

GIYPA ROADMAP



**SUPPORTING YOUNG
PEOPLE LIVING WITH HIV
TO BE MEANINGFULLY
INVOLVED IN THE HIV
RESPONSE**

The Global Network of People Living with HIV (GNP+)

GNP+ is the global network for and by people living with HIV, and advocates to improve the quality of life of people living with HIV. As a network of networks, GNP+ is driven by the needs of people living with HIV worldwide. Based on emancipation and self-determination, GNP+ works with independent and autonomous regional and national networks of people living with HIV in all continents. Under the central theme *Reclaiming our Lives!*, GNP+ implements an evidence-informed advocacy programme focused on: empowerment; human rights; positive health dignity and prevention; and sexual and reproductive health and rights of people living with HIV.

The experience and the range of programming and advocacy expertise that GNP+ offers enhances the Y+ Programme and creates a space where the needs of young people living with HIV (YPLHIV) are incorporated into the broader agenda of the PLHIV community.

For the most up to date information, results and achievements, please visit: www.gnpplus.net

Acknowledgements

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Partnerships

GNP+ has worked alongside the World AIDS Campaign (WAC) to support the development of the Y+ programme and we are grateful for this collaborative partnership and look forward to it developing further in the future.

The Y+ Programme is also pleased to be associated and collaborating with the following agencies, organisations and initiatives: HIV Young Leaders Fund, IPPF, UNAIDS Inter Agency Task-Team on HIV and Young People, UNAIDS, UNESCO, UNICEF and WHO.

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ACRONYMS

ASO	AIDS service organisation
CBO	community-based organisation
INGO	international non-governmental organisation
GIPA	greater involvement of people living with HIV
GIYPA	greater involvement of young people living with HIV
GNP+	Global Network of People Living with HIV
NGO	non-governmental organisation
PEPFAR	US President's Emergency Plan for AIDS Relief
PHDP	<i>Positive Health, Dignity and Prevention</i>
PLHIV	people living with HIV
SRH	sexual and reproductive health
UN	United Nations
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNICEF	United Nations Children's Fund
UNFPA	United Populations Fund
YPLHIV	young people living with HIV
Y+ Programme	Young People Living with HIV Programme of GNP+

INTRODUCTION

Young people living with HIV (YPLHIV) around the world are making a difference in the HIV response. And so can you! This roadmap makes some suggestions on how you can become more involved with different HIV efforts in your community, country or globally.

Whether you want to teach your peers about healthy and satisfying relationships and sex lives, transform social norms and practices that get in the way of your sexual and reproductive rights, make health services more youth-friendly, overcome HIV stigma, fight for access to HIV treatment, or ensure that communities are caring and compassionate for people living with and affected by HIV, you have powerful contributions to make to the HIV response!

As a young person living with HIV, you have the power to make significant changes in your community, country and globally. Nobody knows better than YPLHIV what it is like to be young and positive. YPLHIV also bring insight, new ideas, and energy that can reinvigorate HIV responses.

A FEW WORDS ABOUT GIYPA

The critical need for youth and people living with HIV (PLHIV) to take an active role in the HIV response is recognised in key global documents. Many of these have been endorsed by a large number of countries, for example the Principle of Greater Involvement of People Living with HIV/AIDS (known as the GIPA principle) from the 1994 *Paris AIDS Declaration*¹ and the *Declaration of Commitment on HIV/AIDS* from the 2001 United Nations General Assembly Special Session on HIV/AIDS (UNGASS)². Likewise, key documents from large global HIV networks recognise the role of youth and people living with HIV, such as the 2010 *Positive Health, Dignity and Prevention* (PHDP) framework³ from the Global Network of People Living with HIV (GNP+) and UNAIDS.

DID YOU
KNOW?

What is the Y+ Programme? The Young People Living with HIV Programme (Y+ Programme) is a GNP+ programme for and led by young people living with HIV (YPLHIV). The Global Network of People Living with HIV (GNP+) has established the Y+ Programme to address specific gaps in the HIV response and address the specific needs of young people living with HIV (aged 15–30).

For more information, please consult: www.gnpplus.net/en/programmes/empowerment/young-people-living-with-hiv

1. http://data.unaids.org/pub/ExternalDocument/2007/the-paris-declaration_en.pdf

2. www.unaids.org/en/media/unaids/contentassets/dataimport/publications/irc-pub03/aidsdeclaration_en.pdf

3. www.gnpplus.net/en/resources/positive-health-dignity-and-prevention/item/109-positive-health-dignity-and-prevention-a-policy-framework

The Y+ Programme from GNP+ is committed to seeing the greater involvement of young people living with HIV (GIYPA). We have prepared this roadmap to help YPLHIV figure out how to get more involved and how to get the most out of your involvement. The roadmap is based on the voices of over 300 YPLHIV and almost 175 organisations who participated in our 2010 global survey on GIYPA.

YPLHIV are a diverse group; sometimes the only thing that YPLHIV have in common with each other is their HIV status. This is also true when it comes to getting involved. Some YPLHIV are already involved in the HIV response and want to find their next step. Other YPLHIV want to figure out how to get connected to the HIV response in the first place. And yet other YPLHIV don't want to put their energy and ideas into the HIV response but would rather focus on other things that matter to them.

DID YOU KNOW?

Between November 2010 and January 2011, the Y+ Programme undertook an exploratory study to better understand the current scope of involvement of YPLHIV in HIV responses around the world and how to increase their meaningful involvement. Over 300 YPLHIV aged 15 to 30 years and almost 175 organisations (including PLHIV networks, key population networks⁴, youth-led organisations, and youth-serving organisations) responded to our online surveys. To the best of our knowledge, this is the first study on the involvement of YPLHIV in the HIV response. The study was able to attract a large sample of YPLHIV compared to many other studies – largely due to the involvement of six YPLHIV from around the world on the research team.

