

COMMUNITY ENGAGEMENT: ENABLING A FUTURE OF MEANINGFUL COLLABORATION AT ALL LEVELS OF HEALTH AND HUMAN RIGHTS DECISION-MAKING

OVERVIEW

Community engagement is defined 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.” Over the last two decades, research and practice in public health have increasingly employed community engagement.

The value of community engagement in public health programming cannot be overstated. Community engagement provides a means of navigating complex social, economic, cultural, and/or political settings where scientific research is being conducted or health and HIV services are being provided. Meaningful engagement with communities is often overlooked due to pressures of urgent timelines or perceptions that community members may not be considered experts. Conversely, it is the intelligence of the community that the public health community must use to ensure that risks are minimized, and benefits maximized. Communities add value and enhance the expertise of technical staff, researchers, service providers and others involved in public health programs or research. Examples of community engagement include:

- Mentoring civil society organizations in the use of data to engage health care workers and policy makers at multiple levels to influence health policy and improve uptake of core HIV prevention and treatment services;
- Promoting the ability of community members to identify and demand quality services by encouraging government accountability;
- Developing a structured and routine platform for communities and facilities to encourage joint accountability for health outcomes;
- Reducing legal and policy barriers to an effective response to both the HIV and tuberculosis (TB) epidemics; and
- Fostering sustainability of community organizations in preparation for decreased donor funding.

While community engagement can provide ample fertile soil in which scientific progress can germinate, little data exist that point to the best practices for engagement (and even less on the evaluation of community engagement), demonstrating the association between the quality and quantity of engagement and research outcomes.¹ Community engagement efforts aim to ensure community-led involvement in HIV programming to increase quality and uptake of key HIV-related services.

CDC'S ROLE

In order to reach UNAIDS' “90-90-90” goals (by 2020, 90 percent of all people living with HIV [PLHIV] will know their HIV status; 90 percent of all people with diagnosed HIV will receive sustained antiretroviral therapy (ART); and 90 percent of people receiving ART will have viral suppression), the U.S. Centers for Disease Control and Prevention (CDC) works with stakeholders to design, implement, evaluate, and scale up innovative models to identify HIV-positive individuals, link them to life-saving HIV treatment and services supported by the U.S. President's Emergency Plan for AIDS Relief (PEPFAR), and ensure that they achieve viral load suppression and long-term retention in care. Examples of CDC's strategic partnerships to produce high impact include:

- **Local Capacity Initiative (LCI):** Launched in 2013 through PEPFAR funding, LCI aims to strengthen the capacity of civil society organizations (CSOs) as a component of “country ownership,” particularly focusing on advocacy to enhance the effectiveness of local health systems the initiative aimed to strengthen: 1) political leadership and stewardship; 2) institutional and community ownership; 3) capacity building; and 4) mutual accountability in all sectors, including finance;
- **Community Score Card (CSC) Implementation:** CDC and global partners implemented CSC to increase participation, accountability, and transparency between service users, providers, and decision-makers. A two-way and ongoing participatory tool for the assessment, planning, and monitoring of services, CSC brings together service users and health services providers to jointly analyze issues in service delivery and find common solutions; and
- **Policy Advocacy:** CDC and partners promote the ability of community members to recognize and demand quality services and act as advocates for HIV and TB-related health care needs, aiming to hold governments accountable for service delivery.

