance to daily life
Inclusion in decision making	Input/approval solicited from influential community leaders at start of project	As in Level 1, plus: Leaders and advisory groups involved as ongoing partners in decision making	As in Levels 1 and 2, plus: Community-based organizations (CBOs) and groups collaborate in decision making
Local capacity to advocate to institutions and government structures	Strengthen FP service delivery through community outreach (information, services)	As in Level 1, plus: Build capacity of local leadership and advisory groups to oversee quality of RH/FP services	As in Level 1 and 2, plus: Build capacity of CBOs and foster organizational linkages to advocate for quality RH/FP services and policies
Accountability of institutions to the public	Health services/policies informed by providers and government with limited community input	As in Level 1, plus: Health services/policies have systems for citizen engagement (e.g. health advisory boards)	As in Levels 1 and 2, plus: Health services/policies ensure equitable input from community to inform RH/FP resource allocation

A planning body, health department, or other entity can choose one of these models, make refinements to fit its specific community engagement purpose and desired outcomes, and use it to choose appropriate strategies and develop its desired process.

Experience and Best Practices

Examples of Effective Community Engagement

The principles and models described in this section have been used throughout the U.S. and globally to guide community engagement in a great variety of settings. Following is a summary chart of some examples of successful community engagement (See Figure 6). They include some classic case studies from the 1980s and 1990s and describe some recent and current projects. They are categorized based on the focus area for the community engagement:

- Program planning
- Program implementation involving prevention, health promotion, healthy environment—efforts to change community behavior in ways that improve quality of life and prevent negative influences
- Program implementation involving services to individuals or families
- Policy—efforts to change public or private policies, regulations, or practices

Figure 6:
Examples of Successful Community Engagement Efforts from the Literature

Project/Topic	Description and Community Engagement Methods	Results
Planning		
Brazilian municipal budget – involving residents in budget decisions ⁴⁴	<p>The Municipal Budget Committee of a Brazilian municipality began to hold meetings with 50% civil society representatives:</p> <ul style="list-style-type: none">• Community representatives responded to proposed budget priorities and indicated what they felt needed to change• The group agreed on recommendations about the budget• Public servants were expected to respond to the recommendations, either executing them or explaining why they were not feasible	<ul style="list-style-type: none">• Changes were made, such as delaying a planned park revitalization in order to complete a hospital expansion program first• Public discussion of the budget increased, which increased community participation in later budget processes <p>While these processes involved only a small percentage of the municipal budget, and there were challenges in allowing for diverse viewpoints to be openly expressed and debated, community input did influence decisions, and this created additional participation in the process</p>

Project/Topic	Description and Community Engagement Methods	Results
<p>The Washington, DC Promise Neighborhood Initiative (DCPNI) – planning an initiative to improve educational opportunities and outcomes in a low-income neighborhood⁴⁵</p>	<p>The Promise Neighborhood Initiative is a Department of Education grant program begun by the Obama Administration. Patterned after the Harlem Children's Zone, it supports place-based partnerships among educational institutions and social service providers to develop “a cradle to career pipeline for children to ensure that they obtain a quality education, graduate from college or a vocational school, and grow up to have successful careers and communities.” The original Washington, DC grantee was the Cesar Chavez Charter School, which incubated a new nonprofit, DCPNI, to implement the program. The site is the low-income Kenilworth-Parkside neighborhood in Ward 7. The project received a \$500,000 planning grant, and its planning process involved extensive community engagement. Among the approaches used:</p> <ul style="list-style-type: none"> • Establishment of an Advisory Group to design the program, with membership including residents from each of the six communities within Kenilworth-Parkside, Advisory Neighborhood Commissioners (community-level elected officials), and representatives of the public school system, DC government agencies, community-based organizations, private sector entities, funders, as well as several experts in various level of education—with monthly meetings and special planning sessions to review, refine, and improve implementation plans for the Promise Neighborhood • A Principals Advisory Group including the principals of the public schools located within the “footprint” or serving children and youth who live in the neighborhood • 10 results-driven work groups, each including community residents and local specialists, to deal with specific topics like entering school healthy, which developed recommended goals and initiatives for the Promise Neighborhood to undertake 	<ul style="list-style-type: none"> • After nearly 2 years of planning, DCPNI received a \$2 million implementation grant, one of just 7 implementation grants • DCPNI is now a 501(c)(3) organization overseeing the program • DCPNI has more than 40 partners that have formal written agreements with the program, including Continuum (of education) Providers, Friends of the Footprint, DC Government Agencies and Offices, and Technical Assistance Providers • Community outreach and engagement continue

Project/Topic	Description and Community Engagement Methods	Results
	<ul style="list-style-type: none"> • Development of partner agreements with a wide range of organizations, from tenant associations to a prestigious local university • Monthly neighborhood dinners that provided updates on planning and invited community feedback • Several community planning sessions • A planning session with youth • Tours for funders and public officials to help them understand the community • Broad use of flyers to announce activities, with community leaders helping to “spread the word” 	

Program Implementation: Prevention/Promotion/Healthy Environment

Community health status in Java—creating a healthier environment to reduce health problems ⁴⁶	<p>In this early community engagement effort, a village development committee was established with the intent to have the community involved in decision-making through meetings where they could express their opinions. The community was to determine needs, make decisions, and take responsibility for activities. Guidance was provided to help residents develop “the will and competence to manage their own affairs” and to help with technical implementation. Methods to gain community ownership of the process included:</p> <ul style="list-style-type: none"> • Residents completed a quick survey focusing on physical environment and health, and results were presented at a meeting of 50-100 residents of a specific area within the village • Residents quickly understood the findings and the relationship between negative environmental factors and the increase in illnesses—things like “the clumps of bamboo, the stagnant water, the flooded latrines, and the crowded housing...” • They agreed that it was the community’s responsibility to deal with these things and that immediate action was needed 	<ul style="list-style-type: none"> • The residents began to clean up their village environment within one week after the meeting; basic cleanup was completed in one month—and improved conditions were maintained • The infant mortality rate fell from 153 to 43 per 1,000 within 2 years • The community was proud of its accomplishments and “regained its dignity”
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Project/Topic	Description and Community Engagement Methods	Results
<p>Healthy Eating, Active Communities (HEAC), California – reducing child obesity⁴⁷</p>	<p>Multi-sector community collaboratives in 6 low-income California neighborhoods developed interventions that “enabled residents and youth to have a leading voice in shaping their own communities for better health.” In West Chula Vista (San Diego), the focus was to improve “access to healthy food and physical activity...to reduce childhood obesity.” The focus was on youth leadership of a project to revitalize Lauderbach Park. Approach was support for a youth-led initiative for community improvement, including:</p> <ul style="list-style-type: none"> • Training for the youth in leadership development and policy/advocacy • Collaboration with and mentoring from local <i>promotoras</i> (Spanish-speaking health promoters) • Support from the City's Parks and Recreation Department and a police community relations Crime Prevention through Environmental Design consultant • Youth action, including interviews with residents about their concerns about the park and surrounding area, a public meeting convened by the youth where city officials heard about neighborhood concerns, and presentation to City Council of a set of park improvement recommendations 	<ul style="list-style-type: none"> • City authorized \$320,000 to implement the community recommendations • Park was revitalized to be a safe place for children to play; improvements included: “removal and replacement of a tall, overgrown chain link fence with a low, transparent one, improved lighting, construction of a new children’s play area and restrooms, installation of picnic tables, trash cans, and a water fountain, and enhancement of a pedestrian pathway” • More than 400 residents attended the re-opening of the park • Youth won several awards • Community received new funding for additional efforts to promote violence prevention, healthy living, and healthy eating

Project/Topic	Description and Community Engagement Methods	Results
Program Implementation: Services		
Improving local health services in Uganda ⁴⁸	<p>Demonstration project in 50 communities to determine whether increased accountability at the client population level can improve health services; methods used involved a series of meetings facilitated by local community organizations with community members, with health facility staff, and then with both groups together. Tasks included:</p> <ul style="list-style-type: none"> • Informing communities of their rights • Providing baseline information on health services and community health status through “report cards” developed through resident surveys • Encouraging residents to develop a remedial action plan • Bringing the residents and health facility staff together to obtain consensus on a jointly owned action plan 	<p>After one year:</p> <ul style="list-style-type: none"> • Waiting times and absenteeism at the health centers were reduced significantly • Cleanliness of these health centers improved • Average service use was up 16% • Prenatal visits, births at facilities, and family planning visits all increased • Visits to community healers and extent of self-treatment declined • Significant gains in infant weight-for-age scores • Reduction of 33% in deaths among children under 5 years of age <p>Findings were compared with data from “control” communities where the community engagement project was not implemented; project communities had significantly better results in all these areas.</p>

Project/Topic	Description and Community Engagement Methods	Results
<p>Boston's Healthy Start Initiative – reducing infant mortality⁴⁹</p>	<p>Healthy Start is a federal grant program managed by the Maternal and Child Health Bureau of HRSA, designed to reduce infant mortality through a community involvement model “to encourage individual, community, and organizational empowerment.” One of the selection criteria was the extent of community and consumer involvement demonstrated in the application. Boston was one of 15 original sites. Its program involved a broad-based consortium including the City of Boston Public Health Commission, community-based organizations, and social service providers, with strong consumer participation. Methods of involvement included:</p> <ul style="list-style-type: none"> • Consortium membership that is 60% consumers, 40% staff of community-based organizations and hospitals, mostly front-line rather than top administrators • 7 communities served • Extensive leadership training for consumers, along with a requirement that they participate in at least one other community initiative • Consortium decision making about the type and level of services • Consortium influence on outreach strategies and marketing tools • Program including case management with a focus on home visitation <p>Power sharing with the community was one of the challenges of the program, but there was a strong commitment throughout the program to meaningful roles for consumers</p>	<ul style="list-style-type: none"> • A 50% reduction in infant mortality among African Americans in 2 years • Training provided and health centers developed in five public housing tenant associations • 40 women trained and hired in first 2 years as community outreach workers; City uses consumers for community input and focus groups; Healthy Start negotiated conditions such as payment for time, information provided on how input will be used, and sharing of results with community

Project/Topic	Description and Community Engagement Methods	Results
Policy Issues		
New York – Lead Poisoning ⁵⁰	<p>Formation of New York City Coalition to End Lead Poisoning, which was able to attract diverse constituencies including housing organizations, public health advocacy groups, public interest lawyers, elected officials, and children's rights groups to educate parents, health workers, and policy makers about lead as a major urban health problem, using methods including:</p> <ul style="list-style-type: none"> • Small group meetings • Mass media coverage • Community organizing 	<p>City government made action against lead poisoning in children a priority; results included:</p> <ul style="list-style-type: none"> • Increased screening of children for lead poisoning • Hiring of additional health educators • Increased enforcement of housing code sections addressing lead paint, pipes • Allocation of additional resources to lead poisoning control • A 43% reduction in lead poisoning in children within 4 years, after 10 years of consistent increases

Best Practices

These and other documented examples of effective community engagement—engagement that contributes to positive individual and community outcomes—typically demonstrate the following “best practices” for entities implementing community engagement strategies:

- **Defined purpose:** The people initiating the community engagement determine and then clearly state the purpose and scope of the community engagement effort, including what community or communities should be engaged, for what purpose, at what level, and for how long
- **Relationships:** They take the time to develop and maintain relationships and build trust; they understand that this takes effort, patience, and a willingness to learn from and about the stakeholder group
- **Diverse partnerships:** They seek partnerships with diverse stakeholders, including stakeholders that make or influence policy as well as those affected by it
- **Respect:** They genuinely respect and honor a stakeholder group's cultural and other values and norms, and also its ultimate right to make its own decisions about its desired levels and types of engagement
- **Mutual benefit:** They understand that effective community engagement requires relationships with mutual benefits; they present information showing how participation can contribute to the stakeholder's goals or provide other benefits
- **Self-discovery:** Rather than always presenting their own analysis of information to the stakeholder, they ask for analysis from the stakeholder where feasible; this provides a sense of ownership and increases stakeholder commitment to helping take the actions they identified as needed
- **Communication and feedback:** They ensure two-way communication and information sharing; for example, when a stakeholder group provides input to the planning process, they receive feedback about how their input was used and see the plan or other product
- **Capacity building:** They give priority to building the capacity—knowledge, skills, contacts, access to resources—of the participating stakeholder organization and its members, volunteer leaders, and/or staff
- **Supports:** They provide supports to help overcome barriers to participation
- **Influence:** They share leadership and decision-making authority where possible, and at a minimum allow stakeholders some level of influence on decisions; they carefully consider and often implement stakeholder recommendations; the stakeholder understands that its engagement has positive impact, which contributes to a sustained high level of engagement

3. Community Engagement for HIV Planning

Community engagement is one of the three major steps in HIV planning. For many HPGs and health departments, the major focus of community engagement has been planning group membership—ensuring that it meets parity, inclusion, and representation (PIR) expectations, all members are actively involved, and their voices are heard. The 2012 *HIV Prevention Guidance* creates additional expectations, calling for a comprehensive, collaborative engagement process that goes beyond the HPG membership to include other stakeholders and contributes to “a more coordinated, collaborative, and seamless approach to accessing HIV services for the high-risk populations.”⁵¹

This section reviews the elements of HIV community engagement, summarizes expected health department and HPG roles and responsibilities, and describes the additional expectations for integrated planning bodies that address prevention, care, and treatment—and sometimes other related programs as well. Most important, it provides a detailed step-by-step description of community engagement planning, implementation, and monitoring, using a six-task model that meets CDC and other federal funder requirements and reflects sound practice. It also summarizes some key “success factors” that help a community engagement effort succeed, and some “failure factors” that may limit its effectiveness.

If your jurisdiction has limited experience with broader-scale community engagement, the information in this section can help you plan and use an organized, thorough, and effective process. If you have experience, it can be helpful in orienting new HPG members or health department staff and might offer some new ideas to enhance your process.

Elements of Community Engagement in HIV Planning

The *Guidance* and FOA PS12-1202 both describe the new expectations for community engagement. They include “broadening the group of partners and stakeholders engaged in prevention planning.”⁵² According to the *Guidance*, “HPGs should identify, encourage, and facilitate the participation of key stakeholders and HIV service providers, particularly those not represented on HPG, who can best inform and support the goals of the HIV planning process.”⁵³ The *Guidance* identifies six elements to include in a comprehensive engagement process; they are summarized in Figure 7.

The FOA identifies steps for “increasing coordination across HIV programs (i.e., prevention, care, and treatment) across the state, jurisdiction, and tribal and local governments to reduce rates of new HIV infection,” as shown in Figure 8.

The two-fold purposes of the engagement process influence how these elements and steps are implemented:

- Informing the development and updates of the jurisdictional plan
- Increasing program collaboration and service integration

Figure 7: Elements of a Comprehensive Engagement Process (Guidance)

1. Initiate open dialogue, to understand and provide solutions to jurisdictional challenges
Identify engagement barriers and opportunities
2. Include representation from various entities to ensure support and coordination of funding streams
3. Include community and key stakeholders who are not HPG members
4. Consider health inequities as a priority, to ensure targeting of HIV prevention activities and resources to the most disproportionately affected populations and communities
5. Use national, state, and local surveillance and other data to inform the engagement process and guide the delivery of culturally and linguistically appropriate prevention services

HPG and Health Department Roles in Community Engagement

The HPG and the health department share responsibility for community engagement, but usually one of the two entities has primary responsibility for each major task. It is important that the health department and HPG understand these roles and responsibilities. They need to discuss and clarify how shared roles will be implemented and how each entity will keep the other informed about the activities for which it is solely responsible.

Figure 9 summarizes roles related to community engagement, according to the *Guidance* and the FOA, and who is responsible for each: the HPG, health department (HD), or both.

Figure 9: Health Department and HPG Roles and Responsibilities for Community Engagement

Role	Responsibility
Identify stakeholders to participate in a comprehensive engagement process (as HPG members or non-members)	Shared
Develop appropriate community engagement strategies	HPG as lead HD assists
Identify and request data needed for developing and updating community engagement process	HPG
Provide data and information needed to develop and review/update community engagement strategies	HD
Provide funding, logistical support, and technical assistance	HD
Develop the community engagement process	HPG as lead HD assists
Commit to active participation in developing and implementing an engagement process	Shared
Implement the collaborative engagement process	HD as lead HPG to assist (Workload to be divided based on who has knowledge of and contacts with targeted stakeholders)
Actively engage other planning groups and federally funded grantees in the HIV planning process	Shared
Document and share successful or improved agency collaboration based on development of a comprehensive monitoring mechanism	Shared
Identify and document barriers to engaging key stakeholders	Shared
Document engagement with other relevant federal planning processes (for example, HRSA, SAMHSA)	HD
Provide regular updates on successes and barriers encountered in implementing and engagement process	Shared
Monitor community engagement process	Shared
Review the engagement process and strategies to ensure they meet the needs of the jurisdictional plan	HPG

Figure 8: Steps in the Engagement Process (FOA)

1. Determining the goals of the plan and who to engage
2. Developing engagement and retention strategies for previous partners
3. Developing engagement strategies for new partnering agencies
4. Prioritizing engagement activities
5. Creating an implementation plan
6. Monitoring progress
7. Maintaining partner relationships

Community Engagement for Integrated Prevention-Care Planning Bodies

Many states and an increasing number of metropolitan areas have joint planning bodies. As noted in the Introduction to this toolkit, both CDC and HRSA encourage collaborative or joint HIV planning.

An integrated planning body typically has some flexibility to address issues such as differing due dates for prevention and care plans. However, integrated bodies are expected to meet core planning requirements for both entities, including community engagement requirements. The requirements for prevention bodies have been detailed in this toolbox. The requirements for Ryan White community engagement (beyond the roles of planning bodies) differ by program. The legislation provides more prescriptive roles for Part A (metropolitan area) Planning Councils than for Part B (state and territorial) statewide planning bodies, though best practices are similar. For example, the legislation includes a long list of *required* categories of membership for Part A Planning Councils, and HRSA *encourages* similar representation on Part B statewide planning bodies as a best practice.

Overall, HRSA legislative requirements and expectations for community engagement are distinct from but compatible with those of CDC. CDC's 2012 *Guidance* makes community engagement a key planning task, while HRSA specifies community involvement requirements in relation to specific legislated activities. HRSA places high priority on engaging and obtaining input from people living with HIV, including consumers of Ryan White services. CDC focuses on targeted populations. Both entities describe a number of stakeholder groups that should be considered for representation on the planning body but also for inclusion as nonmember stakeholders. Integrated planning bodies benefit from the combined community engagement experience of prevention and care.

Ryan White legislation specifies community engagement in relation to specific tasks carried out by the grantee and planning body. It expects this engagement to involve input to the planning process and participation in implementation of planning tasks, particularly the following:

- **Needs Assessment:** Ryan White Part A and Part B needs assessment is “a partnership activity” between the planning body, grantee, and the community. One focus of needs assessment is to determine the needs of people living with HIV/AIDS (PLWH), which requires obtaining input directly from PLWH. Both *Manuals* suggest the use of “such methods as surveys, focus groups, community meetings, and individual interviews.”⁵⁴ Planning body needs assessment committees often include individuals who are not planning body members, and some planning bodies engage PLWH not only to provide their own input but also to help identify and interview other PLWH, especially those from those with health disparities and from historically underserved populations. Both *Manuals* explain that HRSA also expects needs assessment to include input from “diverse service providers serving varied client populations,”⁵⁵ and encourages coordination or joint efforts with prevention.
- **Statewide Coordinated Statement of Need (SCSN):** An SCSN is “a written statement of need developed through a locally chosen collaborative process with other Parts of the Ryan White HIV/AIDS Program.”⁵⁶ The Part B grantee is responsible for coordinating the SCSN process, which involves a meeting that includes all Ryan White Parts, PLWH, public agency representatives, and other stakeholders. The *Part B Manual* says that “States are also encouraged to include representation from other major providers or funders of services needed by PLWHA such as substance abuse, mental health, Medicaid, Medicare, Community Health Centers, Veteran’s Administration, HIV prevention, as well as other entities that may be appropriate for developing a coordinated strategy to link newly identified PLWHA to appropriate health and support services.”⁵⁷
- **Comprehensive Planning:** Ryan White Part A and Part B programs are expected to submit a comprehensive plan to HRSA every three years. The Ryan White legislation requires community input to the plan. For example, the Part B grantee must engage in “a public advisory planning process, including public hearings, that includes” the same types of participants as the SCSN and the types of entities that fit planning council membership categories—from consumers of Ryan White services to health or hospital planners, various types of providers, and non-elected community leaders. The public must have an opportunity both to provide input before the plan is prepared and comment on the implementation of the plan.⁵⁸
- **Priority Setting and Resource Allocations (PSRA):** Part A Planning Councils are the decision makers about the use of Part A funds. They must establish priorities among the 29 allowable service categories and allocate funds to those services. Part B planning bodies provide advice or recommendations to the grantee, which is the decision maker regarding PSRA. Decisions are expected to be data based, drawing on needs assessment findings and other information such as client utilization and expenditures data. Community input is expected, especially from PLWH; PSRA often involves town hall meetings or other input sessions that allow consumers, service providers, and other stakeholders to recommend priorities, allocations, and service models.

Like CDC, HRSA expects grantees to ensure community engagement both through the use of planning bodies and the deliberate involvement of additional stakeholders, with a strong focus on people living with HIV (PLWH). Both the *Part A Manual* and the *Part B Manual* recommend that planning bodies seek the involvement of non-member PLWH.

Integrated HIV planning bodies sometimes have responsibility not only for prevention, care, and treatment, but also for other related programs, such as Housing Opportunities for Persons with AIDS (HOPWA) and for STDs. In such situations, the health department and planning body need to understand and address the community engagement requirements and best practices of these additional programs.

Planning and Implementing a Community Engagement Process

The 2012 *HIV Planning Guidance* and FOA PS 12-1201 (FOA) both suggest elements, components, and approaches for developing and implementing a community engagement process. There is no one right way to do it, but the approach used should:

- Meet CDC expectations
- Meet the requirements of other funders if the planning process is integrated
- Reflect sound practice
- Complement the community engagement provided through the HPG
- Be appropriate for your unique state or local environment

The implementation model that follows includes six major tasks. For each one, it provides the purpose, activities—with suggestions for how to carry them out successfully and avoid difficulties—and expected outcomes or products. Whether you are a state or local health department official or an HPG member, the model is designed to help you implement community engagement beyond HPG membership.

Six Tasks for Planning and Implementing Community Engagement

1. Orientation to Expectations and Best Practices
2. Planning: Developing a Community Engagement Process
3. Relationship Building
4. Communications and Engagement
5. Use of Community Input
6. Documentation, Monitoring, and Improvement

Task 1: Orientation to Expectations and Best Practices

The purpose of Task 1 is to ensure that all HPG members and health department personnel involved in the community engagement process have a shared understanding of community engagement purposes, terms and definitions, principles, and strategies. This enables you to develop and use a sound process that everyone understands and supports.