The study and these tools were developed with support from the HIV Young Leaders Fund. Learn more at: www.hivyoungleadersfund.org.

TIP!



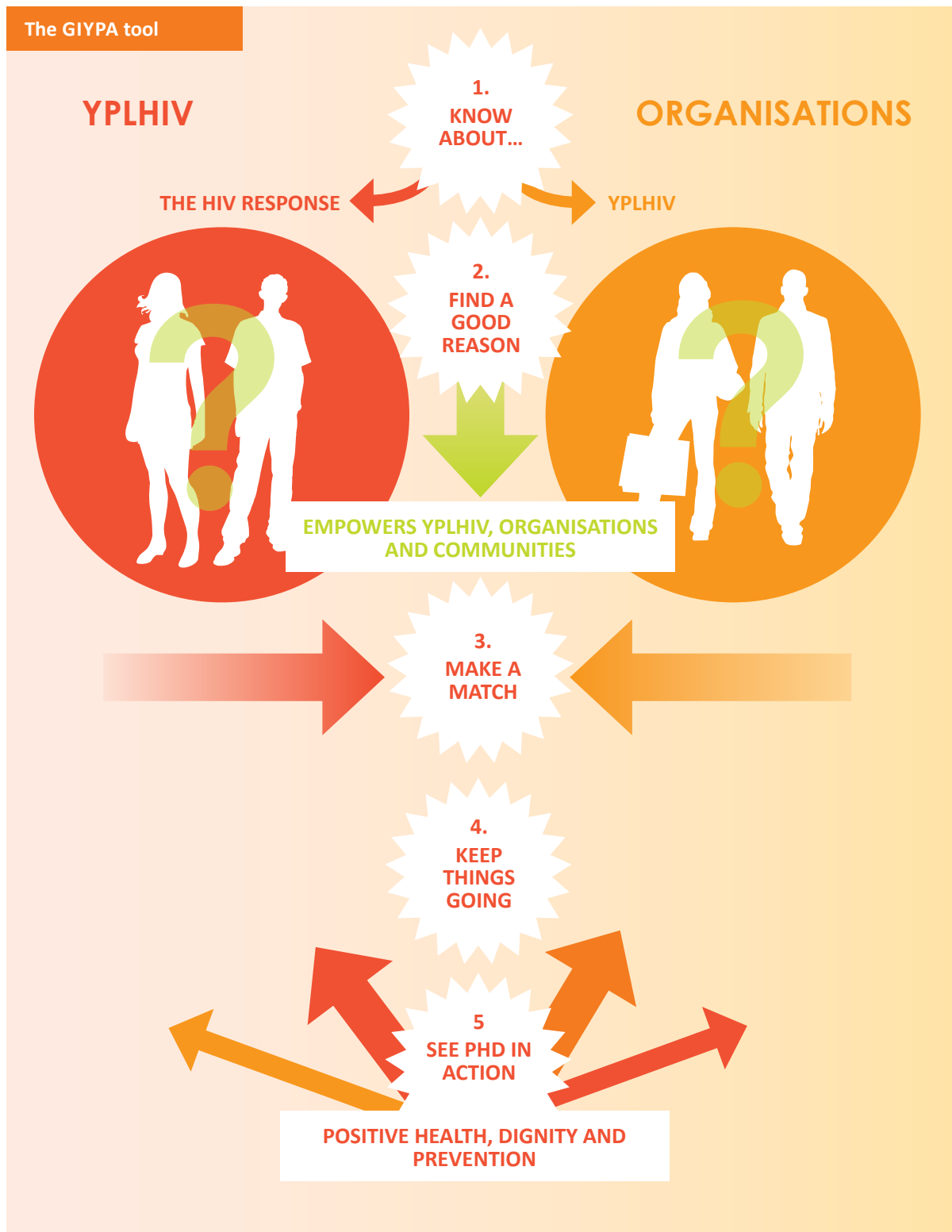
You are the only person who can decide if and how you want to be involved in the HIV response and what would make your involvement meaningful. This roadmap should point you in the right direction.

4. 'Key populations' is a term often used to describe groups that are most heavily affected by the HIV epidemic. It usually refers to women, young people, men who have sex with men, sex workers, people who inject drugs, prisoners and migrants.

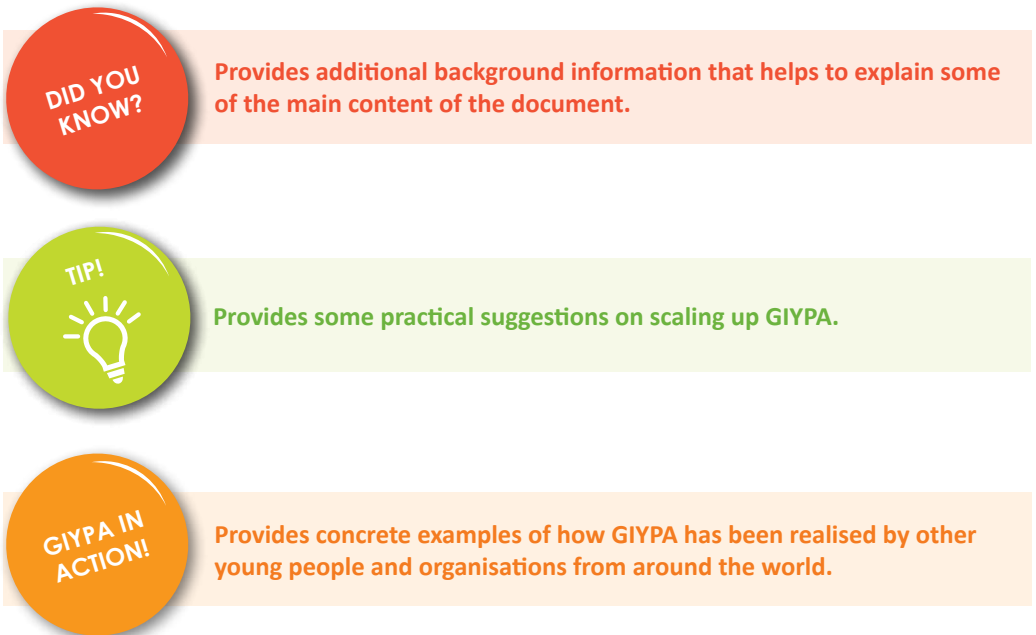
HOW TO USE THIS ROADMAP

Each chapter in this roadmap outlines one of the five steps towards GIYPA:

