UNAIDS 2021

Holding the line: communities as first responders to COVID-19 and emerging health threats

Report of a UNAIDS survey

Contents

Foreword

Soon after its arrival, the COVID-19 pandemic rapidly encircled the globe. The spring and summer of 2020 was a time of shock and disbelief, fear of imminent disaster, and frenetic efforts to mobilize defences against the virus in every region of the world.

But it was also the time of a near miracle. Community-led organizations, run by and for people living with and affected by HIV, rallied to meet the challenge in a completely remarkable way. Spontaneously and yet in unison, they sprung into action to protect the health of people in their communities.

Community-led organizations skilfully fought to ensure access to antiretroviral medicines, HIV testing and counselling, and support for treatment adherence. At the same time, they deployed insights developed in the context of the HIV response to effectively mobilize their communities against COVID-19, delivering protection not only against the virus but also against upsurges in domestic violence and impoverishment from lost income.

The results of the UNAIDS survey presented in this report tell the story of their phenomenal early response. We have community-led organizations to thank for the fact that the combined force of two global pandemics, HIV and COVID-19, did not completely devastate communities of people living with and affected by HIV.

The report also provides an important opportunity to learn crucial lessons about the power of communities.

Community-led organizations have shown themselves to be an invaluable and essential part of our global public health infrastructure. We need to recognize their true role and accord them the full respect they deserve, and we need to begin to provide much more active nurturing and meaningful financial support for such a precious public resource.

Strengthening community-led organizations will powerfully enhance our efforts to respond to HIV and COVID-19. The world will also be much better prepared to respond to the challenges that are coming—those we can anticipate, such as ensuring the universal rollout of COVID-19 vaccines, and new health threats whose shapes we cannot yet envision.

The new Global AIDS Strategy 2021–2026: End Inequalities. End AIDS and the recently adopted United Nations General Assembly Political Declaration on HIV and

AIDS: Ending Inequalities and Getting on Track to End AIDS by 2030 provide urgent momentum for scaling up support and investment in community-led responses. Fully recognized, empowered, resourced and integrated community-led responses are key to transformative and sustainable health systems, including and especially in the face of emerging health threats.

UNAIDS is a firm believer in the centrality of community leadership to equitable and effective health responses, and will continue to advocate for the recognition and resourcing of the critical work of community-led organizations. This report makes recommendations to strengthen community-led responses that I urge all key actors in the field of global public health to consider with seriousness and urgency. The continuing ability of community-led organizations to provide life-saving services and to fully deploy their remarkable capacities is far too important a matter to be left to chance.

On behalf of UNAIDS, I extend profound thanks to community-led organizations from every region of the world run by people living with and affected by HIV who have risen to the challenge of COVID-19. I would also like to express my personal gratitude to the 225 organizations who somehow found the time, in the midst of intensive, exhausting efforts to protect their communities, to respond in such insightful and informative ways to the UNAIDS survey.

Winnie Byanyima
UNAIDS Executive Director

Executive summary

In June and July 2020, UNAIDS conducted a survey of community-led organizations run by and for people living with and affected by HIV. This predominantly qualitative survey sought to gain a deeper understanding of the impact that the COVID-19 pandemic was having on the HIV-related work of community-led organizations, and to learn more about their contributions to the COVID-19 response.

Although this report represents a snapshot from the first months of the COVID-19 pandemic, responses illuminate the high-priority actions needed to ensure the continuity of HIV-related services, and the sustainability of the community-led organizations providing them.

A total of 225 community-led organizations from 72 countries responded to the survey. Thirty-one per cent of the organizations were located in eastern and southern Africa, 25% in western and central Africa, 15% in western Europe and North America, 12% in Asia and the Pacific, 8% in the Middle East and North Africa, 5% in eastern Europe and central Asia, and 4% in Latin America.

These organizations provide services to both urban and rural communities, and to a diverse range of affected populations, including people living with HIV; women and girls living with HIV; young people living with HIV; gay men, bisexual men and other men who have sex with men; transgender people; sex workers; people who use drugs; and people in prisons and other closed settings.

The survey results demonstrated that community-led organizations moved swiftly at the onset of the COVID-19 pandemic to mitigate its impact on members of their communities, undertaking a wide range of new activities to help ensure continuity of HIV-related services and bolster their health and well-being. HIV-related services were rapidly reconfigured and shifted to online formats. Organizations became intensively involved in distribution of antiretroviral medicines, liaising and negotiating with government officials to ensure medicines would be accessible, and personally delivering medicines to beneficiaries.

At the same time, these organizations innovated and undertook new interventions to respond to the COVID-19 pandemic itself. They rolled out COVID-19 awareness-raising and health information campaigns, and provided individual counselling and guidance. They produced and distributed masks, soap and sanitizers, and they provided assistance to survivors of an upsurge in gender-based violence. Material support, including food packages and income supplements, was mobilized and distributed to those in greatest need.

Some organizations were reasonably satisfied that they had been drawn into their countries' national COVID-19 responses in an appropriate way, and that they had been positioned to make meaningful contributions. The majority, however, were frustrated by marginalization and exclusion, and were distressed that their absence—especially from planning and decision-making processes—was resulting in the failure of national COVID-19 responses to address the needs of their communities.

Throughout their efforts, relating to both HIV and COVID-19, community-led organizations kept the people in their communities connected—with the organizations, with each other and with their governments. They engaged in a constant process of tracking what was happening in their communities, identifying the most urgent problems and challenges, trouble-shooting, and informing and advocating with the authorities for needed changes.

Community-led organizations stretched their existing human and financial resources to the fullest extent possible. They did not receive new funding in significant amounts, with the constant effort to mobilize additional funds becoming yet another drain on their time and energy. Too many organizations noted filling critical gaps through contributions from their own staff members' salaries or the mobilization of unpaid volunteers.

The community-led organizations that developed in every region of the world to respond to the HIV pandemic have come to function as an informal global public health infrastructure. This infrastructure evolved and emerged organically over time and has come to play a central role in the HIV response. The COVID-19 pandemic has revealed the essential importance of community-led organizations yet again, underscoring the immense value of having such a global public resource ready to deploy at times of crisis.

Five measures should be adopted as a matter of urgency:

- **Community-led organizations must be fully included and integrated into national pandemic responses, including the continuing COVID-19 responses.** This involvement cannot be limited to consultation, information-sharing, and participation in programme implementation. The views of community-led organizations are essential at the level of policy development, planning, design and evaluation of interventions.
- **Short-term emergency funding must be mobilized and made readily available to community-led organizations.** Their existing resources are stretched to the limit, and they will not be able to continue COVID-19 work much longer without funding dedicated to this purpose. Particular attention should be paid to ensuring funds are structured in a way that makes them accessible to smaller, local and grassroots organizations.
- **A stable, long-term funding base must be established to enable community-led organizations to function effectively.** The strain and uncertainty of constantly seeking new donor support impairs their ability to function and ultimately forces many to cease operation. Major public and private funders in the field of public health must recognize that it is their responsibility to construct a stable resource base for community-led work.
- **The information base on the work of community-led organizations must be expanded and deepened.** The informal public health infrastructure generated by community-led organizations has not benefited from systematic documentation, identification of good practices and information-sharing. The knowledge deficit needs to be corrected to better understand how to expand its capacity and ensure it is deployed most effectively to address the challenges to come.
- **Continuity of HIV-related services must be guaranteed.** The funding provided to community-led organizations must be expanded to account for the challenges involved in providing HIV-related services in the context of COVID-19. Particular attention should be paid to establishing collaborative arrangements between community-led organizations and medical facilities to ensure availability of antiretroviral medicines and harm reduction commodities.

Introduction

In June and July 2020, UNAIDS conducted a survey of community-led organizations run by and for people living with and affected by HIV. The survey was distributed widely through UNAIDS networks, with the assistance of the charity coordinating body Funders Concerned About AIDS.

The primarily qualitative survey was designed to gain a deeper understanding of the impact of the COVID-19 pandemic on community-led organizations' HIV-related work, and to learn more about their contributions to the COVID-19 response.