Research indicates that the broader community engagement specified in the 2012 *Guidance* is a new focus for many HIV prevention grantees. There is a shared understanding of the importance of a diverse HPG membership with parity, inclusion, and representation (PIR), but less familiarity with community engagement efforts that go beyond periodic town halls or listening sessions and needs assessment activities. Planning an effective community engagement process and strategies requires a thorough orientation to ensure a shared familiarity with the new expectations.

There are many ways to approach the orientation. Here is one suggestion:

1. **Assign responsibility for developing the orientation to the appropriate committee or work group.** If you have a Community Engagement Committee or a committee with responsibility for that effort, it could take the lead, with a small temporary subcommittee taking on this task. If not, you may consider assigning this task to an appropriate committee within the planning body.
2. **Set aside at least three hours for the orientation.** You may choose to use one of your meetings for this purpose, or you might schedule a separate time. If it is difficult to get the group together, consider using a webinar.

3. **Make participation mandatory** for voting HPG members and health department personnel that work with the HPG. Strongly encourage participation from the non-voting members who regularly attend your HPG meetings and for any non-members that will serve on the Community Engagement committee or work group that will develop your community engagement process and strategies.
4. **Develop the orientation package**, including an agenda, learning objectives, some interactive exercises so participants can apply knowledge and practice skills, some handouts or reference materials, and a session evaluation form. The responsible committee or work group should work with staff as appropriate to develop the orientation. Think carefully about the interactive exercises. Ideas for these exercises are provided in Figure 10.
5. **Conduct the orientation**. Be sure your facilitator knows the topic and can explain concepts and manage discussions and interactive exercises. There may be one or more people on the responsible committee or working group that can lead or share the facilitation. If not, try to find someone among your stakeholders. The group can share facilitation. Make the orientation as interesting and enjoyable as possible, using lots of examples from your HPG's experience and the experiences of its individual members.
6. **Evaluate the session**. Be sure to have participants evaluate the usefulness of the session, and use that feedback to revise the written orientation package. You will probably need to do an orientation again in a year or two, when you have new HPG members.

Once you have completed the orientation process, you will have a group with a shared knowledge of community engagement, some agreements on how your HPG will define and approach community engagement, and an orientation package that can be re-used in the future.

Now you are ready to develop your community engagement process and strategies.

Task 2: Planning: Developing Your Community Engagement Process

The purpose of Task 2 is to develop a community engagement process and strategies for your HPG. The process should be written and can be done primarily in chart format.

Under the 2012 *Guidance*, developing a community engagement process is a key role for the HPG and a task for which it has primary responsibility. The health department generally participates and provides support, since it has primary responsibility for implementing the process.

This task involves multiple steps, each of which is discussed below. One approach is to complete Step 1, establishing the structure for planning, and then plan to spend one meeting of the committee or work group on each of the remaining steps. Another is to divide into subgroups after completing Step 2, with a different group assigned Steps 3, 4, 5, and 6. Then the groups can come together to report, refine their work and reach consensus where necessary, then work together on Step 7.

1. Assign responsibility to a committee/task force

Before you can begin to develop your community engagement process, you will need to decide on how this work will be done within the HPG structure. To be efficient, you will probably want a subgroup of the HPG to take responsibility for developing the process, with the full HPG reviewing and refining it. Possible approaches include the following:

- Assign responsibility to an existing committee
- Establish a new Committee on Community Engagement
- Establish a task force or working group on community engagement

Steps in Developing a Community Engagement Process

1. Assign responsibility to a committee/task force
2. Agree on the purpose, scope, and rationale for your community engagement process
3. Identify types of stakeholders to target
4. Explore types and levels of involvement
5. Explore strategies
6. Determine roles and responsibilities
7. Lay out your community engagement process

The committee needs to:

- Be diverse enough to identify the full range of potential stakeholders and target groups
- Be an appropriate size—large enough to share the workload, but not so large that it is difficult to manage the work
- Be made up of individuals with the time and commitment to complete their task on time
- Have a chair or co-chairs who will manage its time and assign and review work

Once you have addressed such questions, you will be ready to begin developing your community engagement process.

2. Agree on the purpose, scope, and rationale of your community engagement process

The first step in planning is to review your jurisdiction's approach to HIV planning and agree on **why** and **how** expanded community engagement can strengthen it. One of the most frequently stated principles of successful community engagement is *the need to be clear about the purpose and scope of your community engagement effort*. This clarity is necessary as a foundation for your planning, and in reaching out to target communities and other stakeholders. They need to understand what you want from them and what they (or the community they serve) will gain by assisting you. This is especially important as you reach out to new stakeholders, who might have little or no history of engagement in HIV planning or knowledge about the HPG. As one HPG co-chair explains, you have to be prepared to “market” the HPG and create a sense of “ownership” among new potential partners.

Ultimately, community engagement is designed to help the HPG and the health department improve the lives of at-risk, affected, and HIV-positive individuals. Your process for engaging stakeholders and developing broad community partnerships is likely to have two distinct but interrelated purposes:

- To provide more diverse and comprehensive input to the jurisdictional plan, which can create real change by improving the jurisdiction's response to local HIV prevention needs and community priorities
- Helping to increase program collaboration and service integration

You may have other reasons for community engagement. If you are planning a needs assessment, you may want input from targeted populations and/or service providers. If your HPG does planning for care and treatment, your community engagement may involve outreach related to the Statewide Coordinated Statement of Need (SCSN). As you consider the scope of your community engagement, be sure to identify the specific planning activities for which you need input.

3. Identify types of stakeholders to target

The next step in planning your community engagement is to identify the types of stakeholders to target, and where feasible to identify specific individuals and organizations to engage. This effort is similar to the process of targeting people to serve as HPG members, but should complement and expand on the diversity of member representation. Your focus will be to identify additional stakeholders who can best inform and support the goals of the HIV planning process to inform development of the Jurisdictional HIV Prevention Plan and contribute to increased program coordination and service integration.

CDC provides direction and suggestions for stakeholder identification throughout the *Guidance* and in the FOA, summarized in Figure 11.

Figure 11: CDC Expectations and Suggestions for Stakeholder Targeting

- Representatives of at-risk, affected, HIV-positive, and socioeconomically marginalized populations
- Stakeholders who are not represented on the HPG
- Partners the HPG and health department have been involved with in the past as well as new partners (FOA)
- Partners who can assist with issues related to interagency services, as well as program collaboration and service integration (PCSI), sexual health, and health equity and social determinants of health
- HIV treatment providers
- A range of providers, including nontraditional providers, that address the conditions that often co-occur with HIV (e.g., STD, viral hepatitis, TB, substance abuse, mental health, homelessness)
- Involvement of other planning bodies and other federal grantees—specifically mentioned are the Health Resources and Services Administration (HRSA), the Substance Abuse and Mental Health Services Administration (SAMHSA), and the Housing Opportunities for Persons with AIDS (HOPWA) program under the U.S Department of Housing and Urban Development (HUD)
- Stakeholders, including non-traditional stakeholders, that reflect the jurisdiction's epidemic and meet jurisdictional planning needs

Tool #1: Stakeholder Matrix, in Section 5 of this toolkit, lists a large number of stakeholders to consider. It includes the stakeholders listed in Appendix E of the Guidance and others as well.

In developing your own list of stakeholders, you may want to start with that matrix. You can also go through a brainstorming and analysis process that has several steps. It is based on the assumption that it is much easier to find people or groups when you know exactly what you are looking for. Here is one approach to developing a clear list of community engagement needs and targets. It can be done through a work session of the responsible committee or working group.

Identify target populations: To identify the populations and types of entities to include in your community engagement outreach, first review your existing plan, epidemiological profile, treatment cascade, and other data. This will help you identify what populations are most at risk for HIV, slowest to test, or most difficult to link to and retain in care.

Identify categories of stakeholders: Once you have an up-to-date list of target populations and locations, agree on categories of stakeholders that should be part of your community engagement process. Be sure to reach out beyond your current “HIV circle.” Consider the following:

- What types of stakeholders do we need to include to reach these populations? Membership organizations? Service providers that are part of or serve this community? Community leaders?
- What other types of stakeholders do we need to reach so they can provide input to our plan and/or help us coordinate and integrate services?
- What other types of entities does CDC expect us to reach out to?
- What issues do we need to address that may require new contacts (e.g., implementation of the Affordable Care Act, increasing links with HIV care and treatment)?

Determine which populations and stakeholders need more representation: Consider what populations and stakeholders are:

- Well represented on the HPG?
- Not included on the HPG or among regularly attending non-voting participants?
- So important that additional perspectives and information are needed?

Identify groups or individuals for outreach, as well as the need for new contacts: Once you have a comprehensive list of populations and stakeholders and a sense of the gaps in current community engagement, the HPG can identify specific groups or individuals that should be contacted—as well as targets for which the HPG does not already have contacts or potential contacts. Ask yourselves:

- What individuals or organizations do we know that can help us learn about populations and issues where we have gaps?
- What individuals and groups are already on our mailing lists because they have participated in town halls or other input sessions or planning activities in the past?
- Who are the people or groups we always wanted to reach out to but haven't yet reached?
- What types of potential stakeholders are new to us, so we don't have specific contacts? Who might help us identify appropriate groups or individuals to reach out to?

Focus on promising sources of input, including non-traditional stakeholders: In developing community engagement targets, it is helpful to go beyond the obvious contacts to find groups that may offer new perspectives on HIV prevention and care needs and strategies. Once you have made your basic list, choose some priority targets for additional discussion. You might do this in a separate meeting for which you invite some HPG members or existing partners that are not a part of the committee. Be sure representatives of at-risk populations and PLWH are well represented in the discussion, as well as providers and public agency representatives. Then consider the following:

- Within priority categories, how can we obtain diverse perspectives?
- Are there any additional organizations, including membership groups from targeted population groups, that we should include as well as the current contacts?
- How can we best reach into populations that are priorities in the next year, for needs assessment, service integration, and/or service improvement efforts?

This activity—like your community engagement efforts—benefits greatly from the involvement of individuals that may represent the same populations but offer different perspectives on prevention needs, services, barriers, and priorities. For example, providers and consumers both have valuable input that is often very different, so the HPG should seek input from both. Moreover, one person or organization cannot fully represent an entire community. For example, a single African American woman on the HPG should not be burdened with speaking for all African American women in the jurisdiction who are at high risk or are living with HIV. Community engagement allows the HPG to reach out to individuals and organizations that can complement her perspectives. She can provide valuable input regarding appropriate entities to provide additional input from her population.

The discussion of additional and non-traditional contacts often involves “drilling down” beyond a population to subgroups within that population. For example, if one target population is PLWH who may benefit from prevention with positives services, the group can brainstorm subpopulations that might be targeted, as Figure 12 indicates.

Identifying stakeholder groups is an ongoing process. The HPG should focus on priority populations and stakeholder groups based on the annual calendar and issue priorities. You can hold a brainstorming session to identify specific groups for outreach whenever the need arises.

Use the Stakeholder Matrix tool or another method of your choosing to document your targeting process by listing populations and stakeholders and identifying specific contacts or the need for contacts.

4. Explore types and levels of involvement

Once you have identified the scope of your community engagement and identified targeted stakeholders, you can consider the types and levels of involvement you want to implement. They will be shaped by your calendar of planning tasks, issues, and products along with your issue and population priorities.

One way to categorize types of engagement is by the planned frequency and duration of engagement. Most jurisdictions need one-time involvement from stakeholders for activities like town hall meetings, focus groups, and listening sessions with various populations and in various geographic areas. However, these efforts can generate a contact list for future engagement. Working with service providers and membership organizations to recruit participation provides an opportunity to establish an ongoing relationship with them, which can lead to ongoing engagement.

Figure 13 provides examples of community engagement efforts that involve one-time, periodic, and ongoing relationships. Youth are used in an example at each level, to demonstrate the range of types and levels of engagement and how engagement with a particular population or stakeholder group can deepen over time.

Figure 12: PLWH Groups to Target for Input Regarding Prevention with Positives

- Existing support groups of recently diagnosed PLWH or PLWH considered loosely connected to care—reached through their service provider
- Provider serving recently incarcerated PLWH
- PLWH Caucus
- Peer Community Health Workers employed in Part A or Part B Early Intervention Programs that focus on HIV literacy, referrals to care, and linkage to care
- The Consumer Advisory Board of an HIV service provider that provides outreach, testing, linkage to care, and/or related services

Night clubs • community center • Transgender • Youth
 • Girls • corporations • social media • community •
 Engagement • Physicians • schools • church • synagogue
 Mosque • Temple • Business • Lawyers • social • club

Figure 13: Examples – Categorizing Community Engagement by Frequency and Duration

One-time Involvement	Periodic Participation	Ongoing Engagement
Participation in a town hall or listening session for community of color youth and youth-serving organizations that provides input to an update of the jurisdictional plan	Annual involvement of social service agencies in recruiting individuals to participate in needs assessment activities on HIV prevention—for focus groups, surveys, town halls, or other data-gathering methods	Development of a memorandum of agreement with a drop-in center to have youth clients and staff advise the HPG on improving prevention and testing services targeting youth; involvement includes participation in focus groups or listening sessions, roundtables, feedback sessions, or other activities whenever input from youth is needed
Participation in a focus group or survey of African American MSM under age 25	Regular invitations to updates and consultations provided to youth-serving organizations, with events held about twice a year	Development of an MOU with the Association of Free Clinics to begin routine HIV testing and work with the health department on linkage to care for newly diagnosed PLWH, and to help identify free clinics to host prevention for positives sessions for their clients
Attendance at a roundtable to explore barriers to testing and strategies for reducing late testing of Latinos	(For planning groups responsible for care and treatment) Organizational participation every 3 years in the meeting held to develop the Statewide Coordinated Statement of Need, as well as annual town halls related to updating the jurisdictional prevention plan	Participation in a working group to explore barriers to testing for Latinos and recommend strategies to overcome these barriers; intensive 6-month effort, followed by less frequent update and follow-up sessions

Another way to look at levels of engagement is to use one of the frameworks for community engagement presented in Section 2. For example, you can use a continuum of engagement and explore the levels of engagement the HPG and health department might want as part of the planning process or in implementing prevention activities. Community engagement activities—led by the health department, with HPG support—can be limited to *informing* and *consulting*, or they can go beyond those basic levels to include ongoing *involvement* in the work of the HPG, *collaboration* with the HPG or health department on some aspect of HIV planning or services, and even a *share in decision making* about some aspects of the work of the HPG or health department. The use of more or less intensive engagement depends on your jurisdiction's planning and collaboration/service integration needs. In addition, experience indicates that more intensive engagement is likely to contribute to more meaningful outcomes and also requires more resources and effort.

It is important to be realistic in your planned levels of engagement. Given limited time and resources, you are likely to engage in ongoing relationships involving collaboration or shared decision making with a limited number of stakeholders each year. You may also want to begin with limited engagement and then deepen connections with entities that are particularly helpful and see ongoing, deeper engagement as beneficial for them or the communities they serve.

5. Explore strategies

Another aspect of community engagement the HPG should explore is strategies available for engaging stakeholders. Many strategies exist. The HPG committee should become familiar with a wide range of more and less intensive strategies. This will enable you to choose strategies appropriate for various purposes, target populations, and stakeholders, and to be innovative when new strategies are needed. In considering strategies, remember that community engagement requires proactive outreach from the health department or HPG, and both entities will need to play a role in reaching out to potential partners.

Consider using this two-part activity:

1. Begin by listing all the strategies your HPG has used in planning and those the health department has used in HIV program collaboration and integration.

It can be helpful to list strategies by category. In Section 2, strategies were categorized based on their level of intensity along the Continuum of Care—based on their use in informing, consulting, collaborating, and sharing leadership. Another way is to list strategies and then check off the types of planning or collaboration/integration activities and then listing the populations for which they seem appropriate. Consider whether some current community engagement strategies can be refined to allow for broader or more in-depth participation. Tool #II, Strategies Exploration Tool, in Section 5 provides a matrix you can use for this purpose.

2. Then look at the strategies listed to the right and in other sections of this toolkit, and brainstorm other possible activities. Review those you have not used and identify any you feel should be considered for inclusion in your community engagement process. Think about what strategies might be most useful for what purposes and populations, and add the “strategies of interest” to your matrix.

This activity will help ensure that you consider a variety of known and new strategies in your community engagement efforts.

Figure 14 lists many strategies, categorized by their community engagement purpose or intent.

Figure 14: Examples of Strategies for Community Engagement

Types of Community Engagement Strategies	Examples of Strategies
Strategies for Informing the Community	<ul style="list-style-type: none">• Fact sheets• Websites• Newsletters – electronic and hard copy• Open houses• Information forums• Presentations to existing bodies – e.g., Boards of Directors, Client Advisory Bodies (CABs), membership organizations• Education programs• Press releases• Webinars for stakeholders• Information sharing through Twitter, Facebook, Craigslist, other social media• Announcements during webinars or teleconferences held by stakeholder Organizations

LEARNING FROM EXPERIENCE

Challenges in Modifying Structures and Strategies

Some HPGs are refining their structures to better address the new Guidance and encountering some challenges. For example, many HPGs have had active work groups including many non-HPG members that focus on a particular target population (such as men who have sex with men [MSM] or Women and Children). These work groups engaged a wide range of population-focused service providers, including many who are interested in HIV primarily as it affects their client population. As the HPG revises its structure, moving to intervention-based or other types of work groups is becoming harder to engage population-focused non-HIV-specific providers.

One Community Co-Chair noted that the HPG emphasizes to these groups the importance of having population-focused experts at the table in their Prevention for Positives and Linkage to Care work groups. Special efforts may be needed to demonstrate to such non-HPG members the importance and results of their continuing engagement.

Figure 14: Examples of Strategies for Community Engagement

Types of Community Engagement Strategies	Examples of Strategies
Strategies for Gathering Data	<ul style="list-style-type: none"> • Surveys • Interviews • Focus groups • Key informant sessions • Town hall meetings • Listening sessions • Public hearings or informal public input sessions • Public comment period at HPG meetings • Consultations or group discussions at conferences
Strategies for Dialogue – Gathering and Sharing Information	<ul style="list-style-type: none"> • Community forums • Roundtables on specific topics • Brainstorming sessions • Informal discussions with (groups of) program clients or target groups • Formalized small group discussions • Conference calls • Video conferences (two-way) • Engagement of representatives of target communities who are trained so they can conduct focus groups and engage with populations they represent and/or know well • “Road shows” in which planning bodies meet in various locations, make presentations, and provide opportunities for community dialogue
Strategies for Joint Analysis and Identification of Options	<ul style="list-style-type: none"> • Advisory committees • Caucuses • Planning committees or subcommittees that include community representatives • Task forces or work groups • Charrettes • Community networks • Online community forums and groups • Joint needs assessment with other health-related entities
Strategies for Shared Decision Making and Action	<ul style="list-style-type: none"> • Steering committees • Boards • Policy councils • Strategy groups • Standing committees • Community balloting • Program collaboration and service integration • Joint outreach with partners or coalitions

Section 4 of this toolkit provides examples of how HPGs and other planning bodies are using these strategies.

6. Determine roles and responsibilities

As previously described, the 2012 *Guidance* and FOA both discuss roles and responsibilities for community engagement, giving the HPG primary responsibility for developing a community engagement process. The HPG is expected to assist the health department in implementing the community engagement process.

The appropriate level of HPG engagement will vary by jurisdiction, affected by factors such as the structure of the HPG, planning group structure, staffing and resources, and planning group membership. It is imperative that HIV planning groups and health department staff be well informed, supported, and trained to conduct the community engagement process.

It is important that the HPG and health department agree on and fully understand roles, responsibilities, and boundaries. Responsibilities for community engagement can be stated in standing policies or procedures, including the community engagement process. Some Ryan White Planning Councils, including integrated planning bodies, have developed a Memorandum of Understanding (MOU) between the planning body and the grantees; use of MOUs is considered a best practice for Ryan White Part A Planning Councils and grantees.

7. Lay out your community engagement process

Once the various aspects of community engagement have been explored, the HPG is ready to lay out and document its community engagement process. This can be done efficiently in a chart format.

Before preparing the written process, the HPG should determine the following factors in consultation with the health department. These might be discussed in a full HPG meeting to provide guidance to the committee:

- The overall duration for the planned process—which might be as little as one year and as much as three years, with annual updates
- High priority issues related to planning and service collaboration/integration that should receive priority in community engagement
- Priority target communities and stakeholder groups—for both new contacts and existing partnerships that need further development
- Other factors that might affect the process—such as plans to integrate prevention and care planning bodies or other structural changes
- What level of community engagement is practical and achievable, given capacity and resources: what can be done the first year, and what will need to wait

The documented community engagement process should generally include the components shown in Figure 15. Tool #IV, Community Engagement Process Chart, in Section 5 of this toolkit provides a sample format for charting a planned community engagement process.

Roles for HPG Members in Implementing Community Engagement

- Promoting awareness and disseminating information—e.g., through presentations to nontraditional providers on HIV, HIV planning, and the National HIV/AIDS Strategy
- Reviewing and helping to adapt strategies so they are appropriate for specific populations, locations, and groups
- Helping to develop or reviewing marketing materials and other documents to be sure they are culturally appropriate for specific populations
- Keeping the HPG updated on the community engagement activities in which they are involved and any issues or events that may affect that process
- Helping to document and monitor the community engagement process
- Designing needs assessment tools and collecting needs assessment data

Nonprofits • Politicians • Community Leader • Civic
• Lodge • Student Groups • Hospitals • LGBT • People
with HIV/AIDS • Public Health • STD • Providers •

The HPG and health department should review the engagement process regularly and update it as appropriate.

Task 3: Relationship Building

The purpose of this task is to establish and enhance relationships with stakeholders, in order to strengthen the jurisdictional plan and increase service-related collaboration and integration.