1. Understanding what is meant by 'the HIV response'
2. Finding good reasons to become involved
3. Linking you and organisations together
4. Sustaining and growing your involvement
5. Seeing *Positive Health, Dignity and Prevention* in action



Throughout this roadmap, you will notice that there are different text boxes, providing additional information. These text boxes are explained below.



DID YOU KNOW? Provides additional background information that helps to explain some of the main content of the document.

TIP! Provides some practical suggestions on scaling up GIYPA.

GIYPA IN ACTION! Provides concrete examples of how GIYPA has been realised by other young people and organisations from around the world.

Both YPLHIV and organisations have a role in seeing GIYPA realised. The Y+ Programme has prepared a companion document to this roadmap to support organisations to do their part: *GIYPA Guidebook: Supporting Organisations and Networks to Scale up the Meaningful Involvement of Young People Living with HIV*. It is available in the Y+ section of the GNP+ website: www.gnpplus.net/en/programmes/empowerment/young-people-living-with-hiv

A FEW WORDS ABOUT POSITIVE HEALTH, DIGNITY AND PREVENTION

Positive Health, Dignity and Prevention (PHDP) recognises and encompasses the full range of health and social justice issues for people living with HIV. From the perspective of people living with HIV, *Positive Health, Dignity and Prevention* involves the following: a supportive legal and policy environment; focusing on holistic health promotion, not only on transmission prevention; tailored to setting, key populations, and to the individual; and, defined by people living with HIV.

PHDP espouses the fundamental principles that responsibility for HIV prevention should be shared, and that policies and programmes for people living with HIV should be designed and implemented with the meaningful involvement of people living with HIV.

Obviously, that means that for policies and programming to be responsive to the needs and realities of young people, they should be designed and implemented with the meaningful involvement of YPLHIV. This roadmap provides a tool to support GIYPA – which is a critical element in reaching the goals of PDHP.

By linking the social, health, and prevention needs of the individual living with HIV within a human-rights framework, PHDP results in a more efficient use of resources and ensures outcomes are not only more responsive to the needs of young people living with HIV, but also more beneficial for their partners, families and communities.

For more information on *Positive Health, Dignity and Prevention*, consult: www.gnpplus.net/en/programmes/positive-health-dignity-and-prevention/positive-health-dignity-and-prevention

1 UNDERSTANDING WHAT IS MEANT BY 'THE HIV RESPONSE'

The first question you may have is 'what is the HIV response?' Well, let's try to explain!

The term 'HIV response' is used as a quick way to talk about all of the work being done with people living with HIV, affected by HIV, and at risk of HIV. It includes efforts to prevent new infections and to ensure that people living with and affected by HIV are able to enjoy their rights to live free from stigma and discrimination, and are able to access the commodities, support and services they need. There are many layers of HIV responses happening at the same time: the community, local, state, national, regional and global levels.

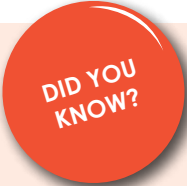
1.1 WHO IS ALREADY INVOLVED?

The HIV response involves many different types of people and organisations, including government ministries, UN agencies, non-governmental organisations, community groups and individual people. Each has a different role to play. This provides a huge range of opportunities for young people to become involved. Some of the key players in HIV responses include:

- >> **PLHIV and other individuals.** They play caring roles, provide education, share their experiences, run organisations, advocate for change, etc.
- >> **Networks of PLHIV.** PLHIV come together to provide information and services to other PLHIV and to stand up for the rights of PLHIV.
- >> **Networks of key populations.**⁵ Some groups of people have been particularly affected in HIV epidemics, such as men who have sex with men, people who use drugs, and sex workers. Members of these groups come together to stand up for their rights.
- >> **Community-based organisations (CBOs).** They provide social and health services to their community on a not-for-profit basis. Some CBOs are faith-based. Sometimes they are called NGOs – non-governmental organisations. Those that have a primary mandate related to HIV are sometimes called ASOs – AIDS service organisation. Many CBOs, NGOs and ASOs are also involved in advocacy.
- >> **International non-governmental organisations (INGOs).** An organisation that is international in scope and provides social and health services to communities in many countries on a not-for-profit basis. Some INGOs are faith-based.

5. For example: the Global Network of Sex Work Projects (www.nswp.org), the Global Forum for MSM and HIV (www.msngf.org), the International Network of People Who Use Drugs (www.inpud.net).