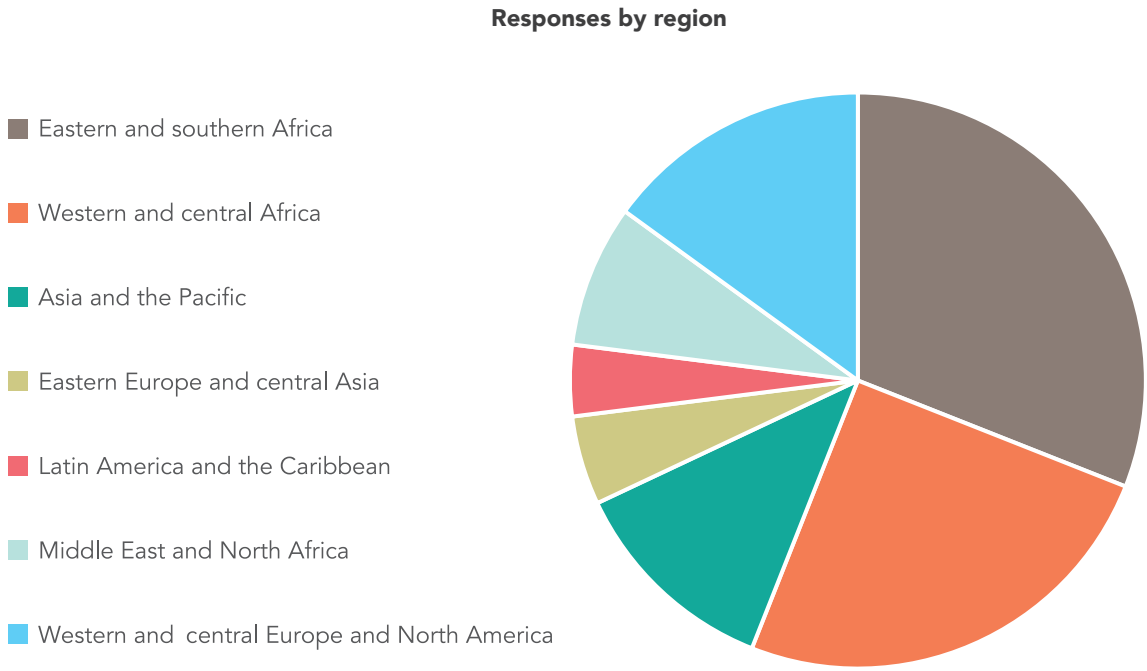
The survey gave community-led organizations the opportunity to describe how they are overcoming multiple daunting challenges to ensure continuity of HIV care, and how they are drawing on a depth of experience developed in the context of HIV to extend protection and support to their community members in the face of this new pandemic.

Although the results provide a snapshot of community-led responses to the first months of the COVID-19 pandemic, the survey allowed community-led organizations to express their views about what needs to change in the broader management of the COVID-19 response to enable them to more fully deploy the remarkable capacities they are demonstrating.

Profile of respondents

A total of 225 community-led organizations from 72 countries responded to the survey. Thirty-one per cent were in eastern and southern Africa, 25% in western and central Africa, 15% in western Europe and North America, 12% in Asia and the Pacific, 8% in the Middle East and North Africa, 5% in eastern Europe and central Asia, and 4% in Latin America (Figure 1).

Figure 1.


Responses by region
Eastern and southern Africa
Western and central Africa
Asia and the Pacific
Eastern Europe and central Asia
Latin America and the Caribbean
Middle East and North Africa
Western and central Europe and North America

Respondents provided services to urban and rural communities in almost equal measures. Figure 2 shows the population groups to whom their support is directed.

A large majority of respondents (92.5%) reported that their organizations are directly involved in the provision of HIV-related services to their communities. The services mentioned most frequently were awareness-raising and education, HIV testing and counselling, linkages to health services, home delivery of antiretroviral therapy and other medicines, antiretroviral therapy adherence support, and distribution of condoms and lubricants.

Multiple references were also made to advocacy work; stigma reduction; home-based care; income generation and nutrition support; services related to gender-based violence; services related to sexually transmitted infections, tuberculosis (TB) and malaria; harm-reduction services for people who use drugs; legal assistance; prevention of mother-to-child transmission; and distribution of antiretroviral medicines.

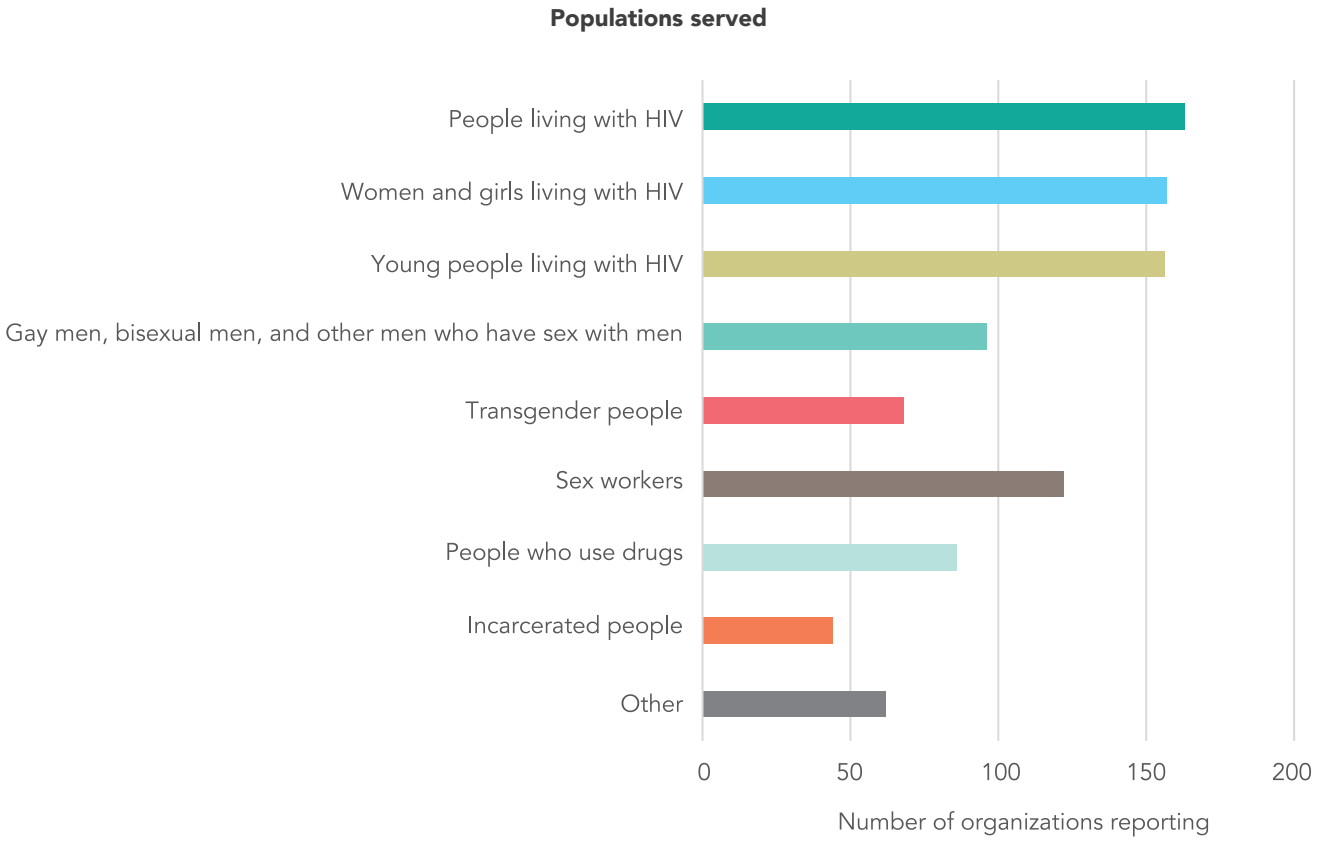
The majority of respondents reported working collaboratively with government-sponsored health facilities and social services. In some cases, partnerships were formalized through memorandums of understanding and joint programmes.

A small proportion of respondents (7.5%), some of whom identified as national coalitions of community-led organizations or international networks of people living with HIV, described themselves primarily as being involved in advocacy, research, policy development and capacity-building for their memberships.