The written community engagement process should provide direction for relationship building by identifying populations and entities to target and by indicating priorities. Generally these priorities will be based on two factors:

- **Timelines:** The timelines for tasks and products for which community engagement is required—for example, if the update of the jurisdictional plan is due in September, community input to inform the plan will be needed well before that date, so relationships will need to be established as early in the year as possible
- **Priorities:** The priority given to a particular stakeholder or type of stakeholder—for example, if the HPG feels it must have additional information on services for transgenders, it may prioritize building relationships with transgender organizations

Making new connections with stakeholders that you want to engage long-term usually involves activities such as the following:

Pre-contact Preparations:

- Agree on who will make the contact
- Learn about the group and/or individual you plan to contact
- Decide whom to approach
- Agree on what will be requested from the group
- Decide what information to provide
- Be prepared to “market” community engagement
- Be sure the person making the contact is briefed on cultural issues that may affect the success of the first meeting

Figure 15: Components of a Written Community Engagement Process

1. The purposes and intent of the community engagement process
2. Populations and types of stakeholders to be reached, with specific names of individuals and entities specified where possible and clear priorities stated
3. Strategies to be used, with the intent and expected use of each strategy (e.g., focus groups with specified populations for use in updating the jurisdictional prevention plan, a work group to explore ways to better reach and serve youth of color)
4. Specific tasks for implementation
5. Responsibility for each implementation task
6. Expected outcomes of the community engagement process, linked to prevention planning and products and tasks
7. An overall timeline for the process, with completion dates for various community engagement activities that are linked to prevention planning and program timelines (such as the due date for the jurisdictional plan update)
8. Responsibilities for documentation and monitoring

Lesson from Experience

When developing materials or preparing a presentation for potential stakeholders:

Remember that people in the HIV world speak a special language, full of acronyms and technical terms. People from “the outside world” won’t understand it. Minimize use of technical terms and when you use them, explain them.

Making the Contact:

- Make the initial contact by telephone or email
- Hold an initial meeting with the President and/or other representatives of the group
- Agree on next steps before leaving the meeting
- Follow up promptly
- Document the contact
- Continue contacts to build the relationship
- As the relationship progresses, consider developing a Memorandum of Understanding (MOU)

Contacts with lower priority partners may involve less preparation, but they too deserve preparation, appropriate materials, clarity in your requests, and respect for their importance and their work.

Lesson from Experience When building a relationship:

Be flexible in your expectations of stakeholders, especially in the beginning of your relationship. Groups that do not focus primarily on HIV probably are not as invested in HIV prevention as you are. It may take them some time and involvement before they feel a sense of ownership and strong commitment.

Some relationships are difficult to establish. Large organizations may be busy and unresponsive. Often the health department can use a senior official to bring the weight of the agency behind the contact. Sometimes you may need to begin by contacting someone at the program level who is interested in HIV prevention issues, and over time begin to engage senior managers.

Developing relationships consumes a lot of time and energy. It usually makes sense to focus on developing an effective approach to relationship building and then building a small number of strong relationships with high priority stakeholders each year. You can add to the relationships each year, and at the same time maintain existing relationships and establish less intensive relationships with a larger number of stakeholders.

Task 4: Communications and Engagement

The purpose of this task is to establish ongoing communications and engagement with the jurisdiction's stakeholders. Accomplishing this is a shared responsibility of the HPG and the health department.

Implementing your Community Engagement Strategies

Community engagement is a year-round effort, and most HPGs have been working with community partners for a long time. What has changed is the priority on broader community engagement as a key planning task for the HPG, along with the focus on this engagement informing the jurisdictional plan.

The community engagement process will include strategies and key stakeholders to target. New strategies in the process can yield multiple perspectives on key issues. The use of technology such as conference calls, webinars, and video conferencing can be beneficial and cost effective for engaging stakeholders without in-person sessions.

This section provides information to support use of specific strategies as well as do's and don'ts that apply to most strategies. Figure 16 describes six community engagement strategies that can provide useful, substantive input to address key questions and issues. Included are suggestions for creative uses of traditional data collection methods, along with less frequently used strategies. Section 4 of the toolkit presents additional strategies used by HIV-focused planning bodies and health departments and Section 6 includes resources that give "how to" advice on many strategies.

Figure 16: Some Strategies for HIV-related Community Engagement

Strategy	Definition/Description as Used in HIV Planning	Creative Applications
Town Hall Meeting	<ul style="list-style-type: none"> • A session held in the community to obtain perspectives on issues, needs, services Usually lasts 1½ to 2 hours • May be open to the public or limited to a specific population group (such as people living with or affected by HIV) • Often used to obtain community input regarding HIV prevention or care needs, barriers, service gaps, and suggested solutions • Sometimes consists largely of time-limited presentations or statements of opinion from participants • Sometimes structured to address specific issues or questions • Usually facilitated by a leader of the planning body • Should include refreshments as an incentive • Often widely advertised in a particular community 	<ul style="list-style-type: none"> • Develop a small number of questions designed to generate in-depth discussion • Questions might focus on a single theme or population, such as what should be done to reduce the rate of HIV infection among young African American MSM—exploring HIV education in schools, views “on the street” about HIV, how to engage youth in prevention, barriers to testing, needs regarding linkage to care, risk reduction models, and culturally appropriate services to maximize “treatment as prevention” • Have a well prepared facilitator raise questions, ask for responses, and encourage in-depth discussion
Webinar	<ul style="list-style-type: none"> • An online session using widely available software that allows participants to see a presentation or a person on the screen, listen either online or through a separate toll-free conference telephone line, ask questions via the telephone or through a “chat” function on the screen, and participate in balloting • Generally used largely for presentations that provide information, but with time set aside for questions and comments • Widely used by federal agencies and some state and local agencies, as well as the private and nonprofit sector • Usually lasts 1 to 1½ hours 	<ul style="list-style-type: none"> • Use a webinar to present and obtain feedback on some aspect of HIV prevention that involves alternatives, such as alternative priorities for high-impact prevention or proposed program models (for example, three proposed models for educating and testing individuals over 55, who in some jurisdictions have a very high rate of late testing) • Rather than presenting a long PowerPoint, HPG leader or health department official presents and describes the program models and why they have been proposed • Ask for comments, using well-trained operators to screen callers—or use several telephone numbers for different types or comments • Use the chat function for specific types of responses—for example, how would you change Model A • Use polling to find out which model is considered most appropriate

Figure 16: Some Strategies for HIV-related Community Engagement

Strategy	Definition/Description as Used in HIV Planning	Creative Applications
Consumer-led Focus Group	<ul style="list-style-type: none"> A structured discussion with a group of individuals with certain common characteristics, facilitated by a trained moderator and using a prepared script and questions Usually includes 8-12 people Usually lasts 1½ to 2 hours Purpose is to obtain perspectives on a particular issue or program Participants often do not know each other; generally only first names are used Groups may be chosen on the basis of gender, age, race/ethnicity, or other factors Requires a safe and private environment Refreshments and transportation cost reimbursement often provided Sessions usually taped—participants must sign permission form 	<ul style="list-style-type: none"> Train individuals from target populations or people living with HIV to serve as focus group moderators After training, individuals co-moderate at least once with an experienced moderator Then community moderators are asked to conduct focus groups with specific groups, as input to needs assessment or planning Community moderators usually work in pairs, with one person responsible for facilitation, the other for note-taking and logistics Process expands capacity for obtaining community input, provides leadership opportunities, and helps ensure availability of culturally appropriate moderators Need to ensure that at least one moderator in each team is trained to prepare summaries; tapes can also be summarized by needs assessment staff
	<ul style="list-style-type: none"> A facilitated discussion session that brings together a small group of individuals with a high level of experience and expertise in a certain subject area, to gain understanding of programs, services, or community needs related to their area of expertise Usually involve 8-12 people with varied affiliations—service providers, researchers, health department personnel Pre-determined questions are asked, but there is also time for discussion of other issues raised by key informants Skilled facilitator needed to manage session and keep it on track Used in HIV needs assessment and planning, often to learn about service needs and existing services for specific populations Participants generally work in a related field; no payment is expected Refreshments are provided Notes are taken or session is taped with participant permission HIV planning groups have typically been more likely to interview individual key informants than to use sessions 	<ul style="list-style-type: none"> Use of key informant sessions rather than interviews, to get the benefit of the interaction of knowledgeable people Participants to include recipients of services and community leaders along with other more typical key informants Can be used to discuss service needs and barriers for a particular population, as well as the adequacy of current services and what changes are needed—for example, session might focus on prevention and care for African immigrants or another target population with a high rate of HIV
Key Informant Session		

Figure 16: Some Strategies for HIV-related Community Engagement

Strategy	Definition/Description as Used in HIV Planning	Creative Applications
Roundtable	<ul style="list-style-type: none"> A single session in which a group of experienced professionals discusses the services they provide with planning body members 	<ul style="list-style-type: none"> Used by Ryan White Planning Councils to bring together dentists or medical case managers or intake workers to discuss their services, what works and what doesn't, and how improvements can be made
	<ul style="list-style-type: none"> Can be used to discuss current programs or services, identify strengths and weaknesses, and suggest and explore appropriate changes 	<ul style="list-style-type: none"> Can be used to bring together groups to explore how to strengthen specific components of the HIV prevention continuum
	<ul style="list-style-type: none"> Generally advertised widely in the appropriate provider or professional community, with an RSVP required 	<ul style="list-style-type: none"> For example, might bring together safety-net clinics that have no HIV funding to explore how to increase their involvement in testing and risk reduction, or how they might collaborate with HIV-focused providers
	<ul style="list-style-type: none"> Participants might include 5-10 experts and a committee of about 4-6 from the planning body 	<ul style="list-style-type: none"> Participation asks individuals to share professional expertise and takes less than half a day of their time
	<ul style="list-style-type: none"> Set of key questions sent out ahead, but time allowed for other discussion as well 	<ul style="list-style-type: none"> Facilitates sharing of information and experience between non-HIV-focused entities and HIV specialists and planners, educational for both
	<ul style="list-style-type: none"> Session taped and summary prepared 	<ul style="list-style-type: none"> May provide input for plan, suggest program priorities, and contribute to new collaborations and changes in policies and practices
Working Group or Task Force	<ul style="list-style-type: none"> Time-limited group established to carry out a specific task or prepare a specific product for a Board of Directors or planning body 	<ul style="list-style-type: none"> Can be used to engage partners in helping to design or redesign some aspect of HIV prevention services, including people with diverse perspectives
	<ul style="list-style-type: none"> Group often includes primarily individuals with task-appropriate expertise who do not serve on the Board or planning body 	<ul style="list-style-type: none"> Can bring together individuals with a high level of expertise
	<ul style="list-style-type: none"> Often used to design a program model or recommend a solution to a problem or service challenge 	<ul style="list-style-type: none"> Sometimes used to develop service standards or other written documents
	<ul style="list-style-type: none"> Time period might range from 3-12 months depending on the task 	<ul style="list-style-type: none"> Cost is low and benefits can be very high
	<ul style="list-style-type: none"> Group is usually relatively small (7-9 people) 	<ul style="list-style-type: none"> Engagement for a limited time period may lead to interest in planning body membership or program collaboration
Working Group or Task Force	<ul style="list-style-type: none"> Staff of planning body provide logistical and communications support 	

In using any community engagement strategy, keep in mind the following lessons from experience:

- Keep in mind the importance of a multi-tiered approach, since same strategies will not work with all stakeholders.
- Ask advice from HPG members knowledgeable about specific target populations and stakeholder groups; they can help you consider what barriers/challenges in engagement you might face and how to overcome them.
- Tailor your strategies to populations you are trying to reach. Frank discussions about risk behaviors in a focus group may work well for young African American MSM with HIV, but are likely to cause extreme embarrassment to a group of older Latinas or senior citizens.
- Try to make every activity educational for your community partners. Provide information they care about in their lives and work, which might be the results of recent prevention studies, the latest epidemiological data, or current information about prevention, testing, and care services.
- Be prepared to identify and remove barriers to participation. Community residents may need transportation. Immigrant leaders may be concerned about the stigma of HIV and unwilling to participate in a town hall that with “HIV” in its theme, but happy to be part of a discussion of “critical health care issues” or to participate in a telephone focus group (where people cannot see each other and anonymity is easier).
- Going broader does not mean implementing 20 strategies at the same time. Consider flexible strategies that allow you to bring a number of different types of stakeholders to the table. For example, suppose you want to address issues faced by youth or transgender populations. Representatives of the transgender community, knowledgeable service providers, clinicians, syndemic agencies, Ryan White providers, community leaders, and researchers can all be brought together for a well-facilitated key informant group, conducted in person or online. You may still want to visit youth or transgender groups, but information gathering will be quicker and the interaction of diverse stakeholders can be illuminating.

Maintaining Communications and Engagement

Implementation of these strategies depends upon developing and maintaining a diverse and engaged group of stakeholders. Once you have established relationships, you need to use them and deepen them. Stakeholders are most likely to stay involved:

- If they play a substantive role in HIV prevention planning or service collaboration and integration,
- If the results of their work are used and disseminated, and
- If their contribution is acknowledged

In implementing community engagement, you can establish procedures that meet these needs, as described below.

1. **Once you have established relationships with partners, activate them as soon as possible.** Your community engagement process identifies the strategies you plan to use and what partners are needed for executing them. Use appropriate strategies that gradually increase in intensity:
 - Invite them to participate in a town hall
 - Ask them to help recruit people for a needs assessment survey
 - Invite them to serve on a working group
 - Ask for feedback on some proposed service models
 - Request assistance

Another way to look at this issue: establish first the relationships you are going to need first.

2. **Be organized and professional in your requests for participation and your follow up.** When you need participation from your stakeholders:
 - Make a clear, written request that is appropriate to their interests and capacity
 - Document their attendance or participation, and send a quick thank you email

- Provide feedback such as a summary of discussion at a working group that shows their ideas were listened to, documented, and considered—stakeholders are much more likely to participate in next year's town hall if they have received a summary of the results from last year's
- Where engagement involves significant time, recognize their assistance in your reports and at your meetings (think of them as volunteers who deserve recognition)

3. **Maintain regular communications and share information with stakeholders by:**

- Immediately adding new contacts to your HPG/health department HIV prevention mailing list, which ideally should allow you to categorize groups based on such factors as whether they can identify individuals to participate in planning activities, bring technical expertise, etc.
- Inviting stakeholders to information-sharing and information-gathering events
- Always providing feedback on input received—e.g., a summary of findings from a town hall meeting they attended, a summary of task force findings based on roundtables with external experts
- Routinely sending communications with useful content several times a year—e.g., a calendar of community events, quarterly electronic newsletters, a summary of the updated jurisdictional plan and a link for downloading the full plan, a summary of needs assessment findings, a calendar of community events
- Requesting email or other written input from partners on key issues—e.g., asking your provider contacts to tell you about any changes in their HIV activities resulting from your partnership
- Being sure the information you provide is in plain language and is culturally appropriate for your diverse stakeholders
- Personally checking in with key partners to provide information of special interest to them, ask their opinion, or request advice

These approaches can help you maintain and deepen stakeholder engagement. It is important to agree on who will be responsible for each of these activities. For example, HPG support staff may maintain the mailing lists. Responsibility for direct contacts with stakeholders might be shared between the health department and HPG based on who works with them more. The health department might share responsibility with the HPG for developing materials to share with stakeholders, with the HPG doing the electronic distribution and getting help from its staff. Be sure to define responsibilities clearly and monitor efforts.

Task 5: Use of Community Input

The purpose of this task is to help HPGs and health departments make good use of the information they obtain from stakeholders.

An all-too-common problem with community engagement is that much of the information and insights gained can be lost unless the sessions or discussions are well documented, analyzed, and shared with the appropriate committee or staff. It is not enough to document that a meeting occurred. The information gained needs to get to the people who will use it in planning and service delivery.

To ensure that community input is documented, analyzed, and made a part of the information bank:

- Develop formats for reporting on community engagement activities and have them used consistently for taking notes and summarizing content of meetings and sessions. This helps less experienced note takers include and organize information. Encourage use of plain language and logical formats.
- Make sure someone is responsible for taking content notes at every event and activity where information is sought.
- If sessions are taped, arrange immediately for someone to listen to the tape and extract and summarize useful information.
- Wherever possible, share summaries with the stakeholders who participated in sessions that generated the information. This demonstrates that the information is being used.
- Have a single “human repository” —one person who is responsible for receiving and cataloguing all types of information.
- Arrange for a presentation to the HPG at least annually that includes and identifies information from stakeholders.
- When preparing summaries, developing products, and making recommendations, give credit to community engagement stakeholders for their

ideas and feedback. They do not need to be named, but make it clear that a work group or town hall meeting or focus group generated important ideas that became part of the plan or influenced changes in the continuum of services. This helps to demonstrate to stakeholders that their input was valued and used. It also shows other users of the documents that they contain and reflect community input.

One warning from groups experienced in community engagement: Do not collect information you do not need and will not use. Do not use a strategy only so you can say, “We consulted with the community.” Make strategies meaningful, or do not use them. Stakeholders become frustrated if they feel their time was wasted or their serious concerns or recommendations were ignored. The program may not adopt their recommendations, but input provided in good faith deserves to be documented and reviewed.

Task 6: Documentation, Monitoring, and Improvement

The purpose of Task 6 is to help jurisdictions establish processes for documenting their community engagement efforts and monitoring progress on their written engagement process.

The 2012 *HIV Planning Guidance* calls for increased accountability and a results-oriented approach. Health departments and HPGs are expected to:

- Document the community engagement process
- Monitor the combined profile of HPG members and stakeholders to ensure “the appropriate diversity of stakeholders and communities in developing and implementing” the jurisdictional plan⁵⁹
- Monitor the community engagement strategies designed to increase agency coordination and service integration

Monitoring is a shared responsibility of the health department, HPG, and CDC as funder. Monitoring activities and key questions from the *Guidance* that relate to community engagement are provided in Figure 17.

A Typical Reporting Format for Community Engagement Activities

- Type of Activity/Title of Event
- Date, Time, and Location
- Name of Person Preparing this Report
- Whether Tape Recording is/is not Available
- Participation (number and description of participants)
- Summary of Issues Addressed and Information Obtained (arranged around agenda topics or questions discussed)
- Key Findings, Areas of Consensus, and/or Recommendations
- Suggested Use of Information Obtained
- Attachments (list of participants with contact information; copy of agenda or questions addressed, other resource materials, other)

Figure 17: Monitoring Activities and Key Questions Related to Community Engagement (from the 2012 HIV Planning Guidance) Monitoring Activities:

1. Working with the health department on monitoring the results from the engagement activities and strategies to ensure that they are in alignment with the Jurisdictional HIV Prevention Plan and the goals set forth in NHAS
2. Reviewing the engagement process and strategies to ensure that they meet the needs of the Jurisdictional HIV Prevention Plan
3. Continually assessing key stakeholder involvement and ensuring that the Jurisdictional HIV Prevention Plan is updated when needed

Monitoring Questions:

1. To what extent did HIV service providers and other stakeholders who can best inform the coordination and collaboration of HIV prevention, care, and treatment services participate in the planning process?
2. To what extent did the engagement process achieve a more coordinated, collaborative, and seamless approach to accessing HIV services for the highest-risk populations?
3. To what extent was input from HPG members, other stakeholders, and providers used to inform and monitor the development (or update) and implementation of the Jurisdictional HIV Prevention Plan?

These activities and questions involve both *process* and *outcomes* monitoring and assessment. They ask whether the community engagement process was implemented as planned (process), what activities were carried out (outputs), how diverse the effort was and what level and range of participation was accomplished (quality and appropriateness). Thus, they ensure that input was obtained from a diverse group of stakeholders with the necessary knowledge and skills to support the development or updating of the jurisdictional plan, and to address the coordination and collaboration of HIV prevention, care, and treatment services. They also address short-term outcomes—whether the input obtained was used to inform and update the plan, and whether results were in alignment with the plan and NHAS goals. In addition, they identify a longer-term desired outcome to “achieve a more coordinated, collaborative, and seamless approach to accessing HIV services for the highest-risk populations.”⁶⁰

Many HPGs have identified monitoring community engagement as among the greatest challenges they face. Most have done documentation and monitoring rather than results-oriented assessment. An added challenge is that results often take years rather than months to become measurable.

One way to approach monitoring responsibilities is to determine your monitoring and evaluation questions and then figure out how you will measure success (indicators), your information sources, and who will be responsible. Figure 18 is a model chart using the three monitoring questions from the guidance. You may want to add specific monitoring questions related to your jurisdiction and your unique community engagement process.

Figure 18: Sample Monitoring and Results-Oriented Evaluation Chart

Question	Indicators	Data Source	Responsibility
Process Evaluation (Progress/Task Completion, Outputs, Quality of Community Engagement)			
To what extent did HIV service providers and other stakeholders who can best inform the coordination and collaboration of HIV prevention, care, and treatment services participate in the planning process?	<ul style="list-style-type: none"> Planning Group Membership Stakeholder list non-members and affiliations indicates necessary mix Documentation of implementation of the process and strategies 	<ul style="list-style-type: none"> Stakeholder Matrix (See Section 5) Documentation of community engagement meetings and other activities Review community engagement process against actual activities 	<ul style="list-style-type: none"> Matrix prepared by HPG Documentation prepared by HPG and health department staff responsible for each activity Analysis and assessment by health department, with assistance from HPG staff
To what extent was input from HPG members, other stakeholders, and providers used to inform and monitor the development (or update) and implementation of the Jurisdictional HIV Prevention Plan?	<ul style="list-style-type: none"> Information in plan obtained through specific community engagement activities or from particular stakeholders Specific implementation activities developed or refined as a result of community engagement 	<ul style="list-style-type: none"> References in plan that specify source of information Information presented to HPG committees and full body regarding use of input from community engagement for plan and implementation 	<ul style="list-style-type: none"> Updated plan reviewed by HPG and health department staff to determine use of stakeholder input Letter of concurrence prepared by HPG describing the process used to provide input or review the plan

Figure 18: Sample Monitoring and Results-Oriented Evaluation Chart

Question	Indicators	Data Source	Responsibility
Outcomes Evaluation (Results)			
To what extent did the engagement process achieve a more coordinated, collaborative, and seamless approach to accessing HIV services for the highest-risk populations?	<ul style="list-style-type: none"> Level of documented change in coordination, collaboration, and access to HIV services: <ul style="list-style-type: none"> Awareness of services as indicated by high-risk populations Number and characteristics of individuals accessing services Data based on the Continuum of Engagement in Care or Treatment Cascade—number of new diagnoses, percent linked to care, percent retained in care, percent with viral suppression Number of MOUs or other collaboration agreements between health department and HIV service providers 	<ul style="list-style-type: none"> Needs assessment (focus groups, target population surveys, town halls, and other sessions with individuals) Provider data on service utilization (testing, linkage to care, retention in services such as prevention with positives, primary care) Annual (“cohort”) data documented in Continuum of Engagement in Care or Treatment Cascade Data collected and compared annually to determine changes (comparison with baseline data) Health department records of MOUs and collaboration/coordination 	<ul style="list-style-type: none"> Health department staff, using data from surveillance unit and providers Assistance from HPG and its staff re needs assessment data

Documentation: As the chart indicates, the community engagement process must include procedures for documentation as a basis for monitoring. Most of the required documentation is integrated into the process presented in this toolkit. For example:

- If the HPG uses the suggested Stakeholder Matrix (Tool #I, in Section 5), it documents the identification and analysis of possible stakeholders. It also has information on the selection of stakeholders that, as a group, provide comprehensive and diverse input to the jurisdictional plan and updates, and to improve service coordination and collaboration. By reviewing the actual participation of these stakeholders, you can assess how adequate your mix of stakeholders is in providing input to your plan and its implementation.
- The written community engagement process should include responsibilities for documenting community engagement activities and the content of information obtained. If you use the model format discussed in Task 2 and provided in Section 5 (Tool #IV), that information can help you determine whether planned strategies were used and planned stakeholders participated.
- If you use a Reporting Format like the one described in Task 5, you will have enough information to document the level, diversity, and content of input obtained through community engagement.