- >> **Government.** From the national to local level, government ministries and agencies are involved in understanding the HIV epidemic and in developing, implementing, and evaluating strategies to respond to the epidemic.
- >> **United Nations (UN).** The UN brings together the nations of the world to work together for peace and development. Several UN agencies – including UNAIDS, UN Women, the United Nations Children’s Fund (UNICEF), the United Nations Population Fund (UNFPA) and World Health Organization (WHO) – are involved in understanding the HIV epidemic and in developing, implementing, and evaluating global strategies and guidance.
- >> **Donors.** Many private foundations and governments provide funds to support the HIV response. Some of these donors are huge and provide money to support entire national treatment programmes, for example (the Global Fund to Fight AIDS, Tuberculosis and Malaria⁶ or PEPFAR – the US President’s Emergency Plan for AIDS Relief⁷). Other donors are small local foundations which have very focussed funding priorities. All of these donors together have enabled great progress to be made over the last 30 years.
- >> **Researchers.** Researchers play an important role in finding out more about the HIV epidemic and about effective ways to prevent new infections and to treat, care for and support those who are living with and affected by HIV.
- >> **Grassroots clubs, projects, and activist groups.** Individuals and groups of people make important contributions by forming clubs to raise awareness of HIV in their school or community, providing support to those living with HIV, and even providing services.
- >> **Artists.** Painters, musicians, actors and others use the arts to help people make sense of the complex issues fuelling HIV epidemics and to find new solutions.



Some organisations are focused specifically on youth. Adult-led organisations that focus on youth are called youth-serving organisations. Youth-led organisations are run by young people – sometimes with the support of adults.

6. www.theglobalfund.org/en

7. www.pepfar.gov

2 FINDING GOOD REASONS TO BECOME INVOLVED

Not sure why you should get involved? YPLHIV and organisations from around the world told us that involving HIV-positive youth in the HIV response is ...



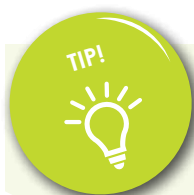
- Discover ways to find healing and hope
- Gain knowledge, motivation and support to live positively
- Make friends
- Connect with mentors
- Feel like you belong
- Get to know your community
- Build your confidence and self-esteem
- Gain knowledge and skills
- Get a job or start a business



- Offer new ideas, strategies, and programmes
- Make services relevant, accessible, and high quality
- Connect with other young people
- Influence decision-makers
- Reach large numbers of people
- Learn how to work with youth

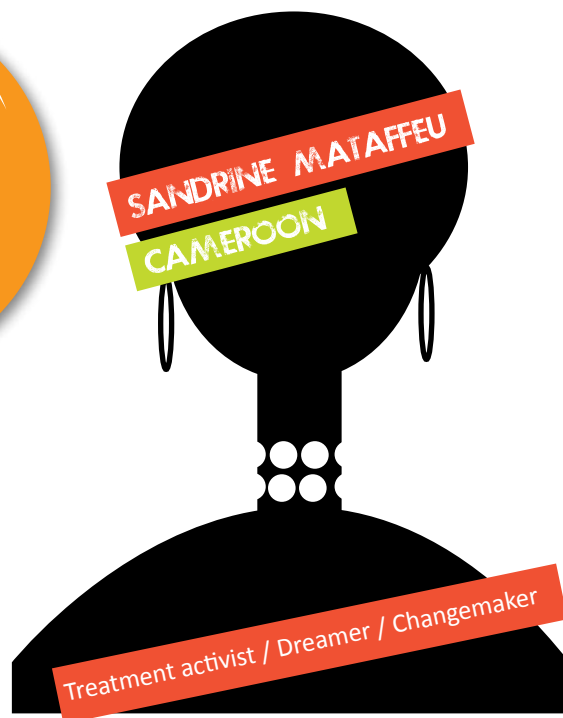


- Reduce HIV stigma and discrimination
- Drive up demand for HIV services among youth
- Promote behaviours that prevent new infections
- Increase YPLHIV's access to treatment, care and support



Not interested in working in the HIV response? You can get many of the personal benefits from being involved in any issue that matters to you. Your involvement can also benefit organisations and communities, just in different ways.

GIYPA IN
ACTION!



I was a student when I found out I was living with HIV. I worried that my parents would feel disappointed in me for having contracted HIV after everything they had given to me. Determined to show my family that nothing was lost for me, I began volunteering with the national PLHIV network during my free time. When I finished my studies, the Central Africa Treatment Action Group hired me as their Executive Assistant. Being involved not only opened doors for me to do something I love and earn a living, it also has provided me with opportunities to gain knowledge and skills and to see that I can have much bigger dreams for my future.

3 LINKING YOU AND ORGANISATIONS TOGETHER

Now that you know the many good reasons to get involved in the HIV response, you may be wondering about the different ways you can get involved and how to find an opportunity that is right for you.

3.1 HOW CAN I GET INVOLVED IN THE HIV RESPONSE?

There are many ways to be involved in the HIV response. When deciding which role is right for you, it's important to think about the knowledge and skills you already have to offer and which you want to gain. Keep in mind that everyone – even the most involved of YPLHIV – had to start somewhere. Many YPLHIV join the HIV response by using services or taking part in existing groups and programmes, and then move into leadership roles.