Most respondents have worked with their communities for a considerable period of time. The average age of these community-led organizations is about 15 years.

Some of the organizations are fairly large and have more than 100 staff members. The majority, however, are more modestly sized, with a median staff complement of 12.5 and an average of 32.6. All organizations reported relatively large volunteer bases, an indication of the close connection and integration with the people they serve.

Figure 2.


Populations served
People living with HIV
Women and girls living with HIV
Young people living with HIV
Gay men, bisexual men, and other men who have sex with men
Transgender people
Sex workers
People who use drugs
Incarcerated people
Other
0
50
100
150
200
Number of organizations reporting

Survey responses

We reproduce here questions from the survey and summaries of representative responses from community-led organizations received in June and July 2020.

Have you had to stop providing any HIV-related services lately? Which ones?

Most respondents reported they had stopped providing at least some regular services over the past several months. A small number reported they had stopped operating entirely for a period of time.

The most common reasons for stopping services were lockdowns, prohibition of public meetings and group gatherings, travel restrictions, stock-outs of antiretroviral medicines and condoms, inability to obtain personal protective equipment (PPE) for staff and volunteers, and concern about spreading or contracting COVID-19.

Respondents said the services most often stopped were those that involved public convenings and events bringing together members of their communities, activities that require beneficiaries to work in groups, and support activities that require beneficiaries to visit an organization's facilities for discussions and interaction. Also mentioned were services involving physical contact or close proximity between staff members or volunteers and beneficiaries. Several organizations reported they could no longer provide assistance in remote areas.

Among the specific services noted were:

- Testing for HIV, sexually transmitted infections and TB.
- HIV education and awareness-raising.
- Distributing antiretroviral medicines.
- Distributing methadone treatment.
- Distributing condoms and lubricant.
- Home-based care.
- Treatment referrals to health facilities.
- Accompanying people to health facilities.
- Monitoring CD4 counts and viral loads.
- Outreach to clients lost to treatment follow-up.
- Personal counselling.

- Visits to schools.
- Visits to prisons and detention centres.
- Feeding programmes for children.
- Group meetings to maintain antiretroviral therapy adherence.
- Group meetings for psychosocial support.
- Group activities for income generation and food production.
- Capacity-building training.
- Child-care services.

These services are not optional or marginal to the community-led response to the HIV pandemic. They play a central role in efforts to reduce the spread of HIV; ensure people living with HIV enter and remain on treatment; mitigate the serious psychological impact of HIV; reduce stigma and discrimination; and ensure some measure of income and food security for people living with HIV who require adequate nutrition to take their medicines effectively.

What are the problems you have encountered in trying to provide HIV-related services?

Community-led organizations report struggling to meet multiple new challenges at the same time. Lockdowns and travel restrictions are severely affecting their ability to deliver assistance and their clients' ability to access services. Many clients have relocated during lockdowns and become difficult to find.

The intense focus of health systems and facilities on COVID-19 is restricting access to HIV-related health care. The scarcity and cost of PPE makes personal interaction with clients difficult and poses a particularly daunting obstacle for organizations that provide home-based care.

Lost employment and income are compromising people's ability to obtain the food they need while on antiretroviral therapy. School closures are reducing access to food for some children and adolescents. Loss of income is leading to homelessness.

Many governments are providing various forms of social support in the context of COVID-19, but it is not always accessible to clients of community-led organizations. Significant difficulties were noted for people living with HIV who are migrants or visitors to countries and for people lacking official identity documents.

"During the quarantine, many people are not going to health-care facilities for their treatments and medicines because most infectious diseases professionals are only receiving COVID-19 patients. Ignorance and mistrust are making many people living with HIV afraid of coinfections—although this does not seem to be the reality—and they are avoiding continuing their treatments."

Argentina, Fundación Huésped

"Young people are afraid of attending clinics as they fear contracting COVID-19. They also fear having to disclose their HIV status to security personnel when asked why they are moving around the community. Those on second-line treatments have to travel to central hospitals."

Zimbabwe, Africaid

"The problem was essentially the lack of access to sexual and reproductive health facilities, since they closed their offices temporarily due to lack of hygiene kits."

Tunisia, Médecins du Monde Belgique Section Tunisia

"We could not direct people who had risky contacts to test centres because they were closed due to COVID-19. With all the hospitals focused on COVID-19, patients could not meet with their doctors, which was a big source of stress, especially for people who were newly diagnosed with HIV. Due to travel bans, the foreigners who must remain in our country are having treatment problems—they cannot get their medicines."

Turkey, Pozitif-iz Association

"Quarantine measures caused significant restrictions in access to public transport. In some regions, taxi was the only way to reach the AIDS centre and get therapy."

Ukraine, NGO Fulcrum UA

"Lockdown in the country meant only limited travel was possible. Beneficiaries have moved around to stay with different family members, particularly children who are not currently at school, and are therefore not necessarily accessible. Some communities have also become more resistant to allowing visits. For example, a local counsellor, part of the municipality framework, instructed an HIV testing team to leave the community as they did not have permission to be there; that same team had tested in the community earlier in the year without any challenges, highlighting that people have become sensitive to allowing access."

South Africa, CHoiCE Trust

"The lockdown measures put in place to curb the spread of COVID-19 have reduced our contact with clients. The social distancing measures are limiting HIV counselling and testing, and follow-up of clients lost to treatment has become a problem. People are locked down in different places, and it is hard to trace their whereabouts."

Uganda, Acholi Renaissance Youth Association (ARYA)

"Certain populations have gone to ground. They have moved home to rural areas, and the hotspots are moving. It is hard to locate people through outreach, and some people are now not trying to access services."

United Kingdom, Frontline AIDS

"Since March 2020, the in-person services of the Population Service Centers have been discontinued or partially provided. Services for the population are available remotely on the Government services portal, but many people living with HIV do not have computers and do not have computer skills. For this reason, they cannot receive paperwork, benefits and social support."

Kazakhstan, Shapagat

"Our biggest challenge is with the previously in-school adolescents and young people living with HIV. Most of them had meals at school and now they are expected to be adherent to medication on an empty stomach."

Eswatini, Swaziland Network of Young Positives (SNYP+)

"One of the pillars of our work is supporting people who have been affected in their employment and economic situation—something that has become worryingly precarious during COVID-19. New jobs have not become available, and some have been eliminated. Above all, it has affected people in situations of administrative irregularity, who worked in the underground economy, and who have seen their already low incomes disappear. The work of our counsellor has been altered, and that of the social worker has been intensified, but with few good final results."

Spain, Asociación para la ayuda a personas afectadas por el VIH/sida (OMSIDA)

"Adherence issues among rural transgender women, transgender youth sex workers and gender-diverse youth have become a problem since most of them live hand to mouth. They have lost their only source of income because they have been forced to stop working indefinitely. When we have been delivering antiretroviral therapy and PrEP, our members have told us how they worry for their next meal and have started defaulting on antiretroviral therapy."

Uganda, Trans Youth Initiative – Uganda

"The girls living in brothels pay rent daily or weekly. Due to the pandemic, there were no customers, so no work and no money. They were thrown out and had to look for places to stay. This resulted in our losing track of some of them. We were also called by some brothels to go and rescue the girls. Right now, the majority are not on treatment because they have relocated and lack money to buy food and get their medicines. Some did not even have the money to recharge their phones to call us and had to borrow phones. Some of the girls died as a result of all of this."

Nigeria, Ohotu Diamond Women Initiative

Many community-led organizations reported that despite their best efforts to mitigate these problems, the cumulative impact on people in their communities is severe.

Community-led organizations are concerned that too many people are stopping taking their antiretroviral medicines. They have also reported an increase in domestic violence against women and against members of key populations. Particular concern has been expressed about the imposition of additional stress on people who are already struggling with the significant emotional and psychological challenges of living with HIV.

Lives that were previously difficult are becoming profoundly difficult.

"It is well known that the mental health of key populations and people living with HIV is already affected because of the life struggles related to their status. With COVID-19 and the restrictions imposed, their mental health is prone to higher risks: feeling depressed, stressed, and isolated.