Monitoring and Assessment: Reviewing and summarizing information that is already being collected will answer most of the community engagement-related monitoring questions. The one question it will not address is: to what extent does the engagement process achieve “a more coordinated, collaborative, and seamless approach to accessing HIV services for the highest-risk populations”?⁶¹ You must typically measure this longer-term outcome over a period of at least several years. However, the health department and HPG collects information annually that can assess progress towards that outcome—and much of the data is already being collected for other purposes.

Evaluation of Results: As summarized in the Evaluation Chart, indicators or measures might include the following required data, which the health department should have access to:

- One indicator of coordinated and seamless services is the extent to which individuals who are at risk for HIV are aware of and can obtain the full range of HIV prevention and testing services available within the jurisdiction. This information can be sought from members of highest-risk populations—as defined based on epidemiological data—through needs assessment and community engagement strategies such as town halls and focus groups, based on appropriate questions.
- Actual access to care can be assessed using provider data on individuals receiving HIV prevention services.
- Changes in perceptions and utilization data year to year can help determine whether improvements are occurring.
- The extent to which an HIV-positive person is informed about available services is a useful question for focus groups, surveys, town halls, and other sessions, particularly sessions with individuals from highest-risk populations.
- Actual linkage to and retention in care are being measured by most jurisdictions through treatment cascades (used in care and treatment) and the continuum of engagement in care (used in prevention).
- Progress in collaborating in the delivery of care can be measured through documenting new MOUs or other collaboration agreements with non-HIV-focused service providers, a direct activity within community engagement.

Responsibilities: Someone should be responsible for summarizing community engagement activities and value, as well as for obtaining provider and continuum of engagement in care data. As suggested in the Evaluation Chart, this might be health department or HPG staff, perhaps with assistance from a subcommittee within the community engagement committee.

Reporting: The use and value of community engagement can be reported to the HPG and CDC through any or all of the following:

- Charting progress on activities and results stated in the written community engagement process
- Regular reports at HPG meetings
- Meeting minutes
- Summaries of community engagement strategies and specific events or activities and the input they generated, included in the plan update
- References to community engagement progress in the letter of concurrence
- A special summary of community engagement that might be prepared annually and used to help engage new partners

Success Factors/Best Practices

A review of HIV-related community engagement efforts and other public health programs' work suggests several key success factors—sound practices that are usually present in successful community engagement initiatives, efforts that over time contribute to positive health-related outcomes.

- **An appropriate structure to guide community engagement and appropriate people to implement it**—including an HPG committee or other entity with primary responsibility for developing and helping to execute the community engagement process
- **Clear and well communicated purposes and priorities for community engagement**—what it is designed to accomplish in the short term and the long term
- **Genuine respect for diverse groups and cultures** and a willingness to learn from them
- **Recognition that a wide range of stakeholders is needed to provide varied perspectives and insights**—including those who establish policies and programs, help implement them, receive services from them, study them, and fund them

- **Clearly defined roles and responsibilities** for the HPG, health department, and partner organizations
- **Use of multiple strategies** in innovative as well as traditional ways, adapted appropriately for particular populations and types of stakeholders
- **Well defined procedures for gathering, summarizing, analyzing and using information gained through community engagement**—ensuring that stakeholders receive feedback on their input
- **Willingness to share leadership and allow involvement in decision making**—increasing stakeholder commitment to community engagement

Challenges and Failure Factors

Just as some approaches, principles and attitudes contribute to successful community engagement, others make success more difficult and unlikely. Absence of the positive factors described above seems to invite failure. Likewise, experience within HIV prevention, care, and treatment and in other areas of public health indicates that the following factors are particularly damaging to community engagement efforts:

- **Unwillingness of leaders to reach out beyond their inner circle and “comfort zone” to engage a wider groups of partners**—decision making is closely held; the same “old guard” makes decisions and consults the same small group of partners each year; emerging high-risk populations are largely ignored, and services are not changed to meet new needs or reflect new knowledge
- **Disorganization**—lack of clearly defined responsibilities, multiple uncoordinated contacts with potential partners, and no one in charge of organizing and coordinating the effort
- **Domination of the process by one group, creating a lack of parity, inclusion, and representation** regardless of whether the leadership group is providers, members of target populations, health department or other public agency personnel
- **Inability to engage high-risk populations** so the perspective of potential users of services is missing and bad decisions are made
- **Politics - with a small “p”** —the planning body is perceived to represent a particular segment of the community and to be unresponsive to others, health department priorities and funding decisions do not appear to be based on data, and the community broadly distrusts the process
- **Insufficient human and other resources**—it is hard to do a good job with community engagement because not enough people are willing and committed to help make it happen, and there are few staff or other resources to support the work
- **Low priority for community engagement due to other responsibilities**—other tasks are seen as more important, the process lacks champions, the view that the program should “do the minimum” to meet funder requirements prevails, and potential partners recognize the lack of genuine commitment to the process
- **Lack of skills and experience**—there is a lack of understanding of community engagement and how to plan and implement it

Media • Community • Community • Engagement • PH
 Schools • Church • Synagogue • Mosque • Temple • I
 Lawyers • Social • Club • Colleges • Universities • CO

4. Examples of Effective Community Engagement

This section provides examples of strategies used successfully to engage a wide range of stakeholders in HIV planning or program implementation. The examples are presented in two charts. Figure 19 describes strategies used by HIV planning bodies—prevention, care and treatment, and integrated—to assist with planning or with increasing program coordination and collaboration. Figure 20 provides examples of collaboration by stakeholders (some of them non-traditional) in the implementation or integration of HIV prevention services. Some of these strategies were initiated by or involve collaboration with health departments. They are included to suggest strategies for increasing access to and integration of HIV prevention services. Some examples were obtained through interviews. Others have been documented in writing, and sources are provided for HPGs and health departments that would like additional information.

Figure 19: Examples of Effective Community Engagement by HIV Planning Bodies

Model/Project/ Topic	Description	Results	Notes/Related Initiatives
Newsletters from consortia and local and state health department ⁶²	<p>A number of HIV consortia and local and state health departments (among them Pennsylvania, Delaware, Kansas City, North Dakota, Connecticut, and New Jersey), inform their stakeholders of HIV news and recent activities through regular newsletters</p> <ul style="list-style-type: none"> Newsletters are usually quarterly or bi-annual Amount of information and depth varies by jurisdiction Some newsletters (e.g., the New York newsletter) are “state of HIV” reports that provide latest data on HIV and AIDS incidence and prevalence and epidemiologic trends in the jurisdiction Newsletters may be distributed by e-mail, by regular mail, and through the Internet through posting on websites Some newsletters (e.g., the Connecticut newsletter) are prepared in English and Spanish 	<ul style="list-style-type: none"> Stakeholders receive regular information about HIV planning and services Stakeholders receive recognition for their efforts Broad distribution and Internet access can lead to new stakeholders 	

Figure 19: Examples of Effective Community Engagement by HIV Planning Bodies

Model/Project/ Topic	Description	Results	Notes/Related Initiatives
Learn+Link+Live Educational Forums – Phoenix, AZ Ryan White Planning Council ⁶³	<p>The Phoenix Ryan White Part A Planning Council (PC) created a series of Learn+Link+Live educational forums to help consumers to learn about available services, how to apply for them, why it is so important to enter and remain in HIV-related care, and how to keep from transmitting HIV. The forums targeted Ryan White-eligible PLWH, with special focus on including people who knew their status but were not receiving HIV-related primary medical care. PLWH in care were encouraged to use the “each one brings one” approach to invite out-of-care individuals to go to a forum with them. The PC’s consumer committee organized and planned the forums, with help from PC support staff. The organizers:</p> <ul style="list-style-type: none"> Involved both PC-member and other PLWH in design and implementation Marketed through local magazines and newspapers, local bars and bookstores frequented by the community, HIV service providers and non-HIV service providers, announcements at planning group meetings, and PLWH word of mouth Insisted on high quality content and logistics, including advertisements, presentations, location, meals, materials, etc. Raised donations from drug companies and a variety of local businesses and other sources to cover most expenses, including raffle items (including major items like TV sets) and incentives (such as gift cards) for PLWH who brought with them their out-of-care peers Involved other county agencies to participate—bringing materials and running workshops, including housing, aging, and other topics Provided testing and linkage opportunities at the forums Included sessions not directly related to HIV but much in demand by PLWH, like poetry readings Had specialized forums, including forums in Spanish Surveyed participants to document and improve the process, and asked individuals not in care to provide contact information for follow up 	<ul style="list-style-type: none"> A number of PLWH were brought into care PLWH participation in the consumer committee and other planning activities increased Participants increased their understanding of available HIV services, eligibility requirements, and how to apply Participants received information and written tools to enable them to make informed decisions about topics such as risk behavior, treatment, and communicating with their health care provider 	<ul style="list-style-type: none"> In addition to broadening community engagement, educational forums provide opportunities for training

Figure 19: Examples of Effective Community Engagement by HIV Planning Bodies

Model/Project/ Topic	Description	Results	Notes/Related Initiatives
Service-focused Roundtables— Washington, DC Ryan White Part A Program	<p>The Washington, DC Regional Ryan White Planning Council uses service-focused roundtables to engage a variety of stakeholders in in-depth discussion about service issues, strengths and weaknesses of particular service models and standards, and recommendations for service improvements.</p> <ul style="list-style-type: none"> Roundtables have focused on such service areas as Emergency Financial Assistance (food vouchers, utility payments, and emergency housing assistance), Medical Case Management, and Oral Health Sessions typically last 2-3 hours Participants include HIV service providers, non-HIV service providers, consumers of services, researchers, AIDS Education and Training Center representatives, and health department and administrative agency representatives from several jurisdictions A set of key questions and topics is developed for each roundtable Some roundtables address identified concerns about services or the need to refine service standards or models Roundtables are facilitated by the PC leadership or someone else knowledgeable about the topic 	<ul style="list-style-type: none"> Roundtables often involve individuals not previously engaged in HIV planning Input often informs decision making about Standards of Care or service models Experts participating in the roundtables often provide new information about technical aspects of treatment or about special considerations in providing services (such as dental care) to PLWH Recommendations can lead to increased access to care, greater consistency in service eligibility across jurisdictions, improved service standards and models, and new partners for the PC 	

Figure 19: Examples of Effective Community Engagement by HIV Planning Bodies

Model/Project/ Topic	Description	Results	Notes/Related Initiatives
Community Forums, Town Halls, and Re- gional Meetings—Con- necticut HIV Planning Consortium ⁶⁴ and the Washington, DC Ryan White Part A Program	<p>Many prevention and care planning bodies use town halls or annual HIV com- munity forums to disseminate information about HIV planning and services and to obtain community input for development or updating of jurisdictional plans and (for Ryan White planning bodies) for the annual priority setting and resource allocations (PSRA) process. The Connecticut HIV Planning Consortium (CHPC) and the Washington, DC Regional Ryan White PC provide examples of how this strategy can be used.</p> <p>In Connecticut:</p> <ul style="list-style-type: none"> Community forums include consortium members and staff, PLWH who are often consumers of services, health department representatives, and HIV prevention and care providers, with and without federal funding The consortia and participants share their perspectives regarding local PLWH needs and gaps in services, and inform community members and agencies about the range of services and resources available in their area Community forums are held in a different location every year Information collected at the forums is shared and incorporated into the integrated prevention and care plan <p>In the Washington, DC area: The Washington, DC Part A program encom- passes the District of Columbia and parts of the three other states, including suburban Maryland, Northern Virginia, and two counties in West Virginia. The PC has a Consumer Access Committee (CAC), as well as four jurisdictional PLWH subcommittees. Prior to development of a new comprehensive plan every three years and as input to the PSRA process each year, the CAC hosts a town hall for the entire service area and each jurisdictional subcom- mittee hosts a town hall meeting. For the PSRA process there are two additional sets of jurisdictional sessions held in the spring and early summer:</p> <ul style="list-style-type: none"> A town hall meeting to obtain PLWH input into service strengths, weaknesses, service needs and gaps; testing issues; factors that keep people in care or keep them out of care; most needed services; and other issues of concern 	<ul style="list-style-type: none"> Planning bodies obtain up-to-date information on perspectives of local target populations regarding HIV- related services, as well as needs and barriers to services Broader community engagement is achieved – when participants see that their input is used in improving service access and quality, they are often more willing to become involved in planning— individuals attending the town halls or community forums may join committees or the planning body Participating providers are able to communicate jurisdictional needs and hear from their clients about issues affecting access to services and retention in care— and sometimes make appropriate improvements on their own initiative In prevention and care programs that must plan for and maintain a continuum of HIV services in multiple jurisdictions (sometimes including parts of several states for Ryan White Part A), carefully planned and well executed town hall meetings or community forums provide important information on the similarities and differences in health care systems and service needs and gaps, which allows for locally determined priorities and improvements in the system of HIV services 	<ul style="list-style-type: none"> CHPC is the integrated prevention and care planning body for the State of Connecticut

Figure 19: Examples of Effective Community Engagement by HIV Planning Bodies

Model/Project/ Topic	Description	Results	Notes/Related Initiatives
	<ul style="list-style-type: none"> • A data presentation session attended by consumers and providers of services as well as health department representatives at which jurisdictions can modify the regional priorities to fit local needs • A session where jurisdictions recommend how funding should be allocated for the coming year, which goes to the PC for review and approval <p>Lessons learned by planning bodies about best practices for community forums and town hall meetings include the following:</p> <ul style="list-style-type: none"> • Especially in rural areas, considerable attention must be focused on outreach to ensure good attendance by PLWH, including the need to arrange transportation and ask PLWH already involved and providers to reach out to PLWH • Invitations should be explicit about the meeting's purpose, specific information sought, who is invited to participate, the meeting's structure and format, and how to request transportation assistance • Since stigma is often a concern, especially among certain populations and in rural areas, invitations should not be HIV-specific • Sessions require clear questions encouraging in-depth discussion, not yes or no answers, and tailored to the jurisdiction and its key target populations • Facilitators should be well prepared and informed about the nature of the local epidemic, and take detailed notes • It is important to provide participants with relevant information, oral and written (e.g., an updated epidemiological profile and client utilization data, definitions and descriptions of fundable service categories, a summary of their input from the previous year, and specific feedback on how their input was used in developing or updating the plan or influencing funding priorities and decisions) 	<ul style="list-style-type: none"> • In one rural jurisdiction that had recently changed service providers, concerns raised at a community meeting led to significant changes in the system of HIV services, to make services more accessible and to better meet consumer needs; for example, a provider: <ul style="list-style-type: none"> - Outstationed medical case management staff one or two days a month in a rural county to reduce travel for clients - Arranged regular weekly hours for the HIV specialist in its clinic to permit more face-to-face meetings of clients with the clinician - Initiated a women's support group 	

Figure 19: Examples of Effective Community Engagement by HIV Planning Bodies

Model/Project/ Topic	Description	Results	Notes/Related Initiatives
Population Access to Services Exercise for Community Meetings—Used in Norfolk, Phoenix, and other Ryan White program locations through Mosaica's Project Consumer LINC (Linking Individuals into Needed Care) ⁶⁵	<p>This exercise was developed for use in community meetings designed to provide input to the planning process. It emphasizes identifying any aspects of the current system of care that may make it hard for a particular group of PLWH to find or enter care. It helps community representatives become informed about service access and quality of care for specific target populations, such as PLWH who are newly diagnosed, new to the jurisdiction, or out of care.</p> <ul style="list-style-type: none"> • PLWH typically have a leadership role in planning; by: facilitating or assisting with facilitation; taking the lead on reviewing and presenting findings and helping to identify ways to refine the system; managing the session through the PLWH committee, with consultation from the committee responsible for coordinating input to plan development. • Session participants are divided into small groups, with each group assigned to take the role of an individual who is from an important group of PLWH and is out of care (aware or unaware) • Tasks are assigned so that most participants are responsible for doing this analysis for a PLWH who does <i>not</i> come from their own background. For example, a group might be asked to “become” a 62-year-old white widow who has just been tested and diagnosed with full-blown AIDS, or a young Latina mother of two who just moved to town, has two children, no car, and has been living with HIV for five years. The groups should include one resource person (a planning body member or volunteer) who is knowledgeable about the population, but consist largely of individuals who do not fit this category • The groups address questions regarding how this PLWH would likely find out about the availability of testing or care services; through what point of entry this PLWH might attempt to obtain services; what barriers this PLWH might face; and whether this PLWH could navigate the system to obtain needed services, as well as to what extent culturally appropriate services are available for such a person 	<ul style="list-style-type: none"> • Through the combination of small group work and full group discussion, all participants gain a better understanding of the system of prevention and care • Participants better understand how the system works (or does not work) for diverse groups of affected and infected community members and experience how planning requires attention to the needs of many groups, not just their own—helps participants become planners concerned about the entire community rather than primarily advocates for groups they represent or know best • This type of engagement in planning for improved access to care and for service improvements contributes to a higher level of community engagement in improving the system 	

Figure 19: Examples of Effective Community Engagement by HIV Planning Bodies

Model/Project/ Topic	Description	Results	Notes/Related Initiatives
Population Access to Services Exercise for Community Meetings—Used in Norfolk, Phoenix, and other Ryan White program locations through Mosaica's Project Consumer LINC (Linking Individuals into Needed Care) ⁶⁵	<ul style="list-style-type: none"> Results of the small group discussions are brought to the whole group—and the group presents both its analysis and its unanswered questions for additional full-group discussion Someone (generally staff) takes notes and provides them to the responsible planning body committee (often the PLWH committee) to be reviewed, analyzed, and presented to the PC Based on the information provided, the PC and grantee work together to develop plans to make needed refinements in the system of care This exercise was originally developed for use with Ryan White planning councils, but was extended for use by task forces, committees, PLWH groups and caucuses, and community forum participants—it works well with both PLWH and other diverse stakeholders, and can address prevention, testing, and care issues Participants should be a diverse group of PLWH, providers, and health department staff, plus other interested stakeholders PLWH have a leadership role to plan; facilitate or assist with facilitation; lead in reviewing and presenting findings, and help to identify ways to refine the system 		
Focus Group Facilitator Training for PLWH—Detroit, MI, through Mosaica's Project LINC ⁶⁶	<p>This initiative of the Detroit Ryan White Part A Planning Council involved training PLWH as focus group facilitators so they could assist with needs assessment and community planning. The State Part B program sent several PLWH to participate.</p> <ul style="list-style-type: none"> 17 community members from Detroit and other parts of Michigan and received training to prepare them to serve as focus group facilitators The full-day interactive training included a number of exercises and small group activities 	<p>A number of peer focus group facilitators are now available</p> <p>PLWH obtained a new set of skills that are both useful and transferable</p> <p>They reported feeling a sense of pride and fulfillment following successful implementation of the focus groups</p>	<p>Experience indicates the importance of ensuring that graduates of the training receive an opportunity to use their skills as focus group facilitators or in similar roles; if this does not occur, the result is disappointment and reduced interest in further engagement with the planning body</p>

Figure 19: Examples of Effective Community Engagement by HIV Planning Bodies

Model/Project/ Topic	Description	Results	Notes/Related Initiatives
	<ul style="list-style-type: none"> The intent was to first have the newly trained facilitators work with a more experienced facilitator and then to have them work in pairs to facilitate, take notes, and summarize input obtained from focus groups Following the training, a number of participants facilitated focus groups as a part of the Part A needs assessment Training was repeated a year later to prepare additional PLWH 	<p>Consumer engagement in the Ryan White planning process has increased</p> <p>A number of the focus group participants became more involved in community planning and were recruited and selected to serve as members of the PC the Michigan HIV/AIDS Council (MHAC), a statewide integrated prevention and care body</p>	<p>A number of other state and metropolitan planning bodies have trained or considered training community members to participate in various aspects of needs assessment, such as interviews and support with surveys, key informant interviews, and community forums</p>
Youth Advisory Group— Connecticut HIV Planning Consortium ⁶⁷	<p>The Youth Advisory Group (YAG) to the Connecticut HIV Planning Consortium (CHPC) gives youth a voice in the HIV planning process. The Consortium looks to YAG for advice and innovative ideas and partners with the group in developing and implementing new programs. YAG:</p> <ul style="list-style-type: none"> Helps develop the youth-focused component of the prevention plan Assists in organizing outreach and education activities, events, and strategies, including the use of social media Produced public service announcements targeting teens, which were shared with media outlets and posted on the Internet (e.g., YouTube; Facebook) Produced a youth magazine for distribution at youth centers and high schools 	<p>CHPC has a reliable source of advice from a youth perspective</p> <p>CHPC and the health department receive assistance in achieving their HIV prevention planning goals</p> <p>Youth are actively engaged and nurtured to become future leaders—for example, YAG graduates who age out of the group can apply for membership on the CHPC</p>	<p>In jurisdictions where planning bodies have difficulty engaging certain populations, planning bodies can either form an advisory group or reach out to an existing community or provider-related group</p> <p>Several planning groups discussed obtaining ongoing youth input from a youth advisory body associate with a Ryan White Part D, the Consumer Advisory Body (CAB) of a youth-serving organization, or an existing group of trained youth mentors or a support group of youth associated with a prevention provider</p>

Figure 19: Examples of Effective Community Engagement by HIV Planning Bodies

Model/Project/ Topic	Description	Results	Notes/Related Initiatives
Work Groups, Task Forces, and Caucuses of Planning Bodies—multiple jurisdictions ⁶⁸	<p>Many planning bodies invite non-members to serve on standing committees or to participate as members of work groups, task forces, or caucuses, which may be time-limited or ongoing.</p> <ul style="list-style-type: none"> • Work groups and task forces are usually topic-specific; they often are responsible for a specific task and/or product, such as providing recommendations for increasing routine testing in specified health care settings or helping to redesign a linkage to care program, and exist only for the time period required to complete that task • They may address issues that are cross-cutting—issues of interest to more than one planning body committee • Caucuses are often ongoing population-specific bodies and serve as liaisons between the planning body and specific communities of interest, such as PLWH, high-risk negatives, African Americans, or Latinos • A planning body member often chairs or co-chair such groups to ensure close coordination with the planning body • Non-planning body members may include providers and researchers recruited for their expertise or other external experts such as clinicians and representatives of other sectors; depending on the group's focus; caucuses often have open membership to anyone who comes from the specified population group • The South Carolina HIV Planning Council (an integrated prevention and care planning body) has work groups for specific populations, including adolescents, incarcerated, and Latinos; they meet between HPG meetings and provide updates to the HPG at each meeting • The Broward County HIV Prevention Planning Council has four workgroups “open to the public” that focus on its four major target groups: Blacks, Latinos, MSM of all races, and Transgender people 	<ul style="list-style-type: none"> • The planning body gains advice and often intensive assistance from diverse stakeholders who often bring a great deal of training and/or experience • Stakeholders who do not have the time to serve as planning body members are able to participate in a time-limited task that uses their expertise • Community members become engaged with the planning body and may decide to seek membership; caucuses and work groups are often sources of new members, including consumers and members of high-priority target populations 	