TYPE OF ROLE	EXAMPLES	EXAMPLES OF COMPETENCIES YOU CAN GAIN	EXAMPLES OF SKILLS YOU MAY NEED TO GET IN THE DOOR
Participant or service user	<ul style="list-style-type: none"> • Post-test club member • YPLHIV social club member 	<ul style="list-style-type: none"> • Connections with other YPLHIV. • Information about your rights and health. 	<ul style="list-style-type: none"> • A desire to meet other people. • Willingness to try new things.
Practical roles	<ul style="list-style-type: none"> • Peer educators • Peer counsellors • Peer researchers • HIV-positive speakers • Outreach workers 	<ul style="list-style-type: none"> • Increased understanding of sexual and reproductive health and rights. • Using the arts, media, and sports and play to influence people. • Facilitating and running groups. • Designing workshops and communication campaigns. • Public speaking skills. • Providing counselling and support. • Data collection and analysis. • Planning and coordinating programmes. • Leadership skills. 	<ul style="list-style-type: none"> • Passion for the issue. • Ability to connect with people. • Willingness to learn.
Structural roles	<ul style="list-style-type: none"> • Advisory committee • Board of Directors • Senior staff 	<ul style="list-style-type: none"> • Strategic planning. • Making decisions about the policies, practices and processes of programmes and/or organisations. • Running organisations and programmes. • Running meetings. • Representing others. • Budgeting and financial management. • Raising funds and political support for programmes and organisations. • Human resource management. • Leadership skills. 	<ul style="list-style-type: none"> • Practical experience in similar positions and organisations. • Ability to represent the target audience or community.
Social change	<ul style="list-style-type: none"> • Activists • Advocates 	<ul style="list-style-type: none"> • Increased understanding of key issues and human rights. • Crafting key messages. • Change tactics such as media advocacy, letter writing, public events, awareness raising campaigns, protests, etc. • Public speaking skills. • Leadership skills. 	<ul style="list-style-type: none"> • Passion for the issue. • Self-motivated. • Willingness to learn.

WORKING WITH TEENS TO SUPPORT THEIR PEERS

Improved treatment for children with perinatally-acquired HIV means that the number of HIV-positive teens is growing rapidly. Botswana-Baylor Children's Clinical Center of Excellence (Baylor COE) launched its Teen Club in 2005 to meet the needs of these YPLHIV. Linking positive youth development principles with the call from PLHIV of 'nothing for us, without us', Baylor COE runs the Teen Club in partnership with YPLHIV.

Each year, Teen Club members elect five boys and five girls to be Teen Leaders who help make decisions about activities and operations, act as peer counsellors and mentors, solicit feedback from other members, and take an active role in outreach, fundraising, advocacy, and even hiring staff.

The Teen Club is regularly featured as a best practice for supporting YPLHIV and is being replicated in other areas of Africa. The success of the Teen Clubs shows that when HIV-positive teens are given a voice and supported to overcome obstacles to good health, their strength, creativity and passion can engender hope, even in the most desperate situations.

3.2 WHICH OPPORTUNITIES ARE RIGHT FOR ME?

The strategies organisations use to attract YPLHIV will differ depending on the type of role (e.g., volunteer, staff, board member), their ability to support and build the capacity of the young people who get involved, and whether YPLHIV feel safe being open about their HIV status in the community.

Your time and ideas are precious. There are many things to consider when deciding how you want to contribute to the HIV response. Take time to reflect on the following when deciding which opportunities are the best for you.

It starts with you!

Your involvement will be most meaningful for you if you're passionate about what you are doing and feel like you're getting something valuable in return. Think about:

- >> **What issues are important to you?** What do you feel passionate about? Promoting safer sex? Standing up for gender equality or against homophobia? Increasing access to treatment? Making HIV services youth-friendly?
- >> **What do you enjoy doing?** Do you like to talking with large crowds, small groups, or one-on-one? Do you like leading groups, planning events, being part of drama troupes or choirs, making videos or radio shows, doing research, writing, following politics, or providing support?
- >> **What knowledge and skills do you already have?** Are you an artist? Have you run a club at your school or in your community? Are you good at writing? Do you know how to use social media to reach other young people?
- >> **What do you want to gain from being involved?** Are you looking to gain particular skills? Make friends? Meet other YPLHIV? Find a mentor? Earn money?
- >> **How much time are you willing and able to give?** Are you looking for a full-time or part-time job in the HIV response? Do you have an evening or two a week to give? Are you only able to commit to being involved in the occasional event?



YPLHIV have many priorities, including earning money for school and living expenses. If you want to be involved but need to earn money, look for staff positions or volunteer positions that provide a stipend or participation support like bus fare.

Assessing and managing risks

While there are many benefits to being involved, there may also be some risks. It's important to take time to identify possible risks and make informed decisions about whether you are willing to take each risk. One potential risk to consider in deciding which involvement opportunity is right for you is whether you want your HIV-status or the fact that you are part a key population to be known by others in the community. Many YPLHIV find it empowering to do so, particularly when standing up for the rights of themselves and their peers. But, it can be impossible to control who finds out about your HIV-status or identity once this information has been shared publicly. There can be positive and negative consequences to sharing your HIV status and/or identifying as a member of a key population.

Finding an organisation that is a 'good fit'

No two organisations are alike. Organisations have different goals and values, programmes, and cultures. Finding an organisation that you want to get involved in can take some work. But the time you invest will pay off! Take the time to find out about an organisation by visiting its website, reading some of the resources it produces, attending events it organises, checking out its offices, and talking to some of the staff or volunteers. Then ask yourself:

- >> How well does the organisation's values fit with your own?
- >> Do you feel comfortable in the organisation and its culture?
- >> Is the organisation welcoming to youth? If not, are you okay with this?
- >> Is the organisation welcoming to people living with HIV? If not, are you okay with this?
- >> Does the organisation have programmes that are youth-focused? If not, are you okay with this?
- >> What incentives or supports does the organisation provide for volunteers? Will they cover your transport costs? Provide an honorarium?
- >> Does the organisation provide opportunities for you to develop personally and professionally; for example, through ongoing supervision, trainings, workshops, and mentorship?

3.3 HOW DO I FIND OUT ABOUT ORGANISATIONS AND INVOLVEMENT OPPORTUNITIES IN MY COMMUNITY?

Finding the right involvement opportunity can sometimes feel like trying to find a needle in a haystack. Here are some ideas to help make this task easier:



Ideas for those just starting off

- >> Ask a teacher, school counsellor, a staff person at your HIV clinic or support group, or another trusted adult to help you find opportunities to get involved.
- >> Talk to other YPLHIV and PLHIV about organisations in your community that they know.
- >> Use the Internet to research organisations.
- >> Visit organisations and ask if they need volunteers.