People in lockdown are stating that they are being harassed by their intimates or by their parents. Some people living with HIV are afraid to take their medicines in front of their parents. For LGBTI people, people living with HIV, and people who use drugs who are now under the supervision of their parents and lack their own free space, it is challenging for them to receive phone calls and online support services."

Lebanon, SIDC

Have you changed the way in which you provide HIV-related services?

Community-led organizations report becoming more involved in distributing antiretroviral medicines. They have faced challenges, such as making available longer-term or local-level supplies of antiretroviral medicines, and they have been negotiating for changes.

Many respondents report that they have distributed antiretroviral medicines directly to clients, often drawing on the assistance of volunteers and other contacts in the community to make home deliveries.

Organizations that were already distributing antiretroviral medicines or methadone treatment have started to provide longer-term supplies, often multi-month dispensations of three to six months.

A number of respondents noted that because they could not continue conducting community HIV testing, they have started to distribute self-testing kits.

"We have established a collection and delivery service for antiretroviral medicines in collaboration with the infectious diseases unit and the pharmacy of the three public hospitals in the city, aimed at people living with HIV with low CD4 counts, women of childbearing age, and people with associated risks for COVID-19, such as older people and people with comorbidities. They were able to renew their prescriptions by calling the infectious diseases unit directly, so our staff could pick up the medicines and deliver to them."

Spain, Adhara HIV/AIDS Association

"We have been doing door-to-door distribution of HIV treatment, longer-term PrEP and antiretroviral medicine refills, and condoms and lubricants to transgender women, transgender youth sex workers and gender-diverse youth, because the majority were unable to walk the long distances to health-care facilities. We have also been offering home-based HIV testing and home-based visits to talk about adherence, and we have put a hotline in place for counselling."

Uganda, Trans Youth Initiative – Uganda

"With our partners ZNNP+ and ZIM-TTECH, we have provided outreach services to ensure medicines get right into the communities and closer to the people who need them."

Zimbabwe, Zimbabwe Young Positives

"We increased the number of online consultations, organized courier deliveries of harm-reduction kits, delivered such kits personally, and organized courier and postal deliveries of antiretroviral medicines."

Russian Federation, St Petersburg Charitable Fund Humanitarian Action

"We have undertaken antiretroviral medicines distribution at the household level to people living with HIV who could not travel to antiretroviral therapy centres due to the lockdown imposed by the Government. So far we have provided antiretroviral medicines 9796 times. Our organization is also leading the nationwide transition to dolutegravir-based antiretroviral therapy in 59 districts during the COVID-19 pandemic. We have distributed the new regimen to 2310 people living with HIV across Nepal."

Nepal, National Association of People Living with HIV/AIDS in Nepal

"Our organization is cooperating with UNAIDS in Myanmar and India to facilitate access to antiretroviral therapy for people who cannot travel to clinics on the Indian side during the border closure."

Myanmar, Myanmar Positive Group

The majority of respondents reported moving quickly to make their services available online. Many now rely primarily on telephone and email contact for personal counselling and for monitoring treatment and health status, but some are making home visits in urgent circumstances.

Efforts have been made to maintain the operation of mutual support groups, focused on psychosocial support and treatment adherence, by transferring them to social media platforms.

More of the awareness-raising and education work is being channelled through the organizations' websites, social media and (particularly in sub-Saharan Africa) radio.

"We have started to offer online support groups to people living with HIV through online platforms, since we are all living with uncertainty over how long it will take to be able to start face-to-face activities again. This type of intervention has shown great capacity to allow people to continue meeting and sharing their concerns and experiences in a safe way, both for the users and for the workers of the entity that lead these groups.

We are also in the process of adapting our intervention programmes with people deprived of liberty in collaboration with prison authorities, replacing face-to-face interventions with videoconferences and tutorials."

Spain, Adhara HIV/AIDS Association

"We formed social media groups with our clients and health providers. Some of our beneficiaries are doing radio interviews, highlighting their needs and advocating for their rights."

Zimbabwe, Zimbabwe Young Positives

"Most of what we do has been turned over to the phone or internet. Where absolutely critical, for instance with a COVID-19 death, with a flooded house or to assist a person without a phone, exceptions were made to organize personal follow-up."

South Africa, CABSA (Christian AIDS Bureau)

"We acquired tablets to support our provincial young positive focal points, so that they can be connected, and we made sure that they had vouchers to get easily connected. We also planned radio and television broadcasts to reach those who might not have access to the internet or to supportive devices to connect with social media like Facebook and WhatsApp."

Mozambique, MozPUD (National Network for People who Use Drugs)

Many organizations are concerned that the switch to providing services by telephone or online has negatively affected the quality of their interactions with clients and left some clients completely behind.

"Our follow-up and support meetings for peer educators in two areas became impossible. We put a lot of energy into trying to contact peer educators by phone. This is an economically disempowered group and therefore easy options like Zoom meetings just won't work. Some do not even have a phone, or a phone that can download Zoom."

South Africa, CABSA (Christian AIDS Bureau)

"Network connectivity and power challenges are affecting our capacity to reach clients. Only 52% of children, adolescents and young people living with HIV in Zvandiri have access to a phone, meaning community outreach is necessary for half our clients."

Zimbabwe, Africaid

"Some of the target groups have no access to modern media or the skills needed to use it."

Egypt, Caritas Egypt Alexandria – AIDS Intervention Unit

"We had difficulty in holding online/virtual group activities due to problems with connectivity and client access to technology."

Philippines, Alliance Against AIDS in Mindanao, Inc. (ALAGAD-Mindanao, Inc.)

"The digital divide is a problem. We are concerned that people who experience digital poverty are missing out on any virtual services provided."

United Kingdom, UK-CAB HIV Treatment Advocates Network

"The interruption of weekly workshops reinforced the already existing isolation among people. The people we welcome do not always have the means to communicate by phone, or they have difficulty speaking French."

France, Association Tempo in Grenoble

Are you providing new services related to COVID-19? What are they?

The new activities most frequently noted were various forms of outreach to communities and the broader public to raise awareness about COVID-19 and share information about how people can protect themselves. This has involved social media and individual communication with beneficiaries. In many cases, organization staff and volunteers went out in-person to their communities to educate people. Several organizations spoke about mobilizing the support groups they had formed with their HIV-positive beneficiaries to help with outreach.

"We have shared facts about COVID-19 and also explained ways in which to access this information, such as from nearby health centres, the Ministry of Health and the media. As an organization, we went to great lengths to go door to door, travelling around villages and teaching people about safety measures to protect themselves in the pandemic. People need to be convinced that the disease exists, as most of them have not come into contact with somebody who has had COVID-19."

Kenya, Consolation East Africa (CEA)

"After the outbreak of the new pandemic, our organization received many questions from our clients. Based on the information gathered, we first launched a social media campaign responding to these questions, while continuing to give one-to-one consultations. As well as health information counselling, we provided guidance on the new needs caused by the COVID-19 pandemic, lack of income, access to health care, and access to hygiene materials. We conducted live broadcasts with the participation of psychologists, lawyers, and other professionals to respond to the most common enquiries received from our clients."

Turkey, Positive Living Association

"We are raising awareness and disseminating information on prevention measures, and we are advising those people who suspect they have symptoms of COVID-19 infection to seek help before it is too late. We conduct online discussions with our beneficiaries, checking up on them and encouraging them to stay safe. We also provide psychosocial support to help them maintain their mental health and well-being during this pandemic period. We have limited resources, and therefore we cannot afford to distribute protection materials."

Zimbabwe, Zimbabwe Young Positives

"Our organization, given its previous experiences with sexually transmitted infections and HIV prevention with UNICEF, participated in the training of trainers workshop on infection prevention and water, sanitation and hygiene in the COVID-19 pandemic, organized by the Ministry of Health in partnership with UNICEF and WHO.

After this training, a debriefing session with our 13 girls in charge of the Listening and Assistance Centre enabled them to set up an awareness-raising programme for adolescent girls and women through social networks. Thousands of girls participated in this achievement."