Figure 19: Examples of Effective Community Engagement by HIV Planning Bodies

Model/Project/ Topic	Description	Results	Notes/Related Initiatives
Work Groups, Task Forces, and Caucuses of Planning Bodies—multiple jurisdictions ³¹	<ul style="list-style-type: none"> San Francisco's HIV Prevention Planning Council (HPPC) uses a small number of task- and time-defined work groups; current work groups include: <ul style="list-style-type: none"> Collaborative Planning—to develop a plan for how HIV prevention and care will work together over the next five years Community Engagement—to implement the 2013 San Francisco HPPC annual community engagement meeting Measurements of Success workgroup—to review and select measures of success for HIV prevention efforts Policies and Procedures—to review, develop, and update HPPC policies and procedures Houston HIV Prevention Planning Group (HPPPG) has six task forces: Latino, Hepatitis C, Syphilis, Youth, African American, Urban, and STDs among MSM 		
Use of New Media—New York City	<p>The New York City HIV Prevention Planning Group uses social networks and online media to engage the community and encourage discussion of HIV prevention issues. For example:</p> <ul style="list-style-type: none"> Frequent postings on the group's Facebook page announce events, provide articles and HIV-related news, and solicit feedback from the broader community Live tweeting during HPG meetings increases and engages followers on Twitter The group developed a video "commercial" with current HPG members describing the value of engagement in HIV planning and why others should become involved; it was put on a YouTube network created by the HPG and is also shown at community events A number of opportunities exist for engagement by non-HPG members, such as participation in work groups (now organized around interventions rather than populations) but committed to diverse participation. 	<ul style="list-style-type: none"> Increased visibility through Facebook, Twitter, and YouTube Increased ability to reach younger people 	

Figure 19: Examples of Effective Community Engagement by HIV Planning Bodies

Model/Project/ Topic	Description	Results	Notes/Related Initiatives
Statewide HIV/AIDS Conferences	<p>A number of jurisdictions use statewide HIV/AIDS conferences as outreach events to the broader community; for example:</p> <ul style="list-style-type: none"> Every other year, Iowa has an annual HIV, STD, and Hepatitis conference designed for community health planners, community leaders, educators, health department personnel, health professionals, faith community members, CBOs, consumers, teachers, and other community members.⁶⁹ The conference is co-sponsored by the Department of Health, Department of Education, and HIV Prevention and Care Planning Group, which has a standing committee in charge of the conference⁷⁰ San Francisco's HPPC holds annual community engagement meetings. It has a work group in charge of the meetings⁷¹ 	HPG identifies and recruits new non-traditional partners	
Broadening Stakeholder Contacts—Pennsylvania	<ul style="list-style-type: none"> Pennsylvania recently integrated its HIV prevention and care planning. The University of Pittsburgh coordinates the HPG and provides other services including needs assessment. It uses a variety of innovative approaches to reach a broader mix of stakeholders throughout the state. Some examples: <ul style="list-style-type: none"> The University has set up the HIV/AIDS Service Providers (HASP) system, which does outreach and collects in-depth information about HIV service providers and providers of a wide range of medical-related and support services needed by PLWH; the system provides information on a variety of potential partners and stakeholders for needs assessment and community engagement The HPG reaches out to non-traditional stakeholders by presenting at meetings and conferences; for example, the Community Co-Chair presented the HPG's work and commitment to community engagement and obtained participant input to update the plan at the annual Department of Health statewide capacity-building conference The HPG and health department use the state's treatment cascade/continuum of engagement in HIV care to identify and target populations, locations, providers, and community groups—for example, if they identify a particular population or location with a low rate of entry into care, they target that population and location, identify providers that can serve as points of entry into care, and engage them in identifying and recommending strategies for overcoming barriers as input to their plan updates 	<p>These efforts are leading to increases in diverse stakeholder contacts and the potential for additional engagement. Important lessons learned include the following:</p> <ul style="list-style-type: none"> It is important to ensure that when a first contact is made with a stakeholder, the request is specific, tailored, and appropriate to who they are and what expertise they have, which means good planning prior to contacts It is also important to go beyond the initial approach and invite broader feedback and additional engagement, providing access to appropriate documents and offering a contact to continue the dialogue Contacts made during needs assessment should be made a part of the community engagement network 	

Figure 19: Examples of Effective Community Engagement by HIV Planning Bodies

Model/Project/ Topic	Description	Results	Notes/Related Initiatives
Older Adults and HIV Work Group— Washington, DC	<p>The Older Adults and HIV Work Group was established as a collaboration between the Department of Health's HIV/AIDS, Hepatitis, STD and TB Administration (HAHSTA), the DC Office on Aging, other DC agencies, community members, and service providers in the District of Columbia, and several experts from outside the District.</p> <ul style="list-style-type: none"> Initiated by HAHSTA, the Older Adults and HIV Workgroup met over a period of months to explore issues related to HIV prevention, testing, and linkage to care for older residents, and to advise HAHSTA on creating program models and materials to engage older adults on sexual health, HIV/STDs, relationships, condom use, and medical care and treatment The group created a framework, including strategies and tools for providers and the community The work brought together a diverse group of people, including public agency personnel, older PLWH, line staff from provider agencies including individuals with extensive practical experience, policy analysts, funders, researchers, etc. Planning included representatives of HIV prevention and care Findings and recommendations of the work group were used in the District's Enhanced Comprehensive HIV Prevention Planning and Implementation (ECHPP) project The working group is now chaired by the DC Office on Aging and includes the DC Department of Health, the Department of Housing and Community Development, Department of Parks and Recreation, and others It coordinates DC, federal and non-governmental agencies to develop an effective HIV awareness and prevention program targeting adults at risk in DC 	<p>The Work Group addressed a high priority issue for the District of Columbia; 41% of PLWH in the District are 50 years old and older, and this group has one of the highest rates of late testing (either have AIDS at first diagnosis or within 12 months after diagnosis)</p> <ul style="list-style-type: none"> In-depth collaboration that guided development of materials and influenced design of programs The Mayor endorsed the recommendations concerning older citizens, including a recommendation to encourage all area jurisdictions to raise the recommended age of HIV screening to age 84 The Mayor agreed to support national advocacy regarding older citizens⁷² 	

Figure 20 describes several examples of collaborative HIV outreach, education, and prevention efforts—community engagement efforts that can increase access to HIV prevention and care services as well as program coordination. These community engagement efforts focus on HIV services rather than planning, and were not necessarily developed as part of a planning effort. They are included because HPGs and health departments may find the strategies and models useful in addressing the second focus of HIV prevention community engagement: increasing program collaboration and service integration. They also illustrate the importance of seeking out non-traditional stakeholders and partners appropriate to a jurisdiction's needs. In these examples such partners include colleges and universities, a hip hop radio station, a marketing company, and an art school. Strategies involve techniques such as addressing HIV prevention along with other public health concerns and the use of photography for needs assessment, analysis, and action on public health issues.

Figure 20: Examples of Service-related HIV Community Engagement

Approach	Description	Notes on Implementation and Value
An annual HIV/Tobacco Prevention and Awareness Symposium—Wrightsville, Arkansas ⁷³	<p>Future Builders, a grassroots nonprofit organization in rural Arkansas, conducts an annual HIV and tobacco prevention symposium. It involves collaboration with a local community college.</p> <ul style="list-style-type: none"> The focus on tobacco prevention addresses a highly relevant issue to the HIV community; substantial evidence indicates that cigarette smoking among people living with HIV/AIDS (PLWH) represents a significant health concern Representatives of state and local health departments, health and human services providers, the faith community, community-based organizations, consumers of services, and other community members from Arkansas and other parts of the country are invited to present and participate During the symposium, local health service providers and vendors exhibit and provide services, including HIV testing, with immediate linkage to care for anyone who tests positive The focus of the symposium changes every year, including topics such as the LGBT community, youth health, cost of care, etc. 	<ul style="list-style-type: none"> Tobacco use and cessation is an important issue to the HIV community By combining the topics of HIV and tobacco, the group can reach a broader and more diverse group of stakeholders than would have participated in an HIV-specific symposium By collaborating with a local community college, the community-based organization can involve young adults and obtain a safe, convenient, well known location for the symposium Exhibitions help in building a larger network of partners, including nontraditional partners and vendors, and greater community participation

Figure 20: Examples of Service-related HIV Community Engagement

Approach	Description	Notes on Implementation and Value
<p>Do One Thing, Change Everything—Southwest Philadelphia, PA⁷⁴</p>	<p>This campaign to increase HIV testing in Southwest Philadelphia engages the community and several non-traditional partners, using neighborhood testing strategies developed and coordinated with input and feedback from local stakeholders.</p> <ul style="list-style-type: none"> • The project is collaboration between Brown University (lead partner), Uniworld's Group for Multi-cultural Marketing, and Clear Channel Outdoor, which specializes in out-of-home advertising. • This community outreach and mobilization campaign includes partnerships with faith-based institutions, community-based organizations, health clinics, and businesses • A federally qualified health center (FQHC) in Southwest Philadelphia, The Health Annex, offers routine HIV testing with the support of the Philadelphia AIDS Activities Coordinating Office (AACO) • The campaign focuses on expanding testing in a specific zip code, 19143, in neighborhoods with the highest HIV burden • HIV testing counselors conduct block-by-block outreach for HIV testing events • Locations of a mobile testing van are tweeted and posted on a Facebook page • Funded by Gilead Sciences 	<ul style="list-style-type: none"> • The university-led collaborative engages diverse partners that bring resources, such as funding and manpower, and include several nontraditional partners • Marketing and advertising firms that specialize in multi-cultural and outdoor marketing provide specialized skills needed for this type of campaign • Community involvement in project design and implementation contributes to increased community engagement • This is a targeted campaign, specific zip code and neighborhoods inside the zip code, consistent with the focus on High-Impact Prevention • Use of social media helps to engage adolescents and young adults

Figure 20: Examples of Service-related HIV Community Engagement

Approach	Description	Notes on Implementation and Value
<p>Photovoice for Healthy Relationships—community-based HIV prevention in rural American Indian community—Wind River, Wyoming⁷⁵</p>	<p>Photovoice for Healthy Relationships is a participatory action research project and collaboration between a local nonprofit organization, a national American Indian leadership program, and the University of Wyoming College of Education. It is designed to address disparities in HIV, STI, and unintended pregnancy rates among young American Indian (AI) people in Wyoming. In 2009, the Wyoming Health Council engaged in dialogues with young people about sexuality education. Participants reported that it was rare for an adult to speak with them about reproductive health, and most said they learned about sexuality and relationships from TV, movies, the Internet, and friends. Participants felt that it would be valuable for parents, teachers, and other adults in the community to have tools for providing relationship guidance to children from an early age. They also noted that peer education is a powerful tool. The project was developed as a result of that initiative.</p> <ul style="list-style-type: none"> • The project is funded by the Wyoming Department of Health HIV Prevention Program and a mini-grant from the Region VIII Office on Women's Health • Photovoice consultation has been provided by a Professor of Counselor Education at the University of Wyoming College of Education • Participants included 18- and 19-year-old American Indians selected to serve as co-researchers • In the summer of 2010 they engaged in three days of storytelling through photography and written narratives • Four months later the group reconvened to participate as co-researchers in analysis • A community conversation was held at the Intertribal Center at Central Wyoming College, where community members and leaders discussed their reactions to the display and identified community strategies for next steps in addressing HIV, STIs, unintended pregnancy, and related youth risks—including identifying additional community events at which to present the project 	<ul style="list-style-type: none"> • Project partners include AI youth, a nonprofit organization, a university professor, and the state health department • The initiative combines education on HIV, other STIs, and unintended pregnancy, a combination of health issues of particular importance to the target population • The project's early success led to increased engagement by the partners, including the young co-researchers • The young co-researchers gained technical and leadership skills and experience • Photovoice is an innovative strategy that has been used successfully in needs assessment and project evaluation • It has proven effective in engaging children and youth in community awareness and improvement efforts, and can also be used with adults

Figure 20: Examples of Service-related HIV Community Engagement

Approach		Description	Notes on Implementation and Value
Photovoice for Healthy Relationships—community-based HIV prevention in rural American Indian community—Wind River, Wyoming ⁷⁵		<ul style="list-style-type: none"> The Photovoice project was presented at the 2nd Annual Native American Education Conference on the Wind River Reservation in October 2011 Additional plans included having the Photovoice co-researchers provide presentations on healthy relationships in community schools, using a peer education format that provides education and support for younger AI children with a focus on strengthening and supporting the wisdom of AI cultural heritage Having strong adult AI role models has empowered the Wind River UNITY Photovoice co-researchers to become positive role models for their younger peers 	<ul style="list-style-type: none"> Collaboration with a college gives the public agency (in this case a school district) access to specialized skills and resources including person power and creativity, and provides for high quality products at a relatively low cost Designer student ages are close to those of the community the campaign is focusing on, which enhances the value of the collaboration and the relevance of the products Individuals from the campaign's target community were part of the development of the campaign through the Teen Leadership Summit; this creates a sense of ownership and encourages ongoing engagement from this group
Project U/HIV-AIDS Awareness—Los Angeles, CA ⁷⁶		<p>This collaboration between the Los Angeles Unified School District (LAUSD), the largest public school district in California, and Designmatters Art Center College of Design is a peer-to-peer project designed to reinvigorate HIV/AIDS prevention efforts and condom use among African American and Latino youth ages 14-22 from the LGBTQ community in Los Angeles.</p> <ul style="list-style-type: none"> The research phase for Project U occurred over six weeks, beginning with a UCLA-led Teen Leadership Summit that focused on peer-to-peer sex education messaging for high-school youth Designmatters students met with experts on teen HIV and STD prevention A campaign was developed, including three types of media: <ul style="list-style-type: none"> Print (from billboards to bus stop ads to temporary wall “graffiti” using wheatpasting techniques) Screen-based (a website, an interactive e-mail newsletter, and smartphone applications) 3-D applications (stickers, buttons and pins, condom packaging, T-shirts, etc.) The plan was for LAUSD and Designmatters to roll the campaign out in all high schools in the school district The project was partially funded with a direct grant from CDC to LAUSD explicitly given to leverage peer-to-peer social networking media. 	

Figure 20: Examples of Service-related HIV Community Engagement

Approach	Description	Notes on Implementation and Value
Georgia Greater than HIV Tour—State of Georgia ⁷⁷	<p>The collaboration between the Georgia Department of Health, the Black AIDS Institute, and the Kaiser Family Foundation, which gave small grants to the participating colleges and universities involved a 2011 four-day testing tour of the Historically Black Colleges and Universities (HBCUs) of Georgia, including Paine College, Savannah State University, Albany State University, Fort Valley State University, and the Atlanta University Center.</p> <ul style="list-style-type: none"> The tour featured appearances from a popular African American rapper, boxer, and poet The tour was part of the national Greater Than AIDS campaign, a national media initiative⁴¹ 	<ul style="list-style-type: none"> This collaboration involved the state health department, a large health foundation, an African American think tank, and a group of HBCUs—an unusual mix of partners The tour received private funding Colleges and universities can include high-risk populations, and the approach can help to reduce perceived stigma related to getting tested
Hip Hop for HIV—Houston, TX ⁷⁹	<p>This annual testing for HIV and STI event is a collaboration between a local Hip Hop radio station and the health department in Houston.</p> <ul style="list-style-type: none"> In order to receive tickets to a concert by popular hip hop artists, participants are required to be tested for HIV and other STIs and receive results of their rapid tests as well as counseling Free testing is paid for by a local foundation About 1,400 people were tested at the 2012 event and another 8,000 prior to the event, using the health department mobile van, and in churches, pharmacies, mobile phone stores, high schools, etc. <p>Testing is done by health department staff and volunteers, including registered nurses and other people certified to draw blood (such as phlebotomists) recruited through Facebook or the event website</p>	<ul style="list-style-type: none"> The project involved a radio station as partner and uses a concert as an incentive for testing The type of incentive offered—in this case the type of concert—helps determine who will participate in the testing Private-sector funding covered the costs of testing and volunteers assisted, so costs were low The relationship between the radio station and health department appears to be ongoing, which provides other engagement opportunities
Faith in Action in Philadelphia—Philadelphia, PA ⁸⁰	<p>A joint campaign of a national Greater Than AIDS initiative and Philly Faith in Action, a collaboration of the Brown University's Global Health Initiative and over 100 community leaders in Philadelphia:</p> <ul style="list-style-type: none"> African American faith community leaders help to promote HIV testing and awareness The campaign uses a combination of billboards in the greater Philadelphia area and social media, including a website and a link to the national Greater Than AIDS Facebook page “liked” by more than 324,000 people A media campaign with African American clergy fights stigma and promotes testing and treatment HIV educational materials tailored for faith settings are made available to congregations 	<ul style="list-style-type: none"> Materials are made available to congregations

Figure 20: Examples of Service-related HIV Community Engagement

Approach	Description	Notes on Implementation and Value
<p>Advocates for Quality— Washington, DC Eligible Metropolitan Area (EMA) quality management con- sumer group</p>	<p>Advocates for Quality (AFQ) is the Consumer Involvement Subcommittee of the Response Team of the Washington, DC Eligible Metropolitan Area (EMA) Cross-Part Collaborative on quality management. The regional collaborative was established at the recommendation of the HRSA HIV/AIDS Bureau.</p> <ul style="list-style-type: none"> • The Collaborative was launched by the National Quality Center (NQC) in April 2011 to establish and sustain a systematic approach to monitoring, evaluating, and improving the quality of HIV care services for all PLWH in the EMA • It includes governmental agencies, health care providers, community partners, consumers of Ryan White services, and other stakeholders, with most of the Ryan White medical providers in the region and a number of other service providers participating in collecting and reporting data on a specified set of performance measures • A group of consumers participated in five collaborative training sessions over a year and received multiple training sessions about quality management designed especially for the group • The group provided feedback on the NCQ training design and its appropriateness for consumers 	<ul style="list-style-type: none"> • Participation in AFQ led to significant positive changes in the lives of AFQ members, who are now more involved in their own health care, have obtained new skills and knowledge, and in some cases have gained employment • With HRSA's approval, NQC is now replicating AFQ as a part of its future cross-page quality management collaboratives • NQC plans to use the patient activation curriculum developed by one of its consultants and used and refined in working with AFQ
<p>Advocates for Quality— Washington, DC Eligible Metropolitan Area (EMA) quality management con- sumer group</p>	<ul style="list-style-type: none"> • AFQ is the first and so far only group of consumers participating in an NQC collaborative that has become an organized body leading a consumer-driven quality management effort • In 2012, AFQ (then Q-PAC) was awarded \$30,000 by the HIV/AIDS, Hepatitis, STD and TB Administration (HAHSTA) of the DC Department of Health, the Ryan White Part A Grantee • Between August 2012 and February 2013, AFQ conducted five training sessions and five presentations for consumers and staff of HIV services providers in the region • Through the training of Ryan White consumers, AFQ is working collaboratively with service providers, the HRSA Part A grantee, and other community stakeholders to improve the quality of care and ultimately the health outcomes of the PLWH in the region <p>The work of AFQ was evaluated early in 2013</p>	

5. Tools

This section provides tools to assist HPGs and health departments to implement and document their community engagement process. It includes tools referenced earlier in the toolkit as well as examples of tools used by HIV planning, Ryan White Planning Councils, and health departments. The first group of tools is arranged in the same order as the Section 3 steps in developing and documenting a community engagement process. The second group follows the Examples of Community Engagement by HIV Planning Bodies chart in Section 3.

Tools for Developing and Implementing a Community Engagement Process

The following tools are designed to guide health departments and HPGs through the community engagement process.

Stakeholder Matrix

This tool is designed to help identify target populations and types of stakeholders, including non-traditional stakeholders not currently involved in your area's HIV prevention planning, that can best inform development of the Jurisdictional HIV Prevention Plan and contribute to increased program coordination and service integration. It lists several types of stakeholders (e.g., populations, planning groups, providers and associations) and can help you prioritize them, identify current HPG and health department relationships, and determine what relationships need to be developed and who is best positioned to do that.

Strategies Exploration Tool

This matrix enables an HPG to explore the full range of community engagement strategies and their appropriateness for various purposes, populations, and types of stakeholders. It provides a framework for listing the strategies previously used by the HPG and the health department and additional possible strategies for brainstorming regarding their possible uses with specific populations (e.g., using a town hall to obtain community input into a needs assessment). Use this tool *after* you have identified highest priority target populations and types of stakeholders for your jurisdiction by completing a Stakeholder Matrix.

Strategies Selection Tool

Use this tool after initial exploration of strategies using the Stakeholder Matrix and the Strategies Exploration Tool. It assists you in selecting strategies to match the purpose of the planned community engagement effort, and in specifying populations and types of stakeholders to involve and the level of stakeholder engagement needed.

Community Engagement Process Chart

Use this chart to create a clear, written, step-by-step measurable community engagement process to meet the requirements of the *Guidance*. Apply decisions made and information collected by using the tools listed above. This chart helps to further develop selected strategies, assign roles and responsibilities to the HPG and health department, establish timelines, and identify expected outputs and outcomes. It is important that the planned process include broad tasks and timelines for documenting, monitoring, and assessing the process—thus enabling you to evaluate their community engagement activities and meet CDC accountability requirements.

Documentation, Monitoring, and Assessment Tool

This tool helps you develop a plan to monitor and assess progress on community engagement tasks as listed in the Community Engagement Process Chart, refine efforts as needed during the year, and assess the extent to which specified activities were completed. It also specifies plans for evaluating annual progress towards longer-term outcomes. This tool should be developed along with the Community Engagement Process Chart.

Sample Community Engagement Tools

Educational Forums

Learn+Link+Live, Phoenix, AZ Ryan White Planning Council: A series of forums to help PLWH learn about available HIV-related services, how to apply for them, the importance of entering and remaining in HIV-related care, and how to keep from transmitting HIV.

- **Outline:** Lists the theme and purpose of the forum, as well as the learning, emotional, and behavioral objectives and provides descriptions of target populations and marketing strategies.
- **Participant Evaluation Form:** Helps you document and improve the process and to ask if out-of-care participants are interested in learning more about free or low-cost HIV medical care and supportive services.