¹ Goodman, M. S., & Sanders Thompson, V. L. (2017). The science of stakeholder engagement in research: classification, implementation, and evaluation. *Transl Behav Med*, 7(3), 486-491. doi:10.1007/s13142-017-0495-z

ACCOMPLISHMENTS / RESULTS

Many of CDC's assessments and investments include components to use community intelligence with internal/external expertise and form effective community, government, and other partnerships. Activities supported and tools developed by CDC include:

LCI – This program seeks to ensure successful capacity for CSOs to engage in each stage of HIV program development and implementation as well as run a sustainable organization beyond the life of donor funding. CSOs actively build coalitions and partnerships when they communicate with officials and track and analyze health and HIV policy processes. These in turn contribute to the policy advocacy environment when public officials use information for decision making and the general public receives information about policy relevant issues. The HIV policy advocacy environment is changed by increased accountability and transparency of the government's national commitments and planned results, legal and policy structural barriers to quality HIV response and stigma/discrimination are reduced, and the financing and revenue environment for CSOs are enabled. Impacts in this area are seen through increased access to uptake and retention in high quality HIV services by key populations (KP) and other vulnerable groups, and improved health for these populations.

CSC – Through this collaborative participatory tool for assessment, planning and monitoring of services, the data collected since 2015 in four countries (Uganda, Zimbabwe, Mozambique, and India) has generated important longitudinal data. Indicators have been created by communities for communities and are directly actionable. The visualization of CSC data provides first-hand evidence supporting the continued investment in policy and advocacy, the value of a two-way participatory tool, and the value of implementing changes to improve the quality HIV services, such as increased availability of HIV testing services or ART, better treatment of KP by health workers, and developing patients' rights charters to make community aware of their healthcare rights.

Advocacy Tracker – This tool is used in conjunction with CSC to visualize advocacy issues. Participants in CSC create an action-item list of health and HIV issues raised during community dialogues, determine the level of advocacy needed (e.g., community, district, provincial, etc.), and assign a lead stakeholder responsible for shepherding change. Successes include:

- Shared accountability and responsibility for progress moving forward;
- Decreased stigma and discrimination;
- Increased trained staff; and
- Development of patients' charter documents defining rights and responsibilities of patients and healthcare workers.

Field Trainings – CDC has led CSO trainings on a variety of topics, including health and HIV data analysis, CSC implementation, policy advocacy, messaging, stakeholder mapping, HIV resource mobilization, and organizational capacity building. Gender and Sexuality Diversity trainings have also been implemented to increase the awareness of healthcare workers and clinical staff of the variety of patients seeking healthcare services, and to reduce stigma and discrimination.

FUTURE EFFORTS

With the LCI program coming to an end in 2018, CDC will continue to support country teams and program experts in taking advantage of lessons learned under LCI. This has allowed for expansion of interventions and development of tools used to assist systematic, continuous and strong community engagement across PEPFAR-funded programs. Stakeholder partnerships and country-to-country technical assistance opportunities will continue to be facilitated in country, through CDC and in-country experts positioned around the world as well as from CDC headquarters. With the success of CSC in countries like Zimbabwe and Uganda, CDC will work with other country programs to introduce CSC into their national programs. In addition, CDC will work with Excella, a U.S.-based technology firm, as part of a public-private partnership to create a framework for administering and visualizing CSC data to add to the data of successful community engagement efforts.

Building on existing community engagement components to address and reduce stigma and discrimination towards PLHIV, KP, and other vulnerable populations, CDC will continue to support the coordination of strengthened and expanded stigma and discrimination prevention and response activities and tools. This will include supporting the Undetectable=Untransmissible (U=U) campaign, an important tool to empower PLHIV and KP, by expanding messaging regarding the importance of HIV treatment and influencing public opinion in support of PLHIV and KP.

BENEFITS OF OUR WORK

Best practices, promising programmatic data, and evidence-based interventions from CDC's efforts to improve community engagement are routinely shared with in-country communities, leadership, and other stake holders, as well as with the broader PEPFAR community, World Health Organization, and UNAIDS. Toolkits soon to be released for use at the country level include: *Community Score Card*, *Policy Advocacy*, and *Resources Mobilization Tips*. CDC is also working on other materials for community engagement, including the *Evaluation Framework*, *Data Visualization Models*, *Minimal Viable Product*, and *Open Data Kit programming of CSC*. Through these channels and in other venues, innovations developed and scaled up in individual countries may be translated to new settings and the broader HIV community in the U.S. and globally.