



**YOUNG PEOPLE
LIVING WITH HIV
PROGRAMME**

INVOLVEMENT // LEADERSHIP // CONTINUUM OF CARE // RIGHTS // DIVERSITY

WHAT IS THE Y+ PROGRAMME?



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 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

Partnerships

GNP+ have 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. We are looking forward to working with further partners in the future.



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).

Why the Y+ Programme?

The UNAIDS 2008 Report on the Global AIDS Epidemic reports an estimated 33 million people are living with HIV. According to the same report 40% of new infections are among 15-24 year olds, with disproportionately higher numbers among young women.

Despite the magnitude of the impact of the epidemic among young people, there is an apparent gap in support to and meaningful and sustained participation of YPLHIV in the design and implementation of responses to the epidemic. Although there is a highly active youth movement, YPLHIV are not proportionately represented. Similarly, young people are often not well represented within networks of people living with HIV. The unique needs of YPLHIV have been largely unexplored, let alone addressed, and the space in which these needs can be articulated by YPLHIV has been missing.

Identifying the priorities of the Y+ Programme

In 2010 two different consultative processes took place: an e-consultation and a face-to-face meeting. The specific objectives of these consultations were to create a space where YPLHIV could share experiences and to identify priorities that require attention. The face-to-face consultation also provided a unique forum for a diverse group of YPLHIV to highlight the key recommendations that will enable YPLHIV to address these priorities themselves. This consultation laid the ground work for the development of the Y+ Programme at GNP+ leading to a sustainable global YPLHIV community that would support and also strengthen the programming of GNP+ and partners.

The final purpose of the consultation was to elect the members of the Y+ Advisory Group to guide and support the Y+ Programme and acts as an accountability mechanism for the programme, towards the YPLHIV community.

The Y+ Programme is structured around four approaches that inform all of our work:

1. To establish a sustainable network of YPLHIV with opportunities for open communication and consultation on an ongoing basis.
2. To ensure existing work on all platforms of GNP+'s strategy responds to the needs of YPLHIV.
3. To develop a programme of activities and projects which equips YPLHIV with tools to develop and drive their own agendas.
4. To support the meaningful involvement of YPLHIV in the governance and programming of regional and national networks of people living with HIV.

The Y+ Programme aims to ensure that the broader priorities that emerge from consultative processes with YPLHIV resonate with the agenda of the PLHIV community, and are reflected in future activities of GNP+ and its partners. Through supporting networks of PLHIV and youth led organisations and initiatives (at national, regional and international levels).

The Y+ Programme will facilitate the more meaningful engagement and involvement of young people in the governance, programming, advocacy and outreach for the HIV response. The Y+ Programme fits within the broad vision of GNP+ *to strengthen the worldwide movement of PLHIV by facilitating leadership and the voices of PLHIV.*¹

GOVERNANCE AND GUIDANCE

How does the Y+ Programme function?

The Y+ Programme is coordinated from within the GNP+ secretariat with guidance and support provided by a peer elected YPLHIV Advisory Group. The activities focus on delivering on a number of recommendations that came from a comprehensive consultation process in 2010. The programme will mobilise YPLHIV across the world to establish a sustainable community of YPLHIV where they are equipped with appropriate tools and support to drive their own agendas and actively contribute to addressing these recommendations.

The Y+ Programme and the Advisory Group collaborate with a variety of partners recognising the need for a multi-stakeholder approach to addressing the needs of YPLHIV. Further engagement with other networks of affected communities has been established to ensure that the full diversity of the YPLHIV community has the space to contribute to the agenda and share their expertise and experiences in the programme.

The Y+ Programme is formally accountable to the GNP+ Board through the normal governance of the organisation. In a more practical way it is accountable to the Y+ Advisory Group, who provide day-to-day support and guidance.

The management of the Y+ Programme is led by the GNP+ Youth Officer and supported by the GNP+ Director of Programmes. The Advisory Group will further support the Youth Officer to ensure that all GNP+ platforms recognise and respond appropriately to the specific needs of YPLHIV as appropriate and support other partners in their efforts in responding to YPLHIV.

Y+ Advisory Group

The current Y+ Advisory Group is made up of six YPLHIV of different ages, from different regions and with varying experiences of the HIV epidemic.

The Y+ Advisory Group was established at the face-to-face YPLHIV consultation held in Amsterdam in June 2010 to: support the development and implementation of the Y+ Programme; ensure that the priorities highlighted by the community of YPLHIV remain the priorities of the programme; and guarantee the programme remains accountable to the community.

The Advisory Group will act as a mechanism to facilitate the effective communication and networking of the diverse community of YPLHIV across the world.

The Advisory Group will contribute and support the achievement of the following objectives:

- >> Create an enabling environment to support YPLHIV, through creating a global structure to foster a community development
- >> Call for meaningful engaged YPLHIV participation in the global response to HIV through advocacy
- >> Support new leadership and capacity of YPLHIV
- >> Connect YPLHIV to support each other, share experiences, best-practices and information
- >> Mainstream YPLHIV into existing PLHIV networks, organisations and initiatives (including GNP+)

In May and June 2010, GNP+, in partnership with the World AIDS Campaign, held two consultations with YPLHIV from around the world. The first, an e-consultation, helped to shape the agenda for a face to face consultation in June, in Amsterdam. During this second meeting participants further explored certain issues that came from the e-consultation and were asked to elect the YPLHIV Advisory Group to support the Y+ programme with GNP+. By the end of the consultations certain key issues had emerged above others, as being of significance to the community of YPLHIV. Over the next few pages these issues are explored. For more information please visit www.gnpplus.net.