Community Forums, Town Halls, and Regional Meetings

Willimantic HIV Community Forum – Connecticut HIV Planning Consortium (CHPC): A two-hour regional meeting to share perspectives regarding local PLWH needs and gaps in services, and to inform the community about the range of services and resources available in the area.

- **Agenda:** Includes an introduction to CHPC, data on HIV epidemic in the Willimantic County, information on available resources, and a discussion of community strengths and needs.
- **Discussion Guide:** Includes “primary” and “follow-up” questions about the local system of prevention and care and how it can be improved.
- **Feedback Summary:** Summarizes participant satisfaction with the process, collected through an evaluation form.

Ryan White Consumer Town Halls – The Metropolitan Washington Regional Ryan White Planning Council: The Planning Council conducted a series of regional PLWH town halls to obtain consumer input to its Comprehensive Plan using *Questions for Discussion to Provide Input for Ryan White Part A Comprehensive Plan*. Data collected through town halls included strengths and challenges of the system of care, gaps and barriers to services, including special barriers or disparities that affect particular populations and what an “ideal” system of care for the region would look like.

Regional Meetings – The Metropolitan Washington Regional Ryan White Planning Council: Community (not limited to PLWH) meetings to obtain community input into the Ryan White Part A planning process, with a focus on decision making about service priorities and allocations.

- **PowerPoint Presentation: Community Town Hall to Provide Input for Ryan White Part A Priority Setting and Resource Allocations Process (PSRA),** including:
 - Description of PSRA process and tasks
 - Key topics for consumer input
 - Questions for discussion
- **Jurisdictional District of Columbia Resource Allocations Meeting – Participant Feedback Survey:** Used to improve the annual PSRA process

Roles and Responsibilities of Planning Body Committees, Subcommittees, and Community Members Involved in Community Engagement Process

The Los Angeles County HIV Prevention Planning Committee: Excerpts from the Policies and Procedures, including descriptions of the roles and responsibilities of:

- **External Activities Subcommittee**—in charge of broad-based community participation
- **Ad Hoc Groups**—sometimes used to accomplish community engagement-related activities
- **Members of the Public and Community**—engaged in HIV Prevention Planning Committee Work

Note: These policies and procedures were last updated on October 30, 2012, before the prevention and care planning bodies merged in 2013.

Tools for Developing and Implementing a Community Engagement Process

Tool I. Stakeholder Matrix

The purpose of this tool is to assist health departments and HIV planning groups in engaging a broader group of stakeholders to meet the requirements of Funding Opportunity Announcement (FOA) PS12-1201, *Comprehensive HIV Prevention Programs for Health Departments (2012-2016)*, further described in the *HIV Planning Guidance*, July 2012. It is designed to help identify those target populations and types of stakeholders—especially non-traditional stakeholders who are not currently involved in the HIV prevention planning—who can best inform development of the Jurisdictional HIV Prevention Plan and contribute to increased program coordination and service integration.

Stakeholder Types/Groups/Organizations	Priority Level	Existing Relationships (Individuals/Entities)		Relationships to Build/Expand	Suggested Responsibility
		HPG Member – Voting or Non-voting	Other		
Populations: At-risk, Affected, HIV-Positive, Consumers of Services*, and Socioeconomically Marginalized Greatest Risk for HIV Acquisition or Transmission in the Jurisdiction†					
<i>[List your target populations. See Section 3 for ideas on identifying target populations- Examples:]</i>					
African American/Black MSM					
Latinas					
IDU					
Transgender MTF					
[Add]					
Planning Groups					
Ryan White planning bodies					
Independent PLHW groups and caucuses					
Substance Abuse and Mental Health Services Administration (SAMHSA) funded planning bodies					
TB, viral hepatitis, and STD programs-funded grantee planning bodies					
Planning body for Housing Opportunities for Persons with AIDS (HOPWA) program					
Other: [Add]					

Stakeholder Types/Groups/Organizations	Priority Level	Existing Relationships (Individuals/Entities)		Relationships to Build/Expand	Suggested Responsibility
		HPG Member – Voting or Non-voting	Other		
Service Providers & Associations - Public and Private					
Prevention services providers, intervention specialists					
HIV clinical care providers					
HIV service providers (e.g., community-based organizations (CBOs), including case management providers)					
Community Health Centers/ Federally Qualified Health Centers (CHCs/FQHCs)					
Free clinics and other safety-net clinics					
Hospitals					
Primary care associations					
Housing service providers					
Homeless service providers					
Mental health service providers					
Substance abuse services providers					
Behavioral or social science services providers					
Pharmacies and pharmaceutical providers					
School health centers					
Other: <i>[Add]</i>					
Public Agencies					
Local health departments (HIV, STD, TB, Hepatitis, Substance Abuse, Mental Health)					
State health departments (HIV, STD, TB, Hepatitis, Substance Abuse, Mental Health)					
Housing Opportunities for Persons with AIDS (HOPWA) grantee agency					
Department of Corrections (DOC)					
Veterans Affairs health care facilities					
State Medicaid program					
Other: <i>[Add]</i>					

Stakeholder Types/Groups/Organizations	Priority Level	Existing Relationships (Individuals/Entities)		Relationships to Build/Expand	Suggested Responsibility
		HPG Member – Voting or Non-voting	Other		
Other groups/communities					
Faith community					
Small businesses					
Large corporations					
Labor					
Private insurance companies					
Elementary and secondary education agencies and schools					
Higher education/academic institutions, including education training centers					
Employment and training entities					
Research entities and think tanks					
Community foundations and other philanthropic entities					
Social clubs (e.g., Bid Whist, Black Girls Run)					
YMCA/YWCA/Boys and Girls Clubs/Latino associations					
Fraternities/sororities					
High school student government bodies and PTAs					
Other professional communities, including epidemiological community					
Other: <i>[Add]</i>					

*If you are an integrated HPG for HIV prevention and care, you will need emphasis on consumers of Ryan White services.

† Includes populations affected by other infectious diseases such as TB, Hepatitis C (HCV), Hepatitis B (HBV), and STDs

Tool II. Strategies Exploration Tool

The purpose of this tool is to assist health departments and HIV planning groups in exploring the full range of community engagement strategies and their appropriateness for various purposes and populations and types of stakeholders. Use this tool *after* you have identified highest priority target populations and types of stakeholders for your jurisdiction by completing a Stakeholder Matrix.

Suggested Strategies	Possible Uses	Use with Which Priority Target Populations/ Stakeholders
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Strategies That Have Been Used by the HD and/or HPG

[See Examples of Strategies for Community Engagement Chart in Section 3]	[e.g., to obtain input into a needs assessment or information to update the Jurisdictional Comprehensive Plan]	[From the Stakeholder Matrix]
Key Informant Sessions	To obtain input for needs assessment or input for updating the Jurisdictional Comprehensive Plan	Young MSM of color; transgenders; immigrants with HIV or at high risk for HIV; recently incarcerated; HIV service providers

Additional Possible Strategies Not Previously Used by the HD or HPG

[See Examples of Strategies for Community Engagement Chart in Section 3]	[e.g., to obtain input into a needs assessment or information to update the Jurisdictional Comprehensive Plan]	[From the Stakeholder Matrix]

Tool III. Strategies Selection Tool

The purpose of this tool is to assist health departments and HIV planning groups in selecting community engagement strategies appropriate for various purposes, populations and types of stakeholders, and level of engagement. It should be used after initial exploration of strategies using the Stakeholder Matrix and the Strategies Exploration Tool.

Purpose of Community Engagement Activity	Priority Target Populations/ Stakeholders	Strategy or Strategies	Level of Engagement – Frequency and Duration		
			One-time	Repeated Periodically	On going
<i>[e.g., to provide information and obtain input into a needs assessment]</i>	<i>[From the Stakeholder Matrix]</i>	<i>[As identified using the Strategies Exploration Tool]</i>			
Example:					
Identify service needs and barriers to testing, linkage to care, and risk reduction for immigrants	• Latina/o immigrants	<ul style="list-style-type: none"> • Key informant session of providers and community leaders • Focus groups 	X		
	• African immigrants			X	
	• Southeast Asian immigrants				

Tool IV. Community Engagement Process Chart

The purpose of this chart is to assist health departments and HIV planning groups in creating a clear, written, step-by-step measurable process for community engagement.

Goals of community engagement:

Goal 1: To obtain diverse input from a wide range of stakeholders to the Jurisdictional HIV Prevention Plan, including HIV service needs, gaps, and barriers, and ways in which current services can be enhanced to increase their use and success overall and for specific populations.

Goal 2: To increase program coordination and service integration among HIV programs and with programs addressing conditions that may co-occur with HIV and/or facilitate HIV transmission, such as Viral Hepatitis, STDs, and TB.

Purposes of Planned Community Engagement Effort/ Expected Use of Community Input	Contributes to:		Strategy	Population(s)/ Type(s) of Stakeholder to Engage	Roles and Responsibilities		Timeline	Expected Outputs*	Expected Outcomes**
	Goal 1	Goal 2			HD	HPG			
[Listed in the order of priority – highest first]			[It is possible to implement a number of strategies to address a single community engagement purpose]	[List for each strategy]					

* As defined by the W.K. Foundation's Logic Model Development Guide, "Outputs are direct products of program activities and may include types, levels and targets of services to be delivered by the program...if you accomplish your planned activities, then you will hopefully deliver the amount of product and/or service that you intended." For example, an output of a town hall meeting might be documentation of a meeting attended by at least 30 people representing at least seven of your priority target populations.

** Outcomes are measurable short- or medium-term changes in plans, programs, program participants, and/or communities resulting from your activities

Purposes of Planned Community Engagement Effort/ Expected Use of Community Input	Contributes to:	Strategy	Population(s)/ Type(s) Engage	Roles and Responsibilities	Timeline	Expected Outputs*	Expected Outcomes**
Example:							
Fill gaps in plan regarding HIV prevention, care needs and barriers of target populations facing high levels of stigma; focus on prevention education, testing, and linkage to care	X	<ul style="list-style-type: none"> Key informant session with leaders and staff of the identified target populations Focus groups with existing entities/ associations Confidential interviews with individuals from target populations 	<ul style="list-style-type: none"> Transgenderers African immigrants 	<ul style="list-style-type: none"> Lead role in implementing strategies <ul style="list-style-type: none"> Develops questions/ guides for each strategy Documents findings Explores service collaboration Uses findings in plan update Lead role in contacts with existing groups (support groups, clubs, etc.) <ul style="list-style-type: none"> Helps to recruit individuals Assists with focus groups 	Completion in time for inclusion in 2014 plan update	<ul style="list-style-type: none"> Completion of key informant session with at least 5 people from each target group Completion of at least 1 focus group for each population, each including 8 or more individuals—or completion of at least 8 interviews with members of each group Specified information obtained 	<ul style="list-style-type: none"> Information included in plan Plan calls for refinements in service system to address barriers and meet identified need Service collaboration established with at least one organization serving each target group

Tool V. Documentation, Monitoring, and Assessment Tool

The purpose of this tool is to help health departments and HPGs develop a plan to monitor and assess progress on community engagement tasks as listed in the Community Engagement Process Chart, refine efforts as needed during the year, and then assess the extent to which specified activities were completed. It also specifies plans for evaluating annual progress towards longer-term outcomes. For examples of end-of-year assessment of the extent to which the program met the expectations listed in the three Monitoring Questions (listed in the chart below), refer to the Sample Monitoring and Results-Oriented Evaluation Chart in Section 3, Task 6 of the Toolkit. This tool should be developed along with the Community Engagement Process Chart, which should include broad tasks and timelines for documentation, monitoring, and assessment.

Planned Output or Outcome	Indicator/Measure	Data Sources/Method	Responsibility	Timeline	Completion
Periodic Monitoring and Process Evaluation (Progress/Task Completion, Outputs, Quality of Community Engagement) To what extent did HIV service providers and other stakeholders who can best inform the coordination and collaboration of HIV prevention, care, and treatment services participate in the planning process?					
<i>Examples:</i>					
Development of ongoing relationship with Youth Program	<ul style="list-style-type: none"> MOU established with Youth Program X At least 15 youth from the Program participate in Youth Community Input Session At least 3 youth and 1 staff member participate in Regional Town Hall At least one staff or Board member participates in provider key informant session 	<ul style="list-style-type: none"> Signed MOU Summaries of at least the listed 3 events documenting involvement of Youth Program 	<ul style="list-style-type: none"> Health department staff member— negotiates MOU HPG member— summary of Youth Community Input Session HPG members, one per region – summary of Regional Town Hall 	<ul style="list-style-type: none"> Signing of MOU by March 31, 2014 Community Input session – May 2014 Regional Town Hall – July 2014 Key Informant Session – March 2015 	
Implementation of 7 regional Town Hall meetings attended by diverse target populations to obtain input for plan update	<ul style="list-style-type: none"> 7 meetings completed Average participation of at least 30 Minimum participation of 15 per meeting Each meeting includes representatives of at least 7 key target populations 	<ul style="list-style-type: none"> Summaries of regional meetings that list number of participants Participant information sheets documenting target population mix 	<ul style="list-style-type: none"> Community Engagement Committee, with regional members responsible for the Town Hall in their region 	<ul style="list-style-type: none"> April-May 2014 	

Planned Output or Outcome	Indicator/Measure	Data Sources/Method	Responsibility	Timeline	Completion
To what extent was input from HPG members, other stakeholders, and providers used to inform and monitor the development (or update) and implementation of the Jurisdictional HIV Prevention Plan?					
Outcomes Evaluation					
To what extent did the engagement process achieve a more coordinated, collaborative, and seamless approach to accessing HIV services for the highest-risk populations?					

Sample Community Engagement Tools

Connecticut HIV Planning Consortium: Community Forums

This package of materials describes and documents how the Connecticut HIV Planning Consortium uses community forums to obtain broad community input about HIV services and issues from residents of various areas within the state. It documents the Willimantic HIV Community Forum.

Included are:

- 1. The Agenda
- 2. The Discussion Guide
- 3. The Feedback Summary, which provides both the written feedback form to assess the Forum and a summary of responses from a sampling of participants



**May 9, 2013 Meeting Agenda
CHPC Community Forum**

**Willimantic HIV Community Forum
Thursday, May 9, 2013**

Generations Family Health Center

- 4. Welcome 12:00 p.m.
- 5. Introduction to the CHPC 12:05 p.m.
- 6. The HIV/AIDS Epidemic in Willimantic/Windham County 12:20 p.m.
- 7. HIV Services & Resources 12:35 p.m.
- 8. Discussion about Community Strengths and Needs 1:00 p.m.
- 9. Next Steps & Evaluation Forms 1:55 p.m.
- 10. Closing 2:00 p.m.

HIV Community Forum Discussion Guide

The Connecticut HIV Planning Consortium (CHPC) uses a “**HIV Community Forum**” approach to **engage community members in a discussion** about HIV/AIDS issues and services in their area.

The CHPC defines the term “**community**” as **all residents and stakeholders** including but not limited to: people living with HIV/AIDS (PLWHA); community-based organizations (CBOs); businesses; public sector agencies; elected officials; and faith-based organizations, among others.

HIV Community Forums:

- Establish a **participatory method** for CHPC to engage local communities – an area of increased emphasis by federal funders
- Provide CHPC with community perspectives that complement other data sets such as surveillance and the Statewide Needs Assessment Survey
- Facilitate information sharing among community members about issues and resources using a few straightforward questions
- Create opportunities for community members to learn more about the CHPC

Primary questions:

1. What does your community do for ...

- HIV prevention?
- HIV testing?
- HIV primary care?
- HIV specialty care? (e.g., I.D. care)
- Other HIV services? (e.g., medical case management)

2. Suppose a friend or acquaintance engaged in high risk behavior, how does your community...

- Prevent the spread of HIV?
- Encourage and support HIV testing?
- Facilitate access to care services?
- Respond to changes in the epidemic?

Facilitator's Questions to use as follow up to primary questions:

- “Where would you recommend individuals go for testing?”
- “What prevents members in your community from being tested?”
- “What makes you healthy?”
- “Where would you recommend individuals go for HIV services?”
- “What services exist in your community?”
- “What does prevention mean for you?”
- “What can be done better?”

Willimantic HIV Community Forum Feedback Summary

Feedback Participation 9 (of 29) participants completed forms

Overall Satisfaction 100% (72 yes / 72 responses)

Feedback Summary Table

Question	Yes	No	Blank	Comments
1. I learned about the Connecticut HIV Planning Consortium (CHPC).	9	0	0	
2. I learned about the HIV/AIDS epidemic in my community.	9	0	0	
3. I learned about the services and resources available in my community.	9	0	0	
4. The discussion about my community's strengths and needs was constructive.	9	0	0	
5. I feel that there was mutual respect for diverse cultures and opinions.	9	0	0	
6. I felt comfortable participating in the discussion, and felt that my voice was heard.	9	0	0	
7. I made new connections in my community.	9	0	0	
8. Participating in the Community Forum was a good use of my time.	9	0	0	

What did you like best about the HIV Community Forum?

- The amount of people that attended
- Knowing what's going on in my community
- Info
- The ability to connect to providers
- Speakers very respectful
- The speakers
- Location, diverse attendants

What would you change about future Community Forums and how?

- That more people from the city participate/attend whether they are HIV+ or -. Knowledge is power.
- Printed list of providers in area; websites
- Nothing

Please share any other comments about the Community Forum.

- Would like to attend local meetings
- Thanks for coming to Willimantic

Use of Town Hall Meetings

The Metropolitan Washington Regional Ryan White Planning Council uses town hall meetings to obtain consumer input to its priority setting and resource allocations (PSRA) process, and to obtain consumer and provider input to the regional HIV comprehensive plan.

The following pages provide:

1. **Comprehensive Planning Town Hall Meeting Questions:** These questions are used at jurisdictional town hall meetings held in various parts of the service area to obtain input from consumers of HIV services, and at a separate town hall meeting to obtain input from providers of HIV services.
2. **Priority Setting and Resource Allocation Town Hall Meeting Questions and Format:** The approach and questions provided here are used to obtain community input at meetings that focus on consumers but have providers present to share their perspectives and address questions from the consumers.
3. **Participant Feedback Form:** A feedback form is used at the end of each town hall meeting, and the results are used to improve the structure and content of town hall meetings. The package includes a sample feedback form.

Questions for Discussion at Regional PLWH Town Hall Meetings Providing Input for the Comprehensive Plan

1. Please consider the current system of HIV/AIDS services – the current “continuum of care” (the system of HIV/AIDS services available to people living with HIV/AIDS), supported by Ryan White and other funding sources) in the metro area and in the jurisdiction where you live.
 - a. What works well?
 - b. What would you most like to see change?
 - c. To what extent are PLWH able to access needed providers and services?
2. What are the *gaps in services*, for people living with HIV and AIDS (PLWH), in the EMA as a whole or for your jurisdiction?
3. What are the current *barriers* to services at each state of the process, for the EMA as a whole and in the jurisdiction where you live:
 - a. What are the most important barriers to *testing*?
 - b. Once people are diagnosed, what are the most important barriers to *entering care*?
 - c. What are the barriers to *obtaining needed services*?
 - d. What are the barriers to *treatment adherence* – to help PLWH reach viral suppression?
 - e. What about *retention in care*?
 - f. What are some important barriers for *specific populations*?
4. What should be done to remove or minimize these barriers?
 - a. To testing?
 - b. To entering care?
 - c. To retention in care?
5. Tell us about specific barriers or disparities (differences) in care that affect particular populations or locations, and what should be done to remove them so that there is parity (equality) in access to care for people living with HIV and AIDS throughout the EMA? For example:
 - a. What are the disparities or barriers for the following groups: transgenders, homeless people, adolescents, injection drug users, men who have sex with men, heterosexuals, women of color, Latinos, African immigrants, older people?
 - b. What are the barriers for people living in the rural parts of the EMA?
 - c. What are the special barriers in your jurisdiction (DC, MD, VA, WV)?
6. If you could design an “ideal” system of care for the EMA, what would it look like? How would it differ from the current system of care?
7. What are the most important actions the Planning Council and its PLWH groups should take over the next three years to work towards an “ideal” system of care and make services more available, accessible, and appropriate for PLWH in the EMA?

HIV Services Consumer Town Hall Meeting

Providing Input to Priority Setting and Resource Allocations

Use: The Planning Council conducts jurisdiction-specific and regional consumer town hall meetings to obtain input from consumers of HIV services for priority setting and resource allocations (PSRA). A similar approach is used to obtain input for the comprehensive plan.

Format: The questions are presented in a PowerPoint format. Before asking for input, the facilitator (usually the Council Chair) explains the PSRA process, so participants understand how their input will be used. The facilitator also provides a list and brief description of the service categories that can be funded under the Ryan White program.

Questions:

1. What are the most important HIV prevention and care service gaps in this jurisdiction – the ones that most need to be filled?
2. What would you recommend to help fill those service gaps?
3. What helped you to get tested?
4. What helped you to get linked to care – or delayed your getting linked to care?
5. What keeps you in care?
6. What would cause you to fall out of care?
7. How can the Planning Council improve the way HIV services are designed and delivered?
8. What are the most important services for you, personally? [Usually, the group states opinions, then reaches consensus on a list of the seven most important services.]
9. Please provide any other input you feel the Planning Council needs in order to make sound decisions about service priorities and the allocation of funds for next year?

Jurisdictional Allocations Meeting Feedback Survey

1. Are you a member of the Ryan White Part A Planning Council for the Washington, DC eligible metropolitan area (EMA)? ☐ Yes ☐ No
2. How did you learn about the allocations meeting? ☐ Email ☐ Poster/Flyer ☐ Word of Mouth ☐ Other

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
3. The utilization information provided was clear and easy to understand.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Before today's meeting, I understood the allocations process.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. After today's meeting, I understood the allocations process.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. The meeting was facilitated so that time was used efficiently and final decisions were not rushed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Handouts and forms were clearly reviewed and explained by the presenters.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Handouts and forms were easy to understand and helpful.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Attendance at the meeting was large and diverse.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. The meeting was well run and well managed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

11. What is the one thing you felt worked *best* about the meeting?
12. What is one thing you would most like *changed* to make the allocations meeting better? Be as specific as you can.
13. How do you feel participation at the allocations meeting can be improved?
14. Please provide any additional desired comments about the allocations meeting process.

Learn + Link + Live

Conference Outline

Theme of the Learn+Link+Live Conference

“The Learn+Link+Live Conference will empower HIV-positive consumers to proactively manage their needs by providing them with essential information, community resources, and useful tools to monitor and maintain their health.”

Purpose of the Learn+Link+Live Conference

The Learn+Link+Live Conference is an educational forum that provides resources to help consumers obtain services and self-manage their health care. Peer co-facilitators may assist the attendees in trusting that the presentations are in their best interests.