Ideas for those already involved who want more

- >> Tell your mentor(s), more experienced HIV-positive leaders, the staff in the organisation, and other people in your social network that you want to take your involvement in the HIV response to the next level and ask for their advice.

- >> Ask the people in your social network to let you know about job openings.
- >> Find out from the leaders of the organisation and its Board of Directors about the timing and process for getting on the Board.



Ideas for everyone

- >> Join the Y+ Facebook Community (www.facebook.com/groups/162631207190708/) and ask other YPLHIV for their suggestions.
- >> Connect with regional and global youth organisations to see how you can get involved. Here are some to get you started: Global Youth Coalition on HIV/AIDS (www.gyca.org), Youth Coalition (www.youthcoalition.org), Youth RISE (www.youthrise.org).
- >> Ask the Regional Network of PLHIV about how to get involved in your country. Find your Regional Network here: www.gnpplus.net/en/regions.
- >> Ask the global networks of key populations how to get involved in your country – International Network of People Who Use Drugs (www.inpud.net), Global Forum on MSM and HIV (www.msmsgf.org), Global Network of Sex Work Projects (www.nswp.org).

GIYPA IN ACTION!

SHAFEEQ REHMAN
PAKISTAN

Stigma fighter / Civil servant / Changemaker

I was in the Pakistan Air Force a few years ago. I tested HIV-positive while donating blood at a military hospital. After stigma and discrimination forced me to change careers several times, I convinced Pakistan's National AIDS Control Programme (NCAP) that they needed a staff member to represent PLHIV and to hire me for this role. I'm now the first person openly living with HIV to work in NCAP. I'm working hard to create a more supportive environment for PLHIV and ensure their participation in Pakistan's national response. In my role with NCAP, I help policy-makers better understand the realities of PLHIV and ensure that PLHIV and the organisations that represent them are involved in Pakistan's national response. I know there are obstacles to involving more YPLHIV in government ministries, but I'm not one to let obstacles get in my way of making change!

3.4 STARTING MY OWN INITIATIVE!

Not all YPLHIV want to participate in the HIV response by getting involved with an organisation. And, in many communities, there may not even be existing initiatives for YPLHIV to get involved with. There are other ways to get involved like:

- >> Set up a club in your school, faith group, or community to support YPLHIV.
- >> Organise social events for YPLHIV.
- >> Hold fundraisers to support initiatives for YPLHIV.
- >> Create workshops for students in your school.
- >> Make your own posters or videos to raise awareness.
- >> Advocate to decision-makers and organisations to focus more on the needs and priorities of YPLHIV.

With a bit of creativity and energy, the possibilities are endless!



Check out the resources listed in Appendix 1 at the end of this roadmap to help you plan your own thing!

GIYPA IN ACTION!

JÓSE ANTONIO MALDONADO RODRÍGUEZ

MEXICO

Volunteer / Advocate / Network builder / Changemaker

I got involved in the HIV response when I was 16 to overcome loneliness and to find a place where I would not face discrimination or questions about how I contracted HIV. At first, I got involved in prevention and care as a volunteer in a local organisation. Being involved helped me feel useful and instilled a sense of responsibility to continue helping others. When I discovered that many adults don't take youth seriously, I decided to work with other young people to change things. I started the Centre for Youth Development and Research through which I advocate for treatment access, stigma reduction, the rights of YPLHIV, and HIV education. I am also building a network of YPLHIV in Mexico called Jóvenes Positiv@s. Being involved gave me the chance to make friends and to learn how to confidently speak about my sexuality and health and stand up for other YPLHIV.

4 SUSTAINING AND GROWING YOUR INVOLVEMENT

Getting involved is one thing. Staying involved is another. Here are some ideas to help you sustain and grow your involvement in the HIV response.

4.1 TOOLING UP! WHAT SKILLS AND RESOURCES DO I NEED?

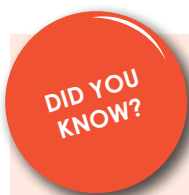
No matter how skilled you already are, there's always more to learn! Investing in your knowledge and skills is important for realising your evolving goals and making a difference.

There are many ways to develop yourself personally and professionally. The first step is to figure out what qualities, knowledge, and skills you want to nurture. The next step is to find opportunities to strengthen them. Here are some ways you can support your personal growth:

- >> **Mentors.** A mentor is a person who can provide guidance and help you learn. Mentors share their experiences, ask questions that help you think things through, and challenge you to grow by trying new or difficult things.
- >> **Formal education.** Completing secondary school and pursuing higher education can lead to many opportunities in the HIV response and other sectors. Some types of positions in the HIV response require specific professional qualifications. Other positions require general skills such as reading, writing, public speaking, math, and computing.
- >> **Workshops and trainings.** There are many free and low-cost opportunities to learn about specific topics or gain skills. The organisation(s) you are involved with may provide these trainings to their staff and volunteers, or pay part of the fee.
- >> **Facilitative supervision.** Most volunteers and staff have a supervisor who is responsible for overseeing their work and providing feedback and coaching. Your supervisor may be able to link you with mentors, workings and trainings if you share your goals for personal and professional development.



YPLHIV who've been active in the HIV response for a while make great mentors! They know what it's like to be young and HIV-positive, and can share their experiences of working with different organisations and groups.