Chad, Centre de Solidarité des Jeunes pour la Formation et le Développement (NGO CSJEFOD)

"We conducted an information campaign under the name Friendly Doctors Online. In this campaign, different health-care professionals, including an infectious diseases specialist, a psychologist and a family doctor, talked with the audience about COVID-19 and HIV."

Ukraine, NGO Fulcrum UA

"The organization has held virtual sensitization sessions with sex workers, raising awareness about COVID-19 and prevention measures. We have also made presentations at the national and regional levels about the impact of COVID-19 on sex workers in Guyana."

Guyana, Guyana Sex Workers Coalition

"We are using our community support groups, such as the savings groups, women's groups, and burial groups. They enlist all of their membership and target them with messages on COVID-19."

Uganda, Integrated Disabled Women Activities (IDIWA Uganda)

"Through our men's action groups, our members have been engaged in raising awareness of people in the community about handwashing with water and soap, wearing face masks, maintaining physical distance, and always going to a health facility when they are sick. Our members tell people that they must never go to traditional healers and that they must make use of the mosquito nets they have been supplied with recently to prevent malaria."

Sierra Leone, Men's Agenda for National Development

"The organization has raised awareness among our members living with HIV, but we can only provide masks and soap to our own staff as we have no funds to distribute to members of the community."

Cambodia, Cambodian People Living with HIV Network (CPN+)

"We have promoted different forms of information on COVID-19 through our social media, and we designed a small survey to identify problems that people living with HIV in Chile were facing because of COVID-19. We also translated a document developed by UNICEF and the Y+Network about specific questions that young people and teenagers living with HIV might have regarding COVID-19 and have shared it on our website."

Chile, Fundación Chile Positivo

The second most frequently noted activities were the distribution of masks, soap and sanitizers, and the construction of handwashing facilities. The cost and availability of masks and soap was often an issue, and many community-led organizations reported finding innovative ways to produce these items themselves.

"We have a technical team that designed and made face masks that are being distributed to people in vulnerable communities. The team also distributes soap and food and offers counselling to people living in vulnerable communities.

We are undertaking sensitization campaigns to encourage people in business places, markets and households to always wash their hands using clean water and soap. Those who can afford to buy sanitizers are encouraged to do so."

Uganda, AIDS Action Uganda (AAU)

"In May we set up a unit for manufacturing masks for the general public that was totally managed by women living with HIV in Oran. We were able to distribute masks to key populations of men who have sex with men, sex workers, people who use drugs, and migrants in Oran and then in Algiers, and we hope to do it very soon in other locations."

Algeria, Association de Protection contre le Sida (APCS Algérie)

"During awareness-raising sessions, community members were shown how to use locally made handwashing facilities using a two-litre bottle tied between two poles."

Malawi, Ekwendeni Hospital HIV/AIDS Programme

"Our organization, in partnership with other youth-led organizations under the banner Cameroon Youth Coalition Against COVID, created Operation One Person One Sanitizer. It has so far produced over 30 000 sanitizers for free distribution to the general population, and vulnerable communities in particular.

We are extending our work to prisons by building the capacity of prisoners to produce soap and masks. This is accompanied by communication on COVID-19.

We are also setting up a call centre to provide psychosocial support."

Cameroon, Body Talk International

"We are supporting community leaders and households to set up washing stations in public meeting areas such as boreholes, markets, trading centres, hospitals, and big homesteads."

Uganda, Integrated Disabled Women Activities (IDIWA Uganda)

Community-led organizations repeatedly expressed deep concern about the economic impact of lockdowns and travel restrictions on their beneficiaries. Many could find no way to stretch their limited resources to provide food and income assistance, although a good number reported that their own staff and volunteers were making personal contributions for this purpose, and in some cases it was possible to obtain donated funds.

Some organizations were closely involved in negotiating and liaising with officials to help their beneficiaries access various forms of support provided by their governments.

"We created a specific campaign to raise funds to support the people living with HIV served by the organization to ensure means for them to stay at home. So far almost 180 families have been supported, receiving monthly (since March) food staples and personal and household hygiene and protection materials delivered to their homes, and small but significant allowances (about US$ 40) wired to their bank accounts, meaning they do not have to leave their homes to receive support. Our social services have also supported users in requesting emergency benefits from the Government, as the way it has been set up by the Federal Government excludes the access of those most in need of it."

Brazil, Gestos—HIV, Communication and Gender

"We found the migrant population does not have enough information about the disease and prevention measures. Most of the problems encountered by our team were essentially social problems, since the migrants lost their jobs and were unable to pay their rent or in some cases even feed themselves."

Tunisia, Médecins du Monde Belgique Section Tunisia

"We have been raising awareness about coronavirus and prevention measures, and distributing protection materials such as masks and soap. We are also providing food and paying rents for some economically affected families, with a focus on female-headed households."

Egypt, Al-Shehab Foundation for Comprehensive Development

"Besides providing information, we provided counselling to respond to the new needs caused by the pandemic, loss of income, access to health care and testing, and access to hygiene materials. In the last month of the COVID-19 lockdown period, one-time rental support was offered to refugee and migrant clients who were unable to receive any governmental support due to their residential status."

Turkey, Positive Living Association

Several organizations described new activities they had undertaken to respond to the increase in gender-based violence, providing counselling and locating shelters and other government services.

"We have been providing counselling on the availability of human rights services and shelters for women living with HIV in situations of violence, due to a sharp surge in violence."

Ukraine, Positive Women

"We are providing appropriate referrals for survivors of abuse. We are conducting data collection and mapping to know more about services available across the country. We are providing sanitary pads to internally displaced adolescent girls and young women who have fled from the conflict in the northwest, southwest and far north of Cameroon who are now faced with the pandemic."

Cameroon, Leap Girl Africa (LGA)

"We are doing COVID-19 awareness-raising and prevention work with key and vulnerable populations on social networks and individually through phone calls. We have set up a counselling and orientation unit for female survivors of gender-based violence and discrimination in the context of COVID-19."

Algeria, AIDS Algérie

Some organizations have been able to mobilize sufficient financial and human resources to roll out comprehensive programmes of COVID-19 support in a remarkably short period of time.

"We distributed 200 face masks and 100 bottles of sanitizer to LGBTI peers and female sex workers in Matungu sub-county to enable them to protect themselves at hotspots (especially due to the fact they are prone to infections from truckers and other visitors from high-risk areas).

We have encouraged key populations to report to the police station all visitors coming to the hotspots, so they can quarantine for 14 days to contain new infections at hotspots.

We are conducting continuous sensitization at hotspots to enhance social distancing, educating key populations on how to use face masks, and educating them on hygiene to enhance continuous sanitization.

We are joining hands to develop concept notes with UHAI to enable us to reach key populations facing challenges such as lack of money to pay for rent and food. We mobilize funds to buy food and support them to meet other expenses such as rent and medicines for their children.

We are working with outreach workers to map key populations who need support during this trying time. We will develop a database of the network with the county government to find out whether they can also be listed as beneficiaries of ongoing direct food aid.

We are working with the county health facility to mobilize enough HIV self-testing kits for use by our nurse as a strategy to contain COVID-19."

Kenya, PITARP (Promoting Interventions Targeting at Risk Populations)

"We have designed and distributed prevention information material: Human Rights in Times of COVID-19, Sexual Health and COVID-19, and Mental Health in Times of COVID-19.

A sanitary kit is being distributed, including masks, liquid soap and antibacterial gel.

Community outreach has been done to promote healthier behavioural changes during COVID-19 among sex workers, migrants, people living on the streets, and men who have sex with other men.

Counselling and support are provided on the organization's social networks.

We provide support and liaise with public health services so people can access their medical care in a timely manner.

Activities to provide prevention supplies have been increased in the most vulnerable places, especially in the clandestine sites that have emerged."

Mexico, Colectivo Seres

"We have provided:

- One-time emergency nutritional support to 2026 people living with HIV, including all 1340 children living with HIV in Nepal.
- PPE to 14 antiretroviral therapy centres across the country and 62 organizations working in the HIV sector.
- COVID-19 insurance to 543 frontline workers of organizations of people living with HIV and to all staff members of NAP+N working in HIV and TB projects.
- Nutrition support to 60 female sex workers living in the Kathmandu valley.