Possible topics:

1. HIV basics—short, concise information about HIV (“nuts and bolts Q&A”)
2. Why it’s important to access medical care and medications
3. Treatment adherence
4. Agency overview with descriptions of services and contact information
5. Housing information
6. How to qualify and apply for Ryan White Title I services
7. Self-management issues regarding the life-changing steps in family life, work, appointment management, exercise, nutrition, support groups, etc.
8. Medication trial programs
9. Ryan White Planning Council overview
10. National organizations for advocacy and support
11. Appropriate non-Title I HIV service/care/wrap providers (but not private doctors).
12. Counseling and testing
13. Disclosure, stigma and discrimination
14. Stress reduction
15. Agency introductions
16. Overview of their grievance processes presented by the Administrative Agent/Quality Management
17. Attendees will be surveyed to identify their interests for the next forum

Learn+Link+Live Conference Learning Objectives

1. Provide information regarding the services available to HIV-positive individuals in Maricopa and Pinal County
2. Educate consumers about how to apply for Ryan White Title I services, and what information they will need to provide
3. Educate consumers as to why it is so important to remain in primary health care
4. Educate consumers as to why it is so important to maintain their medication regimen
5. Steps you must take to keep you from spreading HIV
6. Survey attendees to identify issues of importance for next conference
7. Survey attendees on conference effectiveness and revisions to the event

Learn+Link+Live Conference Emotional Objectives

1. Taking responsibility for managing and directing your healthcare is important
2. Consumers feel empowered to manage and direct their health care
3. Confidence in safe sex behaviors and reduced anxiety about retransmission
4. Connections among services highlight that medical care is part of a continuum of services all meant to support health
5. Sense of empathy and support from others who are affected by the disease and living with similar circumstances

Learn+Link+Live Conference Behavioral Objectives

1. Attendees of the Care Conference will stay in care
2. Attendees will maintain their medication regimens
3. Attendees will understand what Ryan White services are available and how to qualify and apply
4. Attendees will experience improved health because they know where to go for services and are tracking their own health
5. Attendees will have the tools to make informed decisions about treatment and provide better information to their healthcare provider
6. Attendees will make and keep appointments
7. Attendees will assist in bringing other PLWH into care

Who is the primary target market for the Learn+Link+Live Conference?

1. Ryan White eligible HIV positive people from Maricopa and Pinal Counties, and other HIV-positive people, especially individuals who are new to care or returning to care (Out-of-Care)
2. Other HIV positive consumers

How will the Learn+Link+Live Conference be marketed?

1. Advertising in a variety of local magazines/newspapers
2. Post at various public locations (bars, bookstores, etc.)
3. Word of mouth by other PLWH
4. Post at HIV health care and social service agencies
5. Include in mailings from Title I agencies as part of their on-going correspondence
6. Post on the websites of service providers

7. Notify hospitals and clinics
8. Notify HIV-specialized docs
9. It will be announced at the regional planning group meetings, ADAP meetings, “doc talks” and other events targeting the HIV community and/or those at risk

Additional notes

1. Conference must be focused on Ryan White eligible people, but can include other HIV positive individuals
2. Use graphics as much as possible to describe services or steps to receive care
3. Clearly define expectations of keeping appointments and maintaining medication regimens
4. Stress that self-managing your health care needs is essential
5. Execution of the event should be polished and professional without incurring great expense

Learn + Link + Live Participant Evaluation

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
I liked the overall quality of the presentations	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I liked the choice of session topics:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I learned a lot by attending:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I liked the quality of the materials provided:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A day-long event was the right length of time:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The day of the week was good for me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The meeting rooms were comfortable:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The event location was easy to find:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The event location was convenient:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I liked the quality of the food:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I liked the food choices:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Any special needs I had were met:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The volunteers and staff were friendly:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I would recommend this event to others:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Of the sessions you attended, which did you like the most?

Why?

Suggestions or comments about today's event:

What topics would you like to see presented at a future event?

I receive Ryan White Part A services: ☐ Yes ☐ No ☐ Not Sure ☐ I have in the past, but not now

I have seen a doctor in the past year (HIV related): ☐ Yes ☐ No

I am currently taking HIV medications: ☐ Yes ☐ No

I have had HIV lab work (CD4 and/or viral load) done in the past year: ☐ Yes ☐ No

I am:

- ☐ Male
- ☐ Female
- ☐ Transgendered

Race/Ethnicity:

- ☐ White, Not Hispanic
- ☐ Black, Not Hispanic
- ☐ Hispanic
- ☐ American Indian/Alaska Native
- ☐ Asian/Pacific Islander
- ☐ More than one race
- ☐ Decline to say

Age:

- ☐ 13 to 19
- ☐ 20 to 44
- ☐ 45 and over

☐ **I would like to be informed of upcoming Learn+Link+Live HIV Education Conferences**

☐ **I would like information about free or low-cost HIV medical care and supportive services**

Please Print

Name:

Address:

City:

State:

Zip:

Email address:

Phone:

Los Angeles County HIV Prevention Planning Committee Policies and Procedures Supporting Community Engagement

Value of this Tool:

As HPGs plan for community engagement beyond planning body membership, policies and procedures that define and assign clear responsibilities for community engagement can be very helpful. The Los Angeles County HIV Prevention Planning Committee (PPC) Policies and Procedures include several useful models:

- **Responsibilities of the External Activities Subcommittee**, which include several clearly defined tasks related to community engagement
- **Roles and Responsibilities of Ad Hoc Groups**, which define the use, structure, number, membership, and roles of ad hoc groups; membership is to include both PPC members and “other key stakeholders in the community who have an interest in the specific work at hand”
- **Roles and Responsibilities of Members of the Public & Community**, which identify some specific roles for non-PPC members in the HIV planning process

These policies and procedures may be helpful models for other HIV planning groups.

Note: These Policies and Procedures were last revised in October 2012, prior to the integration of the Los Angeles prevention and care planning bodies.

Los Angeles County HIV Prevention Planning Committee Policies and Procedures

External Activities Subcommittee Roles and Responsibilities (page 15)

The goal of this subcommittee is to ensure broad-based community participation, address policy issues, and provide oversight of ad hoc groups. This group will meet monthly for two hours, or as their work plan dictates. For example, depending on the work plan, they may hold town hall meetings, attend Joint Public Policy meetings, or conduct other work in the community, in lieu of having a regularly scheduled meeting. This subcommittee will be responsible for the following activities:

1. Ensuring development of work plan (accountability)
2. Coordinating and overseeing ad-hoc meetings as needed and reporting on progress
3. Promoting HIV prevention in other disciplines
4. Identifying emergent prevention issues
5. Engaging community and expert support
6. Supporting broad-based community participation
7. Educating and informing PPC on the legislative process and relevant issues. Conduct advocacy efforts.

Roles and Responsibilities of Ad Hoc Groups (page 18)

Ad hoc groups will be formed as needed in order to address key tasks (e.g. PPC restructuring), identify specific population needs (e.g. Latinos); and/or address emerging HIV prevention issues (e.g. CA budget cuts). Ad hoc groups will be comprised of PPC members as well as other key stakeholders in the community who have an interest in the specific work at hand. These groups will exist and operate within a specific timeframe (e.g. 3-18 months) to accomplish a particular task. Anyone can recommend the formation of an ad hoc group, but the coordination of these groups will be managed by the External Activities Subcommittee. There will be no more than three ad-hoc groups at any given time. In the case that there are multiple requests for various ad hoc groups, the Steering Subcommittee will review and determine which ad hoc group(s) will be prioritized.

Roles and Responsibilities of Members of the Public & Community (page 26)

1. Community members shall be allowed to provide public testimony at PPC meetings.
2. Community members may review and comment on the Comprehensive HIV Prevention Plan at public hearings or otherwise to PPC members.
3. Community members may attend and observe PPC meeting activities as desired. Community members may also attend and participate in subcommittee meetings and workgroups.

References and Resources

This section provides references and resources on community engagement. Many of these sources were referenced in the document with end-notes. The section is arranged by category. To make it easier to find materials, individual references and resources are organized within sections alphabetically by document name or website rather than by author. All are annotated to indicate the kinds of information or tools provided.

Federal Guidance and Expectations

These references provide guidance on HIV prevention, care planning, and services and/or expectations for community engagement. Depending upon the program, they include legislative requirements, federal guidance and expectations, policies, standards, and/or best practices.

CDC-HRSA Integrated Planning “Dear Colleague” Letter from Jonathan H. Mermin, Director, Division of HIV/AIDS Prevention at CDC and Laura W. Cheever, Acting Associate Administrator and Chief Medical Officer, HIV/AIDS Bureau at HRSA, dated May 22, 2013.

CDC and HRSA wrote this letter to indicate that the two agencies support and encourage collaboration and integrated planning for care and treatment. It was sent to CDC and Ryan White grantees in May of 2013, and was to be made available on the TARGET Center website, <https://careacttarget.org/topics>

CDC-RFA-PS12-1201, Comprehensive HIV Prevention Programs for Health Departments. Issued by the Centers for Disease Control and Prevention, 2011.

This Funding Opportunity Announcement called for implementation of comprehensive High-Impact Prevention programs. The RFA preceded the *HIV Planning Guidance*, but offered similar guidance regarding community engagement.

From Guidance to Implementation: Navigating the HIV Planning Guidance. Washington, DC: National Minority AIDS Council, 2013. Available at: <http://nmac.org/wp-content/uploads/2013/08/From-Guidance-to-Implementation.pdf>

This manual is designed to help HPGs and health departments understand and successfully implement the 2012 *HIV Planning Guidance*.

HIV Prevention Community Planning: An Orientation Guide. Washington, DC: Academy for Educational Development, January 2005. Available at: http://www.cdc.gov/hiv/topics/cba/resources/guidelines/Orientation_Final.pdf

This document provides orientation to the HIV Guidance preceding the 2012 Guidance.

Ryan White *Part A Manual*. Washington, DC: Health Resources and Services Administration, HIV/AIDS Bureau, Division of Metropolitan HIV/AIDS Programs, updated 2013. Available at: <https://careacttarget.org/content/part-manual>

This manual provides legislative requirements and HRSA expectations regarding Part A programs funded under the Ryan White HIV Treatment Extension Act of 2009, including legislative requirements, HRSA guidance, and best practices around community involvement in HIV planning. The legislation defines specific roles for Planning Councils and describes their responsibilities for ensuring broad community engagement from diverse stakeholders in specific legislated activities such as needs assessment, comprehensive planning, and priority setting and resource allocations. See particularly Section X: “Planning Council Operations,” which includes a chapter on PLWHA/Consumer Engagement, and Section XI: “Planning and Planning Bodies.”

Ryan White *Part B Manual*. Washington, DC: Health Resources and Services Administration, HIV/AIDS Bureau, Division of State and Territorial HIV/AIDS Programs, updated 2013. Available at <https://careacttarget.org/library/part-b-manual>

This manual provides legislative requirements and HRSA expectations regarding Part B programs funded under the Ryan White HIV Treatment Extension Act of 2009, including requirements and best practices around community involvement in HIV planning. Community engagement beyond planning bodies is provided in Section XI: “Planning and Planning Bodies,” which includes a chapter on PLWHA/Consumer Participation.

“Ten Essential Services of Public Health.” Atlanta, GA: Centers for Disease Control and Prevention. Available at <http://www.cdc.gov/nphpsp/essentialservices.html>

This list provides the framework for the National Public Health Performance Standards Program (NPHPSP). Two of the essentials address com-

community engagement: “Inform, educate, and empower people about health issues;” and “Mobilize community partnerships and action to identify and solve health problems.” The website describes the NPHPS and provides a set of assessment tools used by state and local public health agencies and governing bodies.

Community Engagement Theory and Practice (United States and Worldwide)

This subsection provides history, theoretical constructs, and models of community engagement, and standards and principles, as well as examples of successful engagement and methods of evaluating the results of community engagement.

History

Alma-Ata Declaration, adopted at the World Health Organization International Conference on Primary Health Care in September 1978, in Alma-Ata, Kazakhstan. Available at:

http://www.who.int/publications/almaata_declaration_en.pdf

This was the first international declaration focusing on the importance of primary health care, including community engagement. The fourth of its ten provisions declares that, “The people have the right and duty to participate individually and collectively in the planning and implementation of their health care.” It has been adopted by member countries of the World Health Organization. It is historically important in increasing attention to primary health care and to community participation in health care.

A Seat at the Table: Place-Based Urban Policy and Community Engagement, by Hayling Price. Cambridge, MA: *Harvard Journal of African American Policy*: 2011 Edition. Available at:

<http://sites.harvard.edu/icb/icb.do?keyword=k74757&pageid=icb.page414112>

This article addresses the use of community engagement to “allow citizens the opportunity to influence the policies that impact their well-being.” It notes that community engagement often is strong during initial outreach activities, but then decreases. The paper traces the history of community engagement in urban revitalization, and describes President Obama’s Neighborhood Revitalization Initiative, focusing on Promise Neighborhoods. It describes the extensive community engagement during the planning for the Washington, DC Promise Neighborhood Initiative (DCPNI) as a model of appropriate community engagement and makes recommendations for effective community engagement in “the development of anti-poverty neighborhood-based policy.” Though the program focus of this article is neighborhood revitalization rather than HIV prevention, many of the strategies used are relevant, particularly given the emphasis on policy change as a major component of CDC-funded prevention initiatives.

Theories, Concepts, Definitions, and Models

The Active Community Engagement Continuum, ACQUIRE Project Working Paper, July 2008.

Prepared by Nancy Russell et al. Available at:

http://www.acquireproject.org/fileadmin/user_upload/ACQUIRE/Publications/ACE-Working-Paper-final.pdf

The working paper presents the Active Continuum of Engagement (ACE), a conceptual framework to improve rural health and family planning services and help “integrate community engagement into service delivery projects.” It presents three levels of engagement across five characteristics of engagement: community involvement in assessment, access to information, inclusion in decision-making, local capacity to advocate to institutions and governing structures, and accountability of institutions to the public. The paper describes how this framework was applied in the project, which adopted the definition of community engagement from the original 1997 *Principles for Community Engagement*. The ACQUIRE Project (Access, Quality, and Use in Reproductive Health) was a five-year global initiative initiated in 2003, supported by the U.S. Agency for International Development (USAID). The project concluded that, “community engagement is not a one-time event, but rather is a process, and is an important consideration in the planning and evaluation of programs.”

“Community Engagement in Public Health,” Mary Ann Morgan and Jennifer Lifshay. Contra Costa Health Services, California, March, 2006. Available at: http://cchealth.org/public-health/pdf/community_engagement_in_ph.pdf

This article was designed for use by local public health departments. It reports on a conceptual framework for community engagement in public health called a Ladder of Community Participation. The Ladder shows a range of strategies for community engagement around public health issues, and provides community engagement examples from Contra Costa Health Services, a county health department.

“Community Participation in Local Health and Sustainable Development: Approaches and Techniques,” European Sustainable Development and Health Series: 4. Copenhagen: Centre for Urban Health, WHO Regional Office for Europe, 2002. Available at: http://www.euro.who.int/__data/assets/pdf_file/0013/101065/E78652.pdf

This document describes the use of community engagement strategies in support of five aspects of an action planning model: “assessing needs and assets, agreeing on a vision, generating ideas and plans for action, enabling action, and monitoring and evaluation.” The model has been used in the World Health Organization’s Health21, WHO’s strategy for health for all in the 21st century, and two related programs, Health Agenda 21 and Healthy Cities. Community engagement is described as requiring “going beyond consultation to enable citizens to become an integral part of the decision-making and action process.” The document provides many examples and case studies from Europe and other parts of the world. It presents two models of community engagement, a “ladder of community participation” and a “wheel of engagement,” both identifying varying levels of participation. Included is a toolbox of 15 community engagement techniques and methods, each linked to one of the five aspects of the action planning model. A number of case studies involving use of these methods are included, each including background, aims, and process. This document is particularly helpful for a health department or planning body that wants to use community engagement to support both planning and program implementation.

“Foundations of Public Participation.” International Association for Public Participation (IAP²), undated. Available at: <http://www.iap2.org.au/resources/iap2s-foundations-of-public-participation>

IAP² is an international membership organization with regional websites that has developed several widely used models and tools that they see as forming “the foundations for public participation processes.” They include the Public Participation Spectrum, a set of Core Values, and a Code of Ethics, all designed to help guide public participation. The Spectrum is a model that identifies five defined levels of involvement and then describes the goal, “promise to the public,” and some sample strategies or tools for implementing each one.

Theory of Change: A Practical Tool for Action, Results and Learning. Prepared for the Annie E. Casey Foundation by Organizational Research Services, 2004. Available at: <http://www.aecf.org/upload/publicationfiles/cc2977k440.pdf>

The guide was developed for the Foundation’s *Making Connections* Program, which was designed to create change in the lives of vulnerable children and families in selected communities. Theory of change provides a useful framework for community engagement planning. This guide describes several approaches to developing a theory of change for a community. It could also be used to develop a theory of change for an HPG, health department, or HIV prevention program and then use the theory of change to support action.

“What is Community? An Evidence-based Definition for Participatory Public Health,” Kathleen M. MacQueen, et al. *American Journal of Public Health*, 2001 December 91(12): 1925-1938. Available at: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1446907/>

This article describes a study carried out to support community participation in HIV vaccine trials that involved interviews with diverse groups—African Americans, gay men, injection drug users, and HIV vaccine researchers—in four different parts of the country to determine how they define *community*. The information about definitions and “themes” from varied populations can be useful to an HPG or health department in targeting communities for engagement in HIV planning and services.

Principles, Standards, and Tools (Often with Examples)

Community Engagement. Minnesota Department of Health, Available at: <http://www.health.state.mn.us/communityeng/intro/>

Minnesota has gathered a considerable amount of useful information on community engagement from sources such as *Principles for Community Engagement*. It provides topics such as “Benefits,” “Two-Way Communications,” and “Models.” This resource was developed for use by nonprofits and schools as well as planning bodies, but some of the information is helpful in planning community engagement activities.

Community Engagement Framework. Canada: Fraser Health, June 2009. Available at: <http://www.fraserhealth.ca/media/Community%20Engagement%20Framework.pdf>

Fraser Health is one of the six publicly funded health regions in British Columbia and a provider of health services. It developed a community engagement framework to guide its employees “respond to key stakeholders, community and client needs, to improve clinical quality, and to improve health outcomes.” The Framework uses the IAP² spectrum of participation. It includes a number of useful models for aspects of a community engagement plan, among them community engagement goals, vision, guiding principles, conditions for success, and commitment to community engagement.

Community Engagement to Improve Health, NICE Public Health Guidance 9. Manchester, England: National Institute for Health and Clinical Excellence (NICE), February 2008. Available at: <http://www.nice.org.uk/PH009>

This document was developed to provide national “public health guidance on community engagement and community development approaches to health improvement” for the United Kingdom’s National Health Service (NHS) and for “other sectors who have a direct or indirect role in – and responsibility for – community engagement,” including “local authorities and the community, voluntary and private sectors.” It provides principles and strategies, and is particularly strong on methods and measures for evaluating community engagement, describing “pathways from participation, empowerment, and control to community improvement.” The NICE website also includes a number of resources, including studies on “supporting evidence” on the effectiveness and value of community engagement. See: <http://guidance.nice.org.uk/PH9/SupportingEvidence>

National Standards for Community Engagement. Edinburgh: Scottish Executive, 2010. Available at: <http://www.scotland.gov.uk/Resource/Doc/94257/0084550.pdf>

These standards were developed “to set out best practice principles for the way that government agencies, councils, health boards, police and other public bodies engage with communities.” The Standards were developed with diverse stakeholder input, and were endorsed by a wide range of public and private entities, among them the Convention of Scottish Local Authorities, the Scottish Council for Local Organisations, the Association of Chief Police Officers, the Scottish Health Council, and the Poverty Alliance. The standards were developed to guide public bodies throughout Scotland in their community engagement efforts, and to be used by other sectors. Indicators are set out for each principle, providing a useful model for measuring progress and success.

Principles of Community Engagement, Second Edition, NIH Publication No. 11-7782, June 2011. Prepared by the Clinical and Translational Science Awards Consortium, Community Engagement Key Function Committee, Task Force on the Principles of Community Engagement with funding from the National Center for Research Resources, National Institutes of Health, through the CTSA program. Developed as a collaborative effort of the CTSA Community Engagement Key Function Committee, which included members from the National Institutes of Health, Agency for Toxic Substances and Disease Registry, and Centers for Disease Control and Prevention. Available at: http://www.atsdr.cdc.gov/communityengagement/pdf/PCE_Report_508_FINAL.pdf

This is a widely used guide to community engagement. It is based on—but more detailed and more technical and theoretical than—the original 1997 primer of the same name (referenced below). The National Institutes of Health funded this version; CDC was represented on the committee that oversaw its development. A foreword by the Surgeon General says that the second edition “adheres to the same key principles laid out in the original booklet. It distills critical messages from the growing body of information and commentary on this topic. At the same time, it provides more detailed practical information about the application of the principles, and it responds to changes in our larger social context, including the increasing use of “virtual communities” and the growing interest in community-engaged health research.” This edition is more technical and less “plain language” than the original document.

Principles of Community Engagement, 1997. Published by the Centers for Disease Control and Prevention and the Agency for Toxic Substances and Disease Registry. Available at: <http://www.cdc.gov/phppo/pce/>

This document on community engagement was developed for the Centers for Disease Control and Prevention, and includes “definitions of key concepts and insights from the literature that support and influence the activities of community engagement,” as well as case examples. It is written in plain language.

Outcomes and Evaluation (Generally with Case Studies or Examples)

“Helpdesk Report: Community Engagement in Health Service Delivery.” London: Human Development Resource Center, UKAid, United Kingdom Department of International Development, November 16, 2011. Available at:

<http://www.heart-resources.org/wp-content/uploads/2011/11/Community-Engagement-in-Health-Service-Delivery-November-2011.pdf>

This document was developed to address questions about evidence that “community participation and accountability in health service delivery leads to improved access to quality health services and increased government ownership/responsibility,” as well as linkages between “community accountability and improved health outcomes.” It provides summaries from many countries that demonstrate how community engagement in the delivery of health services can contribute to improved health outcomes, service quality, the sense of government ownership and responsibility, and participation and peace building/state building. It also provides a history of community involvement in health care.

Painting the Landscape: A Cross-Cultural Exploration of Public-Government Decision-Making, Executive Summary of Preliminary Findings. International Association for Public Participation, August 2009. Available at: <http://unpan1.un.org/intradoc/groups/public/documents/un-dpadm/unpan044066.pdf>

This document reports key findings from an international survey of public participation, including many examples of government and civil society partnerships. The report was designed to “stimulate discussion and reflection amongst government officials, public participation practitioners, professional associations and civil society leaders.”