The Y+ Leadership Initiative is a web-based one-stop shop for YPLHIV involved in the HIV response. You can connect with established HIV-positive leaders who want to share their experience and mentor emerging leaders; access tools and resources; and find internships, scholarships, training programmes, and other opportunities. Learn more about the Y+ Leadership Initiative at the Y+ section of the GNP+ website: www.gnplus.net/en/programmes/empowerment/young-people-living-with-hiv

4.2 TAKING CARE OF MYSELF!

You can't take care of others if you're not feeling good yourself. Here are some things to consider:

- >> **Disclosure.** Decisions about sharing your HIV status are a personal matter. You have the right to choose if, when, to whom and how to disclose your HIV status. You shouldn't be pressured to disclose your status in order to be involved, nor should an organisation share your status without your permission. Take time to figure out whether you want your HIV-status or identity to be commonly known in your community, what the negative and positive consequences might be, and what supports will be available to you.
- >> **Burnout.** Burnout can be a problem for people involved in social causes like the HIV response. Burnout happens when people give too much of their time and energy, and end up feeling worn out or even used. Avoid burnout by taking time out to do other things you enjoy and being realistic about how much you can do and how much change to expect. Make sure you speak regularly to your boss or supervisor about the amount of work you have and about how you're feeling. Burnout can often creep up on you without you realising it.
- >> **Tokenism.**⁸ Make sure you are being involved for the right reasons and aren't being used or tokenised. Here are some things to consider:
 - >> Are you regularly consulted on issues and decisions for which you feel you are well placed to contribute?
 - >> Is the work you do well integrated into the rest of the work of the organisation?
 - >> Do other members of staff and volunteers understand how your work fits in with their work?
 - >> Do you feel like you are meaningfully contributing?

4.3 HIV AND BEYOND: OTHER THINGS TO CONSIDER AND EXPLORE

You likely have many dreams and goals for your life, which may or may not involve ongoing participation in the HIV response. You're more likely to realise your dreams and goals if you have an idea of where you want to go and how you can use your experiences to get there.

Keep your resumé or CV up-to-date so you are ready to apply for scholarships, internships, jobs and other opportunities when they arise. Highlight your key achievements and the knowledge and skills you gain through your participation in the HIV response that are transferable to other jobs and opportunities: for example, skills in communication, team work, social media, event planning, etc.

Ask for a letter of reference when you have completed a big activity or are getting ready to leave your current position. Such letters can be important testimonials for future opportunities. Whenever possible, it's a good idea to get these letters customised to the specific opportunity you are pursuing. If possible, build a portfolio of examples of your work and/or news articles that feature your work.

Here are some questions to help you reflect on your experience in the HIV response. Take the time to think about these questions every once in a while. They could help you decide whether and how you'd like to remain involved in the HIV response.

- >> What do you like best about being involved? Why?
- >> What do you like least about being involved? Why?
- >> How has your work contributed to the HIV response?
- >> What have you learned from being involved in the HIV response? Consider interpersonal skills, programme management skills, research skills, and HIV knowledge.
- >> How would you like to further influence the HIV response to make it more responsive to the perspectives and realities of YPLHIV? How could you help to make this happen?

8. Tokenism is the inclusion or reference to a person or issue for the sake of appearances and, in many cases, to meet a minimum requirement of law. It is often considered to be a symbolic gesture in place of meaningful involvement. This means that tokenism is the complete opposite of GIYPVA.

GIYPA IN
ACTION!

PRINCESS NURU NUBUMBU

UGANDA

Peer counsellor / Writer / Policy advocate / Changemaker

I discovered I had been born with HIV when I was 20 years old, after falling into a coma. Even though my father passed away when I was 10 years old and I experienced many HIV-related illnesses, no one had told me about my status. Since learning my status, I have been standing up against HIV stigma and standing up for the rights for YPLHIV – including their sexual and reproductive rights. I first got involved in the HIV response after meeting some Straight Talk* members while waiting at a clinic for counselling and drugs. Soon after, I agreed to be featured in their magazine. This led to my becoming a volunteer writer and then a staff working with YPLHIV. Now, I am a UNAIDS Special Youth Fellow, influencing policy-makers at the national level and supporting youth organisations involved in the HIV response. Because of my work, YPLHIV are now included in Uganda's prevention strategies and their rights are more visible.

**Straight Talk is a Ugandan CBO that has been providing information for young people and adults through a number of media for over 15 years – one of the key areas of information provided is around sexual and reproductive health and HIV. For more information please go to their site.*

5 SEE POSITIVE HEALTH, DIGNITY AND PREVENTION IN ACTION

Young people are at the centre of HIV epidemics around the world. There are over 12 million people under the age of 24 who are living with HIV – 2.3 million of whom are children under 15 years old, and 10 million who are youth aged 15 to 24.⁹ This means that the vision of *Positive Health, Dignity and Prevention* cannot be achieved if the needs and priorities of YPLHIV are not understood and addressed.

By bringing your voice, ideas, experience and skills in the HIV response, you can help ensure that efforts to improve the dignity, quality, and length of life of people living with HIV are relevant for YPLHIV like yourself.

GIYPA IN ACTION!

PUTTING YPLHIV ON THE NATION'S AGENDA

Young Positives of Uganda knew they had to increase the attention given to YPLHIV in the national response. They decided the best way was to get on the national bodies that make decisions about the priorities, funding allocations, and policies. When invited in 2002 to participate in consultations on a multi-sectoral response policy, YPLHIV seized the opportunity to advocate for a seat on the Uganda AIDS Partnership Committee. This opened doors to get on the Country Coordinating Mechanism of the Global Fund to Fight AIDS, Tuberculosis and Malaria and the Civil Society Fund Steering Committee, and then the Health Policy and Advocacy Committee. Young Positives of Uganda has achieved many successes through their involvement in these bodies; for example, having the age of consent for HIV testing lowered to 12 years and ensuring a focus on YPLHIV in all HIV projects. Young Positive of Uganda has learned that their ability to influence decision-making bodies is affected by the chair of the committee, as well as the confidence and skill of representatives and their ability to meet with the young people they represent.