Staff members contributed 5 days of salary, which enabled us to provide meals for 10 days to people stranded due to the lockdown."

Nepal, National Association of People Living with HIV/AIDS in Nepal

"We completed a rapid assessment of over 150 people living with HIV to hear their needs, and presented the findings to our partners. We negotiated with a food bank to get food to our communities' members in time of hunger. We received 120 boxes of food and distributed them in the national capital district. We used our Facebook page to provide correct information from the World Health Organization about COVID-19. We ran two training sessions in the capital city with our HIV peer outreach workers."

Papua New Guinea, Key Population Advocacy Consortium

Have you encountered problems trying to provide COVID-19-related services? What have you done to help solve these problems?

Community-led organizations reported continuing difficulties in obtaining PPE and travel approval, public transport or private vehicles for their staff. These organizations reported they are shouldering extremely heavy burdens with little external support. They are expending a great deal of energy negotiating and liaising with governments and United Nations officials to find assistance for their beneficiaries—but these efforts are not always successful.

At the same time, community-led organizations have been forced into a constant state of fundraising, with positive responses few and far between. Staff and volunteers are concerned for the well-being of their community members and struggle with the reality that, without additional resources, there is often little they can do to help.

This emotional and psychological strain is significant and compounded by the knowledge that in attempting to maintain essential contact with the people in their communities, they are exposing themselves to infection.

"We cannot count on the Federal Government to support us, although we and other organizations have been formally demanding it do so, through advocacy before the Congress and presenting cases before the courts. We have been in constant dialogue with local governments to highlight demands outside the scope of health care for COVID-19, including social services, mental health care, provision of antiretroviral medicines and other commodities for people living with HIV, adequate responses for women, LGBTI people and children in unsafe houses or refuges during isolation, and provision of water in communities without regular sanitation.

These demands have been well received and addressed to some extent, but they are far from being sufficient. Local governments state they are already being spread too thinly trying to provide a response to COVID-19, and this is aggravated by the loss of revenue during the lockdown."

Brazil, Gestos—HIV, Communication and Gender

"We do not have protection equipment like masks, which the Government only gives to health workers and other frontline workers. We do not have financial support to go out to the provinces. We are looking for funding opportunities, but we are still waiting. Right now we can only use social media to disseminate information—but a large part of our community cannot read or write, so we need to go out there and explain things in simple English or local languages."

Papua New Guinea, Key Population Advocacy Consortium

"It has not been possible for us to redistribute funds from existing projects to respond to the urgent needs of women in the context of COVID-19. We are lacking resources to pay for transportation for specialist appointments related to physical or mental problems or due to situations of violence, such as forensic examinations and visits to police stations.

We do not have the financial means to assist with food needs, personal hygiene products or protection products for low-income and single women.

To try to fill the resource gap, we have been writing project applications to access emergency funds. We have organized activities to enable women within self-help groups support themselves. For example, some members of the groups have sewn masks and sent them to other women in need.

Local fundraising has been carried out among individuals and medium-sized businesses to help pay for transport of medicines and other essential goods to the countryside."

Ukraine, Positive Women

"The resources available to face the challenges of COVID-19 are limited. We have reached very few people with food and hygiene products, compared with the number of key population members in need. We have tried to match the available resources with the most vulnerable beneficiaries, and our staff have managed to make some contributions themselves for those in need.

At present only the urban areas of Kigali and second cities are targeted for community mobilization. However, the rural areas of different provinces also need to be covered."

Rwanda, National Association for Supporting People Living with HIV/AIDS (ANSP+)

"COVID-19 services for the local population and migrants had to be implemented without question, but safety has been an issue due to the difficulty of procuring safety gear and disinfectant. All of these items now cost more than before the outbreak, and at one point it was impossible to import or buy these goods in the country.

We connected up with partners who were supplied these items by governments or donors from different countries and had enough to share with other organizations.

It has also been very difficult to fund our activities. Funding calls are very specifically defined, with no possibility to add things such as a water, sanitation and hygiene component for the migrant population."

Bosnia and Herzegovina, Caritas (Bosnia and Herzegovina)

"Another challenge has been the impact of COVID-19 on our team. While almost all services provided to our public have been switched to the phone or online, there is still the need to be physically present at our headquarters to receive and sort donations, prepare care packets with staples and hygiene, cleaning and protection products, and deliver them.

Although we have set up a system to cycle team members and to reduce interaction to a minimum, over time members of our team have experienced symptoms or developed the disease."

Brazil, Gestos—HIV, Communication and Gender

"We are working with the Ministry of Health and National Disaster Management Agency to coordinate rapid response teams for community-based case-finding, contact tracing and screening, dissemination of health promotion materials, and referrals to follow-up services.

We experienced some Government hesitancy in engaging civil society organization partners at the beginning. As the coordination has improved, however, so has the engagement with non-state actors. We also experienced a delay in our accreditation as essential service providers, which restricted travel and led to inefficiencies—for example, we were subject to roadblocks and interrogations over our movements."

Eswatini, Kwakha Indvodza

"There is a high demand for services that is greater than the resources we have. To help solve this problem, we have mobilized more youth to become volunteers to provide COVID-19 services in their communities. These services include disseminating COVID-19 prevention and management information, and promoting improved hygiene practices at household levels, while ensuring HIV services are still being implemented accordingly."

Malawi, Fountain of Hope (FOHOP)

"The problem is with funding to support our groups with handwashing utensils, such as buckets and soap, food for the aged and sometimes quarantined homes—and above all, funding to support our men's action groups with resources for transport and incentives for their services. I am always talking with them, asking them to bear with me, saying that God will reward them, and some humanitarian organization will come to our aid."

Sierra Leone, Men's Agenda for National Development

Are you being included in or excluded from your country's response to COVID-19? In what way?

Several community-led organizations reported being closely integrated into the national response.

"There is a system in place. The Government set up a presidential taskforce on COVID-19, which provides technical direction on the response. In each district there is a committee for the COVID-19 response. Then different instruments were developed to guide implementation. We are included at the district committee level. Our organization is a member of the Blantyre District Committee in the Southern Region, and the Karonga District Committee in the Northern Region of Malawi."

Malawi, Fountain of Hope (FOHOP)

"We are involved because we are included as part of the Government emergency response task team to represent the community voice. Community and resource mobilization work is organized by us."

Viet Nam, Blue Sky Social Enterprise Limited Company

"We have been fully included in the country's response at the national, provincial, district and community levels. At the national level, our role in supporting the response for children, adolescents and young people living with HIV has been fully recognized.

We have been working closely with the Ministry on the development and dissemination of information for children, adolescents and young people living with HIV, and piloting virtual training for enhanced adherence counselling and differentiated service delivery for children, adolescents and young people living with HIV.

We have provided technical assistance on planning for and responding to the service delivery needs of children, adolescents and young people living with HIV during the outbreak; virtual training for health-care workers; and age-appropriate information, education, and communication materials."

Zimbabwe, Africaid

"We are included through the organization's membership in the coordination working group, which includes the national AIDS programme, some United Nations agencies and civil society organizations."

Egypt, Al-Shehab Foundation for Comprehensive Development

It was quite frequently noted, however, that where community-led organizations are included in national COVID-19 response processes, they are not engaged at the decision-making and planning levels and are treated only as implementers.

"We are part of the health cluster formed to coordinate the health-sector response to COVID-19. But we have not been appreciated or acknowledged by the Government agencies, international nongovernmental organizations, and donor agencies. We are not included in the planning meetings conducted by the country coordinating mechanism or other international nongovernmental organizations and donor agencies."

Nepal, National Association of People Living with HIV/AIDS in Nepal

"Yes, but not in a frank and transparent way. We are involved more in the execution than in the planning and decision-making. There needs to be less centralized decisions, made closer to the populations concerned and without discrimination, especially for people who inject drugs and migrants."

Algeria, Association de Protection contre le Sida (APCS Algérie)

"We do not participate in the national monitoring committee, but we are consulted to serve as an information relay to our members and their target groups. We do not participate in the national monitoring committee and do not benefit from government grants."