“A Review of Collaborative Partnerships as a Strategy for Improving Community Health,” by Sergios Tsai Roussos and Stephen B. Fawcett, *Annual Review of Public Health*, 2000, 21:369-402.

This paper provides a detailed review of studies involving collaboration and the extent to which they document three types of outcomes: “(a) community and systems change (environmental changes), (b) community-wide behavior change, and (c) more distant population-level health outcomes.” The paper includes some useful examples of public health initiatives that involved multi-sector partnerships, usually involving community members. Many of the examples involve both program planning and implementation.

“What is the evidence on effectiveness of empowerment to improve health?” by Nina Wallerstein. Copenhagen: World Health Organization Regional Office for Europe, Health Evidence Network Report, 2006. Available at: http://www.euro.who.int/__data/assets/pdf_file/0010/74656/E88086.pdf

The document is described as a “Health Evidence Network (HEN) synthesis report on the effectiveness of empowerment strategies to improve health and reduce health disparities.” In charts based on the IAP² spectrum of community engagement, Empowerment or Shared Leadership is seen as the most intensive types of engagement. Reviewing a variety of studies, the document concludes that empowerment is a viable public health strategy that can lead to positive health outcomes. It references a wide range of studies and examples from all over the world.

“Consumer and Community Engagement Framework.” Queensland, Australia: Health Consumers Queensland (a government agency), February 2012. Available at: <http://www.health.qld.gov.au/hcq/publications/consumer-engagement.pdf>

Examples of Community Engagement in Public Health, Including HIV Prevention and Care

This subsection provides references to many of the community engagement strategies and examples provided in this toolbox. It provides sources for sample newsletters, other tools, and additional information about the use of community engagement in public health and other programs and services.

“Contributions of Community Involvement to Organizational-Level Empowerment: The Federal Healthy Start Experience,” Meredith Minkler, Mildred Thompson, et al. *Health Education & Behavior*, Vol. 28 (6): 783-807 (December 2001). Available at: <http://sophe.org/ui/communityinvolvement.pdf>

This article describes findings from a nine-site case study of the use of consortia and other community engagement strategies in the Healthy Start Program, funded by the Office of Maternal and Child Health. It describes both successes and challenges.

“HEAC Six Communities: When communities take action – the food and physical activity environment changes,” Partnership for Public Health, 2004-2010, at: <http://www.partnershipph.org/projects/HEAC>; and Kailee Neuner, “Transforming Active Living Policy into Practice: Municipal Best Practices,” a Policy Brief, Buffalo: Food Systems Planning and Healthy Communities Lab, University at Buffalo, The State University of New York, 2012, at http://www.bnmc.org/wp-content/uploads/HKHCBuffalo_AL3_MunicipalBestPractices.pdf.

These two sources provide different perspectives on the same project for effective engagement of communities, including youth, in developing healthier environments and encouraging healthy living.

“Health education, public policy, and disease prevention: a case history of the New York City Coalition to End Lead Poisoning,” Freudenberg and Golub. *Health Education Quarterly*, 1987 Winter: 14(4):387-401.

This article documents successful efforts by a multi-sector coalition to increase policy maker attention to the issue of lead poisoning and to reductions in lead poisoning in New York City.

“Ingredients for Change Community Action Guide,” associated with Food, Inc., (a 2008 documentary film), 2009, available at: http://www.activevoice.net/pdf/IFC_Community_Action_Guide_final_low_res.pdf and the Hartford Food System website, at: <http://www.hartfordfood.org/>

These sources describe and assess community engagement efforts designed to convince food stores in the Hartford, CT area to stock more healthy foods. Also provided is a resource guide developed as a part of the Ingredients for Change Campaign, including ways to use the documentary film in action to improve community access to healthy foods.

“Power to the People: Evidence from a Randomized Field Experiment on Community-Based Monitoring In Uganda,” by Martina Björkman and Jakob Svensson, 2007. *Quarterly Journal of Economics*. Available at: http://people.su.se/~jsven/PtP_QJE.pdf

This paper describes the success of community involvement efforts involving community-based monitoring in Uganda. The field experiment demonstrated that use of community meetings that gave responsibility and authority to village residents led to large increases in the use of health services and improved health outcomes including reduced child mortality, as well as positive changes in provider accountability and performance.

Project Consumer LINC (Linking Individuals to Needed Care), a cooperative agreement between the HIV/AIDS Bureau and Mosaica: The Center for Nonprofit Development and Pluralism. Models and tools available on the TARGET Center website, listed under “Strategies to Involve Ryan White Consumers in Linking other PLWH into Primary Medical Care and Other Needed Services,” page 18, https://careacttarget.org/sites/default/files/file-upload/resources/Project_LINC_Strategies_2011.pdf.

This project developed a variety of models and tools for engaging consumers of Ryan White HIV services to help link other people living with HIV to care. Included are activities, many of which are consumer led, that can be used to increase the depth and value of information obtained through town hall meetings or community forums.

“Photovoice for Healthy Relationships: Community-based HIV Participatory HIV Prevention in Rural American Indian Community,” Susan F. Markus, MS, LPC. American Indian and Alaska Native Mental Health Research, Colorado School of Public Health, Centers for American Indian and Alaska Native Health Journal, Volume 2019/19. Available at: [http://www.ucdenver.edu/academics/colleges/PublicHealth/research/centers/CAIANH/journal/Documents/Volume%2019/19\(1\)_Markus_Photovoice_102-123.pdf](http://www.ucdenver.edu/academics/colleges/PublicHealth/research/centers/CAIANH/journal/Documents/Volume%2019/19(1)_Markus_Photovoice_102-123.pdf)

This article provides an example of a culturally appropriate, community-based project for addressing social determinants of health in rural American Indian communities by empowering youth. In collaboration with a local nonprofit and a national leadership program, the researchers used the Photovoice photography technique in working with a group of young people to help them to learn about the role of healthy relationships in prevention of HIV, STIs, and unintended teen pregnancy; explore their own experiences; and share their knowledge with their community.

Endnotes:

- ¹ *HIV Prevention Community Planning: An Orientation Guide*. Washington, DC: Academy for Educational Development, January 2005. Available at: http://www.cdc.gov/hiv/topics/cba/resources/guidelines/Orientation_Final.pdf.
- ² *HIV Planning Guidance*. Atlanta: Centers for Disease Control and Prevention, 2012, p 10.
- ³ *Principles of Community Engagement*, Second Edition, NIH Publication No. 11-7782, June 2011. Prepared by the Clinical and Translational Science Awards Consortium, Community Engagement Key Function Committee, Task Force on the Principles of Community Engagement with funding from the National Center for Research Resources, National Institutes of Health, through the CTSA program. Developed as a collaborative effort of the CTSA Community Engagement Key Function Committee, which included members from the National Institutes of Health, Agency for Toxic Substances and Disease Registry, and Centers for Disease Control and Prevention. First edition developed for the Centers for Disease Control and Prevention in 1997. Available at: http://www.atsdr.cdc.gov/communityengagement/pdf/PCE_Report_508_FINAL.pdf.
- ⁴ *Ibid.*
- ⁵ See especially a review of studies involving community collaboration: Sergios Tsai Roussos and Stephen B. Fawcett, "A Review of Collaborative Partnerships as a Strategy for Improving Community Health." *Annual Review of Public Health*, 2000, 21:369-402.
- ⁶ See *Community Engagement to Improve Health*, NICE Public Health Guidance 9. London: National Institute for Health and Clinical Excellence (NICE), February 2008. Available at: <http://www.nice.org.uk/PH009>.
- ⁷ See, for example, summaries from many countries in the "Helpdesk Report: Community Engagement in Health Service Delivery." London: Human Development Resource Center, UKAid, United Kingdom Department of International Development, November 16, 2011. Available at: <http://www.heart-resources.org/wp-content/uploads/2011/11/Community-Engagement-in-Health-Service-Delivery-November-2011.pdf>.
- ⁸ *Community Engagement to Improve Health*, op. cit.
- ⁹ Hayling Price, *A Seat Place at the Table: Place-Based Urban Policy and Community Engagement*. Cambridge, MA: Harvard Journal of African American Policy: 2011 Edition. Available at: <http://sites.harvard.edu/icb/icb.do?keyword=k74757&pageid=icb.page414112>.
- ¹⁰ Alma-Ata Declaration, adopted at the World Health Organization International Conference on Primary Health Care in September 1978, in Alma-Ata, Kazakhstan. Available at: http://www.who.int/publications/almaata_declaration_en.pdf.
- ¹¹ *Principles of Community Engagement*, op. cit.
- ¹² Malcolm Chisholm, Minister for Communities, in the Ministerial Foreword to the *National Standards for Community Engagement*. Edinburgh: Scottish Executive, 2010. Available at: <http://www.scotland.gov.uk/Resource/Doc/94257/0084550.pdf>.
- ¹³ See the CDC-HRSA Integrated Planning "Dear Colleague" Letter from Jonathan H. Mermin, Director, Division of HIV/AIDS Prevention at CDC and Laura W. Cheever, Acting Associate Administrator and Chief Medical Officer, HIV/AIDS Bureau at HRSA, dated May 22, 2013.
- ¹⁴ The *Part A Manual* is available at: <https://careacttarget.org/content/part-manual>, the *Part B Manual* at <https://careacttarget.org/library/part-b-manual>.
- ¹⁵ See the Centers for Disease Control and Prevention's "Ten Essential Services of Public Health," which provide the framework for the National Public Health Performance Standards Program. Available at: <http://www.cdc.gov/nphsp/essentialservices.html>.
- ¹⁶ *Principles of Community Engagement*, Second Edition, op. cit.
- ¹⁷ Kathleen M. MacQueen et al., "What is Community? An Evidence-based Definition for Participatory Public Health." *American Journal of Public Health* 2001 December 91(12): 1925-1938.
- ¹⁸ NICE, *Community Engagement to Improve Health*, op. cit.
- ¹⁹ *Principles of Community Engagement*, Second Edition, op. cit.
- ²⁰ See, for example, dictionary definitions at <http://www.thefreedictionary.com/stakeholder> and <http://www.merriam-webster.com/dictionary/stakeholder>.
- ²¹ Definition adopted at the 2002 World Summit on Sustainable development. See "Principles for Engagement with COMMUNITIES and STAKEHOLDERS." Canberra, Australia: Ministerial Council on Mineral and Petroleum Resources, 2005. Available at: http://www.ret.gov.au/resources/Documents/mcmpr/Principles_for_Engagement_with_Communities_and_Stakeholders.pdf.
- ²² *Painting the Landscape: A Cross-Cultural Exploration of Public-Government Decision-Making*, Executive Summary of Preliminary Findings. International Association for Public Participation, August 2009. Available at: http://www.iap2.org/associations/4748/files/Kettering_FINALExecutiveSummaryReport.pdf.
- ²³ Quoted in *Principles of Community Engagement*, Second Edition, op. cit. Original document: *Principles of Community Engagement*, 1997. Published by the Centers for Disease Control and Prevention and the Agency for Toxic Substances and Disease Registry. Available at: <http://www.cdc.gov/phppo/pce/>.
- ²⁴ *Principles of Community Engagement*, Second Edition, op. cit.
- ²⁵ "Community Participation in Local Health and Sustainable Development: Approaches and Techniques," European Sustainable Development and Health Series: 4. Copenhagen: Centre for Urban Health, WHO Regional Office for Europe, 2002. Available at: http://www.euro.who.int/__data/assets/pdf_file/0013/101065/E78652.pdf.

- ²⁶ “Consumer and Community Engagement Framework.” Queensland, Australia: Health Consumers Queensland (a government agency), February 2012. Available at: <http://www.health.qld.gov.au/hcq/publications/consumer-engagement.pdf>.
- ²⁷ *Community Engagement*. Minnesota Department of Health. Available at: <http://www.health.state.mn.us/communityeng/intro/>.
- ²⁸ *Principles of Community Engagement*, Second Edition, op. cit.
- ²⁹ *Principles of Community Engagement*, 1997, op. cit.
- ³⁰ *Principles of Community Engagement*, Second Edition, op. cit.
- ³¹ Health Consumers Queensland, op. cit.
- ³² *Community Engagement Framework*. Canada: Fraser Health, June 2009. Available at: <http://www.fraserhealth.ca/media/Community%20Engagement%20Framework.pdf>.
- ³³ Nancy Russell, et al., “The Active Community Engagement Continuum,” ACQUIRE Project Working Paper, July 2008. Available at: http://www.acquireproject.org/fileadmin/user_upload/ACQUIRE/Publications/ACE-Working-Paper-final.pdf.
- ³⁴ Nina Wallerstein, “What is the evidence on effectiveness of empowerment to improve health?” Copenhagen: World Health Organization Regional Office for Europe, Health Evidence Network Report, 2006. Available at: http://www.euro.who.int/__data/assets/pdf_file/0010/74656/E88086.pdf.
- ³⁵ *Ibid*.
- ³⁶ *Principles of Community Engagement*, 1997, op. cit.
- ³⁷ *Principles of Community Engagement*, Second Edition, op. cit.
- ³⁸ *National Standards for Community Engagement*, op. cit. The standards were developed “to set out best practice principles for the way that government agencies, councils, health boards, police and other public bodies engage with communities.” Available at: www.scotland.gov.uk/Resource/Doc/94257/0084550.pdf.
- ³⁹ See <http://www.health.state.mn.us/communityeng/index.html>.
- ⁴⁰ Mary Ann Morgan and Jennifer Lifshay, “Community Engagement in Public Health.” Contra Costa Health Services, California, March, 2006. Available at: http://cchealth.org/public-health/pdf/community_engagement_in_ph.pdf.
- ⁴¹ *Principles of Community Engagement*, Second Edition, op. cit.
- ⁴² “Foundations of Public Participation.” International Association for Public Participation, undated. Available at: <http://www.iap2.org.au/resources/iap2s-foundations-of-public-participation>.
- ⁴³ ACQUIRE Project, op. cit.
- ⁴⁴ “Painting the Landscape: A Cross-Cultural Exploration of Public-Government Decision-Making,” op. cit.
- ⁴⁵ Hayling Price, *A Seat at the Table*, op. cit. Also see the DC Promise Neighborhood Initiative website, at: www.dcpni.org.
- ⁴⁶ “Helpdesk Report,” UKaid, op. cit.
- ⁴⁷ See “HEAC Six Communities: When communities take action – the food and physical activity environment changes,” Partnership for Public Health, 2004-2010, at: <http://www.partnershipph.org/projects/HEAC>; and Kailee Neuner, “Transforming Active Living Policy into Practice: Municipal Best Practices,” a Policy Brief, Buffalo: Food Systems Planning and Healthy Communities Lab, University at Buffalo, The State University of New York, 2012, at: http://www.bnmc.org/wp-content/uploads/HKHCBuffalo_AL3_MunicipalBestPractices.pdf.
- ⁴⁸ Bjorkman and Svenson, 2007, as described in UNAIDS, “Promising practices in community engagement for elimination of new HIV infections among children by 2015 and keeping their mothers alive,” Case Study, 2012. Available at: http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2012/20120628_JC2281_PromisingPracticesCommunityEngagements_en.pdf.
- ⁴⁹ Meredith Minkler, Mildred Thompson, et al., “Contributions of Community Involvement to Organizational-Level Empowerment: The Federal Healthy Start Experience.” *Health Education & Behavior*, Vol. 28 (6): 783-807 (December 2001). Available at: <http://sophe.org/ui/communityinvolvement.pdf>.
- ⁵⁰ Freudenberg and Golub, “Health education, public policy, and disease prevention: a case history of the New York City Coalition to End Lead Poisoning.” *Health Education Quarterly*, 1987 Winter: 14(4):387-401.
- ⁵¹ CDC 2012 HIV Planning Guidance, op. cit., p17.
- ⁵² *Ibid*, p 18.
- ⁵³ *Ibid*, p 7.
- ⁵⁴ *Ryan White Part A Manual*, p 165; *Part B Manual*, p 150.
- ⁵⁵ *Ryan White Part A Manual*, p 174; *Part B Manual*, p 158.
- ⁵⁶ *Ryan White Part A Manual*, p 235; *Part B Manual*, p 211
- ⁵⁷ *Ryan White Part B Manual*, p 213..

- ⁵⁸ See Ryan White HIV Treatment Extension Act, Section 2617(b)(7)(A) and the *Part B Manual*, p 228.
- ⁵⁹ CDC 2012 *HIV Planning Guidance*, op.cit., p 22.
- ⁶⁰ *Ibid*, p 17.
- ⁶¹ *Ibid*, p 17.
- ⁶² *Delaware*: Voices, quarterly newsletter of the Delaware HIV Consortium, available at: <http://www.delawarehiv.org/voicesnewsletter.html>; *Kansas City*: The Quarterly, newsletter of the Kansas City HIV Planning Council, <http://www.kcmo.org/CKCMO/Depts/Health/HIVAIDSInformation/index.htm#PCQN>; *North Dakota*: HIV Newsletter, newsletter of the North Dakota Department of Health, <http://www.ndhealth.gov/hiv/Documents/Newsletter/FallWinter2011.pdf>; *Connecticut*: HIV Planning News and Notes, newsletter of the Connecticut HIV Planning Consortium, Comprehensive Jurisdictional Plan for HIV Care and Prevention, page 235: http://www.ct.gov/dph/lib/dph/aids_and_chronic/care/pdf/comprjuris_ct_plan.pdf; *New Jersey*: New Jersey HIV Semi-annual Newsletter of the State Department of Health, <http://www.state.nj.us/health/aids/aidsqtr.shtml>; *Pennsylvania*: Pennsylvania HIV Prevention Community Planning Update, quarterly newsletter produced at the Graduate School of Public Health, University of Pittsburgh, Pennsylvania Prevention Project for the Pennsylvania Department of Health's Division of HIV/AIDS Pennsylvania HIV Prevention: http://stopshiv.org/hp_joomla_15/media/newsletters/2012_03newsletter.pdf.
- ⁶³ Consumer LINC Project: LINC Project: Strategies to Involve Ryan White Consumers in Linking other PLWH into Primary Medical Care and Other Needed Services, page 42. Available at: https://careacttarget.org/sites/default/files/file-upload/resources/Project_LINC_Strategies_2011.pdf.
- ⁶⁴ Connecticut HIV Planning Consortium, Comprehensive Jurisdictional Plan for HIV Care and Prevention, page 15, available at: http://www.ct.gov/dph/lib/dph/aids_and_chronic/care/pdf/comprjuris_ct_plan.pdf; and Connecticut HIV Planning Consortium on Facebook, available at: <https://www.facebook.com/pages/CT-HIV-Planning-Consortium-CHPC/410354169014444>.
- ⁶⁵ Developed by HRSA consultants Harold Phillips and Emily Gantz McKay and documented and used through a cooperative agreement between the HIV/AIDS Bureau and Mosaica: The Center for Nonprofit Development and Pluralism, the Consumer LINC Project. Available on the TARGET Center website, "Strategies to Involve Ryan White Consumers in Linking other PLWH into Primary Medical Care and Other Needed Services," page 18, https://careacttarget.org/sites/default/files/file-upload/resources/Project_LINC_Strategies_2011.pdf.
- ⁶⁶ Developed by Mosaica's Project LINC, op. cit.
- ⁶⁷ Connecticut HIV Planning Consortium, Comprehensive Jurisdictional Plan for HIV Care and Prevention, page 18, available at: http://www.ct.gov/dph/lib/dph/aids_and_chronic/care/pdf/comprjuris_ct_plan.pdf.
- ⁶⁸ *South Carolina HIV Planning Council*, available at: <http://www.schpc.org/workgroups.html>; *Broward County HIV Prevention Planning Council*: Broward County Unveils New HIV Prevention Plan, *South Florida Gay News*, February 20, 2013, <http://southfloridagaynews.com/articles/broward-county-unveils-new-hiv-prevention-plan/108914>; *San Francisco HIV Prevention Planning Council*, <http://www.sfhiv.org/community-planning/hiv-prevention-planning-council/full-council-and-work-groups/>; *Houston HIV Prevention Group*, <http://www.houstontx.gov/health/HIV-STD/preventionplanning.html>.
- ⁶⁹ See description of the 2010 Iowa HIV, STD, and Hepatitis Conference. Available at: http://www.idph.state.ia.us/adper/common/pdf/hiv_aids/11th_conference.pdf
- ⁷⁰ *From Guidance to Implementation: Navigating the HIV Planning Guidance*. Washington, DC: National Minority AIDS Council, 2013, p 34.
- ⁷¹ San Francisco's HIV Prevention Planning Council (HPPC). Available at: <http://www.sfhiv.org/groups/2013-community-engagement-planning-work-group/>
- ⁷² District of Columbia Department of Health, "Oversight – HIV/AIDS, Hepatitis, STD, and Tuberculosis Administration (HAHSTA) – FY 2012," page 13.
- ⁷³ Future Builders, The Eight Annual Arkansas HIV/Tobacco Prevention and Awareness Symposium. Available at: http://www.futurebuilderssite.com/the-eight-annual-arkansas-hivtobacco-prevention-and-awareness-symposium_5163_ct.aspx.
- ⁷⁴ Brown University, Research at Brown, Amy Nunn Research, available at: <https://research.brown.edu/research/project.php?id=133794937>.
- ⁷⁵ Susan F. Markus, MS, LPC, "Photovoice for Healthy Relationships: Community-based HIV Participatory HIV Prevention in Rural American Indian Community" American Indian and Alaska Native Mental Health Research, Colorado School of Public Health, *Centers for American Indian and Alaska Native Health Journal*, Volume 2019/19. Available at: [http://www.ucdenver.edu/academics/colleges/PublicHealth/research/centers/CAIANH/journal/Documents/Volume%2019/19\(1\)_Markus_Photo-voice_102-123.pdf](http://www.ucdenver.edu/academics/colleges/PublicHealth/research/centers/CAIANH/journal/Documents/Volume%2019/19(1)_Markus_Photo-voice_102-123.pdf).
- ⁷⁶ Project U, available at: <http://www.designmattersatartcenter.org/proj/project-u-hiv-aids-awareness-campaign-with-laUSD/>.
- ⁷⁷ Georgia Department of Community Health and the Black AIDS Institute bring "Greater Than AIDS" HBCU Testing Tour to Georgia, press release from the Black AIDS Institute. Available at: http://www.blackaids.org/index.php?option=com_content&view=article&id=795:georgia-gaids-hbcu-testing-tour&catid=87:news-2011&Itemid=55.
- ⁷⁸ About Greater Than AIDS, available at: <http://greaterthan.org/about/#.UdQ3bPk3ujk>.
- ⁷⁹ Houston Hip Hop for HIV Awareness, available at: <http://www.hiphopforhiv.com/>.
- ⁸⁰ Faith in Action in Philadelphia, available at: <http://greaterthan.org/articles/faith-in-action-in-philadelphia/#.UeSKWl03ujk>.

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