9. UNAIDS, UNICEF, WHO (2007). *Children and AIDS: A Stocktaking Report*. Available at: www.unicef.org/publications/files/ChildrenandAIDSStocktakingLoResPDF_EN_USLetter_15012007.pdf

APPENDIX 1

MORE RESOURCES TO HELP YOU MAKE A DIFFERENCE

We referred to many of the following resources when developing this document. These are good places to find further information, strategies, and activities to help you become meaningfully involved.

GUIDES AND TOOLKITS

Canadian AIDS Society. *One Foot Forward: A GIPA Training Toolkit*.
www.cdnaids.ca/onefootforwardagipatrainingtoolkit

Global Network of People Living with HIV (GNP+) (2012). *GIYPA Guidebook: Supporting Organisations and Networks to Scale up the Meaningful Involvement of Young People Living with HIV*. (See the Y+ section of the GNP+ website: www.gnpplus.net/en/programmes/empowerment/young-people-living-with-hiv)

Global Network of People Living with HIV (GNP+) (2011). *Young People Living with HIV Advocacy Brief: A Briefing Document to Support the Advocacy Messages Developed for the 2011 High Level Meeting on AIDS*. (See the Y+ section of the GNP+ website: www.gnpplus.net/en/programmes/empowerment/young-people-living-with-hiv)

International HIV/AIDS Alliance (2011). *Good Practice HIV Programming Standards*.
www.aidsalliance.org/Publicationsdetails.aspx?Id=451

International HIV/AIDS Alliance and Global Network of People Living with HIV (GNP+) (2010). *Good Practice Guide: Greater Involvement of People Living with HIV (GIPA)*.
www.gnpplus.net/resources/empowerment-of-people-living-with-hiv-a-their-networks/item/47-good-practice-guide

International Institute for Child Rights and Development (IICRD) (2010). *Changing the Landscape: Involving Youth in Social Change*.
www.issuu.com/youthscape/docs/ys_guidebook_print

International Planned Parenthood Federation (IPPF) (2008). *Inspire: an IPPF resource pack on youth friendly programming*.
www.ippf.org/en/Resources/Guides-toolkits/Participate+The+voice+of+young+people+in+programmes+and+policies.htm

Ontario Public Health Association (2011). *A Project Lead's Guide to Planning, Implementing and Sustaining Youth Engagement Programming*.
www.youthengagement.ca/sites/default/files/YEGuide_Final_Web.pdf

Ontario Public Health Association (2011). *Youth Engagement Toolkit – Working with Middle School Students to Enhance Protective Factors and Resiliency: A Resource for Health Professionals working with Young People*.
www.youthengagement.ca/sites/default/files/OPHAYouthEngagementToolkit-April2011.pdf

Restless Development. *Youth Advocacy Toolkit*.
www.restlessdevelopment.org/file/final-toolkit-pdf

TakingITGlobal. *HIV/AIDS Youth Guide to Action!*
www.tigweb.org/action-tools/guide/hivaids/network.html

ONLINE RESOURCES AND NETWORKS

Advocates for Youth. www.advocatesforyouth.org

HIV Young Leaders Fund. www.hivyoungleadersfund.org

NGO Code of Good Practice. www.hivcode.org

Young People Living with HIV Facebook Community, Global Network of People Living with HIV (GNP+). www.facebook.com/groups/162631207190708

Y+ Leadership Initiative (Young People Living with HIV Leadership Initiative) Global Network of People Living with HIV (GNP+). www.gnpplus.net/en/programmes/empowerment/young-people-living-with-hiv

Y+ Programme (Young People Living with HIV Programme) Global Network of People Living with HIV (GNP+). www.gnpplus.net/en/programmes/empowerment/young-people-living-with-hiv

Youth Coalition. www.youthcoalition.org

Youth RISE. www.youthrise.org

Youth, the Arts, HIV and AIDS Network. www.yahanet.org

REPORTS

Global Network of People Living with HIV and UNAIDS (2011). *Positive Health, Dignity and Prevention: A Policy Framework.*

www.gnpplus.net/en/resources/positive-health-dignity-and-prevention/item/109-positive-health-dignity-and-prevention-a-policy-framework

UNAIDS, UNICEF, WHO (2007). *Children and AIDS: A Stocktaking Report.*

www.unicef.org/publications/files/ChildrenanAIDSAStocktakingLoResPDF_EN_USLetter_15012007.pdf

DECLARATIONS

The Paris AIDS Declaration (1994).

http://data.unaids.org/pub/ExternalDocument/2007/theparisdeclaration_en.pdf

United Nations General Assembly Special Session on HIV/AIDS (2001). *Declaration of Commitment on HIV/AIDS.*

www.unaids.org/en/media/unaids/contentassets/dataimport/publications/irc-pub03/aidsdeclaration_en.pdf

United Nations Special Session on Children (2004). *A World Fit for Children.*

www.unicef.org/specialsession/wffc/index.html

United Nations High-Level Meeting (2006). *Political Declaration on HIV/AIDS.*

www.unaids.org/en/aboutunaids/unitednationsdeclarationsandgoals/2006politicaldeclarationonhivaids/

United Nations High-Level Meeting (2011). *Political Declaration on HIV/AIDS.*

www.unaids.org/en/aboutunaids/unitednationsdeclarationsandgoals/2011highlevelmeetingonaids/

GLOBAL AND REGIONAL NETWORKS

Global Forum on MSM and HIV. www.msngf.org

Global Network of People Living with HIV (GNP+). **Regional Network of PLHIV.** www.gnpplus.net/en/regions

Global Network of Sex Work Projects. www.nswp.org

Global Youth Coalition on HIV/AIDS. www.gyca.org

International Network of People Who Use Drugs. www.inpud.net