Cameroon, Coalition de la Société Civile du Cameroun contre le SIDA, le Paludisme, la Tuberculose et les Hépatites (CSCC SANTE)

Many community-led organizations have expressed concern about being completely side-lined from the national response and the consequences this has for the communities they represent.

"There is a roundtable with experts from different disciplines and institutions. And that's it. There has not been any formal invitation from our government or from local authorities to include us in the response to COVID-19. We have not been invited, and nor has any other organization working in the field of HIV, to join the roundtable of experts."

Chile, Fundación Chile Positivo

"There is a system that has been set up for COVID-19 in our country, but it is very unplanned and is not inclusive. The system was not planned keeping in mind the situations of female sex workers, migrants or people living with HIV."

India, Srijan Foundation

"They have not considered the needs and particularities of our key populations. The conditions in which we operate have not been considered. We have not participated in the design, operation or monitoring of the actions of the COVID-19 response system."

Mexico, Colectivo Seres

"As a civil society organization of people with disabilities, the Government has given us approval to operate and support communities in any way we can to respond to COVID-19, but we are not represented on the COVID-19 taskforces. We feel we are excluded because we are not represented on the different task forces, and yet we play a major role in sensitizing on COVID-19 epidemiology in the communities we serve.

There are no clear guidelines on handling people with disabilities. Many are dying in their houses during the lockdown because they cannot access treatment for HIV and other underlying conditions and other services such as family planning.

There is a need to include people with disabilities on the COVID-19 taskforces to provide expert opinion on disability management during and in the aftermath of COVID-19."

Uganda, Integrated Disabled Women Activities (IDIWA Uganda)

"The system of our country's response to COVID-19 did not include organizations that were not part of the Ministry of Health system. During the quarantine period, meetings of the coordinating councils on HIV and TB and on gender issues—during which gender-based violence could have been discussed, and a quick response plan to COVID-19 challenges could have been drawn up—were not held, even online.

Our organization was not involved at the state level in collecting information about the needs of women living with HIV that arose due to COVID-19.

If studies were done, the gender-sensitive needs of women living with HIV, including those who find themselves in situations of violence, were not taken into account."

Ukraine, Positive Women

What role do you think you should be playing in your country's response?

Many organizations emphasized the importance of the deep connections they have with their communities, and the significant role they can therefore play by reaching people with information, raising awareness, and improving communication between communities and governments.

"As a local and field-based organization, we need to play an intermediary role between the local population and the Government, educating and supporting the masses to get through this difficult moment and providing feedback to both parties."

Cameroon, Sustainable Women Organization (SWO)

"We have played a role of auxiliary to the public authorities with people on the fringes of the health system. Our partnership with Social Affairs and Health allowed us, despite the traffic bans, to care for the most vulnerable people and direct them to the appropriate care structures."

Tunisia, Médecins du Monde Belgique Section Tunisia

"Networks of people living with HIV could play a big role in disseminating correct information because we reach all of the states and counties. This will help communities understand how to protect themselves, reduce stigma and change behaviours. To date, most people in my country think that COVID-19 is for the western world, not us."

South Sudan, National Empowerment of Positive Women United (NEPWU)

"Community-based organizations need to be trained and engaged because we reach the majority of people as well as reaching our own networks."

Papua New Guinea, Key Population Advocacy Consortium

"Our role is to provide support to populations who are isolated and disconnected from conventional channels for the delivery of public assistance and aid. We are a link and meeting point between these populations and national and international actions in response to COVID-19."

Algeria, Association de Protection Contre le Sida (APCS Algérie)

Above all, community-led organizations stressed the need to recognize the very substantial knowledge and capacities they have developed over decades of work to combat HIV. These organizations have become, in a quite significant sense, "pandemic experts", and they expressed the desire to be fully engaged in the COVID-19 response on that basis.

"Our role as a civil society organization with many years of proven experience in the field of prevention of HIV and sexually transmitted infections deserves to be respected and integrated into the process of combating this pandemic. We believe that if we are associated, it will allow us to put all our experiences into practice to positively influence the community to adopt responsible behaviour towards this disease."

Chad, Centre de solidarité des Jeunes pour la Formation et le Développement (NGO CSJEFOD)

"The achievement of the best current results on HIV and TB and even malaria is thanks to the efforts of communities. We must play this same role in the COVID-19 response in Benin, mobilizing communities and leading the fight at the grassroots, by and for the priority targets because they are the most vulnerable, and also reaching out to the general population."

Benin, Initiatives des Éducateurs contre le SIDA (Association EDUSIDA)

"We have an important role to play in HIV primary and combination prevention. We believe we have a great deal of expertise. We have worked for years on behaviour change approaches and in providing health services, including promoting screening, but later also with monitoring and evaluation and epidemiological surveys."

Algeria, AIDS Algérie

"There should be collaboration with us to benefit from the information and experience we have developed in health emergencies such as HIV and the experience we have gained in promoting and establishing strategies for behaviour change and developing healthier life skills for people; identifying and working with vulnerable groups; attending to emotional crises; identifying and working in areas and sites of greatest risk; and eliminating stigma and discrimination."

Mexico, Colectivo Seres

"Our role is community monitoring and ongoing community support, and connecting communities to the public health system; counselling, outreach, support and direct care, and communication activities for people living with HIV and key populations; and representing the voices of communities in policy developments in response to COVID-19."

Viet Nam, Blue Sky Social Enterprise Limited Company

"With HIV, communities have acquired important communication skills for behaviour change. Donors and government must involve communities to avoid the mistakes made at the start of the HIV pandemic."

Côte d'Ivoire, Centre Solidarité Action Sociale (Centre SAS)

"Health and HIV actors believe there is no effective fight against an epidemic without coordination, synergy and participation with civil society, and without specific consideration of human rights. The fight against HIV has proven this.

COVID-19, like HIV, makes its nest in the absence of consultation, therapeutic education and risk reduction policy, and by the creation and maintenance of social inequalities. The fight against COVID-19 must be based on the same methods as those against HIV. A non-judgemental and human rights-conscious public health policy, mobilizing doctors, researchers and elected officials, and involving citizens and representatives of fragile populations, is a smart and effective policy.

It is this model that works and allows us to obtain the concrete results that we bring to life in the Alpes-Maritimes in the fight against HIV. The fight against an epidemic is only won when civil society and representatives of those most affected are involved in political and scientific decisions."

France, Objectif Sida Zéro, Nice et les Alpes-Maritimes s'engagent

"Community organizations working in the HIV/TB sector can play a very important role, because for many years we have been working in the area of prevention and can transfer our experience and expertise into the COVID-19 response, making sure it does not become a "monster" as was HIV at the beginning."

Republic of Moldova, GENDERDOC-M Information Centre

What needs to change and what do others need to do to support you in providing COVID-19 services?

The respondents made many specific concrete proposals for high-priority actions. These ranged widely and included measures such as reducing stock-outs of antiretroviral medicines; ensuring continuity of HIV-related health services; improving access of key populations and migrants to social benefits; improving access to shelters for survivors of gender-based violence; providing economic empowerment programmes for women and key populations; better provision of PPE to community-led organizations; and disseminating information on COVID-19 more simply and in local languages.

Two common themes stood out strongly. The first was funding: community-led organizations expressed the need for greater resources to support their work, and emphasized the need for donors to reassess and adjust their existing procedures and priorities in the context of COVID-19.

"Provide funding, right now during the pandemic—and after for the post-pandemic, when we expect to have to deal with severe repercussions. We need calls for projects, with adequate funding, easily accessible, taking care not to exclude small community-based organizations, and flexible grants that trust local organizations to manage the grants to best address the demands in their communities."

Brazil, Gestos—HIV, Communication and Gender

"Donors need to simplify the process of donating during this period, and there should be disclosure of all available opportunities of funds."

Rwanda, Solidarité pour l'Épanouissement des Veuves et des Orphelins visant le Travail et l'Auto promotion (SEVOTA)

"Governments should consider supporting community-based organizations since only by involving communities on the ground will we be able to limit the pandemic. Donors need to be flexible, and should not reprioritize or retract existing resources but should increase support to community-led responses to the COVID-19 pandemic."

Uganda, Trans Youth Initiative – Uganda

"Continue opening up funding opportunities to ensure support for young people, so we do not reverse the gains made with this vulnerable population where HIV outcomes were already behind those of adults. Ensure funding for mental health interventions—we have found a high prevalence of mental health disorders among adolescents living with HIV, and this has been further compounded by COVID-19."

Zimbabwe, Africaid

"Besides some small amounts of funding and donations, such as for masks and disinfectants, organizations providing larger funds have not announced a special needs funding call responding to COVID-19 yet. A targeted call for funds should be opened for people living with HIV during this epidemic, since people living with HIV have special needs."

Turkey, Positive Living Association

Respondents also underlined the importance of ensuring funding reaches smaller, local organizations, which often have the closest connections with their communities.

"Donors must also be considerate of smaller, younger organizations in their programmes, since most of their requirements for accessing funds cannot be met by starters like our organization."

Ghana, Well-Live Ghana

"The country's own nongovernmental organizations have to be engaged in the response because they are close to the community. Most of the time the international nongovernmental organizations win the funding, but the national capacities are not built."

South Sudan, National Empowerment of Positive Women United (NEPWU)

"Since we are at the grassroots, we have first-hand information about what people want and how they want it. We request meaningful involvement and financial support because we cannot operate on a zero budget."

Eswatini, Swaziland Network of Young Positives (SNYP+)

"Donors should provide funds to facilitate service delivery. We particularly suggest that donors should provide small or seed grants to local community-based organizations that serve the people of their immediate communities. This has proven to be an effective approach, but it is sometimes neglected in favour of large grants to very big organizations."

Cameroon, Hope for Vulnerable Children Association (HOVUCA)

Community-led organizations call for greater inclusion in the COVID-19 response. Based on many months of intense and demanding work, they can clearly see the potential of what they could be contributing if the doors were to open.

"The relationship between the public sector and civil society must change, since currently we are considered more as a barrier than as an important ally in dealing with social problems. Dialogue spaces are needed for the exchange of experiences. Inclusive public policies should be designed that ensure the effective participation of civil society and groups at greatest risk. A philosophy of co-participation, co-responsibility and inclusion should be promoted."

Mexico, Colectivo Seres

"Draw on our experience of mobilization against HIV. Do not confine yourselves to political and medical experts but integrate civil society associations and affected people."

Monaco, Fight AIDS Monaco

"Request our support, subcontract us, fund us, and invite us to take part in establishing a long-term strategy related to COVID-19, especially among vulnerable people who already have difficulty in accessing medical and social services. Organizations that work in vulnerable communities should become agents for COVID-19 prevention among these people."

Romania, Romanian Association Against AIDS

"We need to be at the centre of consultation, planning and implementation in the country's national COVID-19 response plan."

Uganda, Trans Youth Initiative – Uganda

"Ensure our effective involvement, and better coordination of the action of civil society alongside public authorities and other development actors in the national response to COVID-19. We should be fully integrated into the national committee in charge of the response."

Cameroon, Coalition de la Société Civile du Cameroun contre le SIDA, le Paludisme, la Tuberculose et les Hépatites (CSCC SANTE)

"The world needs the movement of people living with HIV. Engage our networks and communities and use our expertise to strengthen the COVID-19 response at national and global levels. Ensure we have the funds and political support we need to be meaningfully engaged in every stage. Involve us in gathering data to inform the response, to plan how to deliver information and services and how to ensure the response promotes human rights and equity."

Netherlands, Global Network of People Living with HIV (GNP+)

Conclusion and recommendations

The community-led organizations that responded to the UNAIDS survey have moved swiftly to mitigate the impact of the COVID-19 pandemic on their communities, undertaking a wide range of new activities to ensure continuity of HIV care and bolster their health and well-being.

HIV support services were rapidly reconfigured and shifted to online formats. Community-led organizations became intensively involved in distributing antiretroviral medicines, liaising and negotiating with government officials to ensure medicines would be accessible, and personally delivering medicines to beneficiaries.

At the same time, these community-led organizations have innovated and undertaken new interventions to respond to the COVID-19 pandemic. They rolled out COVID-19 awareness-raising and health information campaigns and provided individual counselling and guidance. They produced and distributed face masks, soap and sanitizers and provided assistance to survivors of an upsurge in gender-based violence.

Material support, including food packages and income supplements, has been mobilized and distributed to people in greatest need.

Throughout all of these efforts, relating to both HIV and COVID-19, community-led organizations have kept the people in their communities connected—with the organizations, with each other, and with their governments. They have been engaged in a constant process of tracking what is happening in their communities, identifying the most urgent problems and challenges, troubleshooting, and informing and advocating with authorities for needed changes.

This work has been driven by pressing concern for the well-being of their beneficiaries. Community-led organizations have extended their human and financial resources as far as they possibly can. Constant efforts to mobilize additional funds are yet another drain on these organizations' time and energy, but there is little indication that any significant additional funding has arrived.

Too many community-led organizations have filled critical gaps through contributions from their own staff salaries or through the mobilization of unpaid volunteers.

Some community-led organizations are reasonably satisfied that they have been drawn into their countries' COVID-19 responses in an appropriate way, and that they have been positioned to make meaningful contributions at the local and national level. The majority, however, are frustrated by marginalization and exclusion, and distressed that their absence—especially from planning and decision-making processes—is resulting in the failure of national COVID-19 responses to address the needs of their communities.

Community-led organizations have come to a very important realization. They possess a great depth of knowledge and experience in the field of HIV, and these skills are transferable: they are pandemic response experts.

It took little time for community-led organizations to begin acting on this realization and to embrace a new role. What is required at the current juncture, as the organizations themselves have stressed, is recognition from governments, the United Nations system, funding organizations and other key actors of the impressive capacities that lie within community-led organizations, and concrete action to ensure greater inclusion and increased support.

The many diverse community-led organizations that have developed during the past few decades in every region of the world to respond to the HIV pandemic have come to function as an informal global public health infrastructure. This infrastructure has evolved and emerged organically over time and has come to play a central role in the HIV response.

The COVID-19 pandemic has revealed its essential importance yet again, underscoring the immense value of having such a global public resource ready to deploy at times of crisis. It would be profoundly irresponsible to take this resource for granted or to overlook its potential.

Five measures should be adopted as a matter of urgency:

- Community-led organizations must be fully included and integrated into national pandemic responses, including continuing COVID-19 responses. This involvement cannot be limited to consultation, information-sharing, and participation in programme implementation. The views of community-led organizations are essential at the level of policy development, planning, design and evaluation of interventions. Their engagement at every level must be actively supported and facilitated through the provision of protective equipment, recognition as providers of essential services, and consideration in budgetary planning.

- Short-term emergency funding must be mobilized and made readily available to community-led organizations. Few of the survey respondents reported any additional funding to support the activities they have undertaken to respond to COVID-19. Their existing resources are stretched to the limit, and they will not be able to continue COVID-19 work much longer without funding dedicated to this purpose. Particular attention should be paid to ensuring funds are structured in a way that makes them accessible to smaller, local and grassroots organizations.

- A stable, long-term funding base must be established to enable community-led organizations to function effectively. To date, the financing of these organizations has largely been left to chance. The strain and uncertainty of constantly seeking new donor support impairs their ability to function and ultimately forces many to cease operation. Major public and private funders in the field of public health must recognize that it is their responsibility to construct a stable resource base for community-led work, and undertake the necessary review and revision of existing funding structures.

- The information base on the work of community-led organizations must be expanded and deepened. The informal public health infrastructure generated by community-led organizations working in the field of HIV is not the product of any centralized planning. For this reason, their work has not benefited from systematic documentation, identification of good practices, and widespread information-sharing. The knowledge deficit needs to be corrected as soon as possible to help maintain this resource and to better understand how to expand its capacity and ensure it is deployed most effectively to address the challenges to come.
- Continuity of HIV-related services must be guaranteed. Community-led organizations are making every possible effort to ensure their communities continue to receive care, but they are not being adequately supported. Their funding must be expanded to account for the challenges involved in providing HIV-related services in the context of COVID-19. Particular attention should be paid to establishing collaborative arrangements between community-led organizations and medical facilities to ensure antiretroviral medicines and harm reduction commodities are available at the local level.

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