Y+ PROGRAMME PRIORITY AREAS



1. INVOLVEMENT

“ We recognise the importance of our participation in the PLHIV community at national, regional and international levels and call upon networks of PLHIV to work with us to ensure that the challenges we face in our communities are addressed with our full involvement. At the same time we must ensure that the community of YPLHIV has its own space to network, gain skills, share experiences and develop in a safe, supportive and sustainable way.

The partnerships and collaborations with youth initiatives and youth led organisations is essential to ensure we can contribute to advocacy agendas that can bring change to our lives. Moreover, we have unique skills and experiences that can strengthen and enhance all aspects of the HIV response for young people: prevention, treatment, care and support. In particular we feel we have valuable contributions we can make to all HIV prevention efforts.”

Global YPLHIV Consultation Statement, Amsterdam June 2010

RECOMMENDATIONS

- >> Research is needed to ascertain the levels to which YPLHIV are currently involved in networks of PLHIV (at all levels) and youth led and serving organizations and initiatives and best practice developed accordingly.
- >> Develop guidelines directed towards networks of PLHIV and youth led and serving organizations and initiatives, enabling the greater and more meaningful involvement of YPLHIV.
- >> Support YPLHIV that are already engaged with networks of PLHIV and youth led and serving organizations and initiatives, to strengthen programmes and ensure advocacy messages are responsive to the needs of YPLHIV through strong networking across the YPLHIV community.



GNP+ RESPONSE

GNP+ is committed to the greater and more meaningful involvement of YPLHIV in all levels of the HIV response; acknowledging the value that this community bring to the HIV programming and recognizing that networks of PLHIV and youth led organizations and networks are the two most critical entry points for this participation to grow. The role of partnerships in these efforts is crucial in order to be effective.



2. LEADERSHIP

“ The empowerment of YPLHIV requires urgent attention – our voices and our concerns are still unheard in many areas of the world. The ongoing empowerment of YPLHIV is crucial to the creation of an atmosphere of opportunity that will ensure a sustainable movement of YPLHIV. The skills and experiences of previous leaders in the YPLHIV movement are of critical importance as well as the need to develop new leadership. We recognise the progress that has been achieved in the past and we must build on this and continue to develop our own agendas. Strong leadership in the YPLHIV community will foster a supportive and conducive environment for other young HIV positive people to come forward and speak out.”

Global YPLHIV Consultation Statement, Amsterdam, June 2010

RECOMMENDATIONS

- >> A strong mentorship programme needs to be developed and be supported by other partners, at all levels. It must recognise the gaps in the capacities of young emerging leaders and support them to gain new skills.
- >> An open and consultative space needs to be established with support of people living with HIV (PLHIV) networks for the regular transfer of skills and experiences to strengthen new leaders’ capacities and continued development.
- >> YPLHIV must raise awareness among stakeholders as to the array of opportunities that exist to support the development of members of the YPLHIV community for the benefit of the HIV response more broadly.

GNP+ RESPONSE

GNP+ is committed to the leadership of YPLHIV, recognizing the ageing out phenomenon and ensuring that there are adequate mechanisms for transference of skills and experience to ensure a strong, responsive and sustainable network of YPLHIV. Collaboration with other initiatives that are contributing to the leadership and empowerment of young people is essential to support and empower YPLHIV in the HIV response more generally.

3. CONTINUUM OF CARE

“ We strongly believe that YPLHIV need a continuum of comprehensive and accessible services that help us to live a safe, healthy and positive life, during the period of continuing development from childhood to adulthood. This continuum must recognise the different points at which we enter HIV care – from voluntary counselling and testing from a health care provider, to disclosure from a care giver for perinatally infected young people, to our health care in general. There is a real need for specific psychosocial support for our emotional, mental and sexual and reproductive health needs as they change through different stages of our young lives through to adulthood. With the support of many partners we can make sure that this is a reality for all YPLHIV.”

Global YPLHIV Consultation Statement, Amsterdam, June 2010

RECOMMENDATIONS

- >> Services must be integrated either in-facility, or through a robust facilitated referral system that supports all YPLHIV at every stage of their development.
- >> Further research is needed to understand the effect of HIV, and HIV treatment, on the physical, cognitive, psychological and sexual development of YPLHIV.
- >> A framework needs to be developed that can be applied to programmes and policies to ensure a smooth transition between service settings through the continuous growth of children (paediatric – adolescent – young adult – adult) according to a set of criteria including but not exclusively age.

GNP+ RESPONSE

GNP+ is committed to ensuring the fullest attainable standard of access to HIV prevention treatment care and support services in accordance with the different needs of YPLHIV. A variety of partners must be engaged to identify the different factors that affect YPLHIV and how they engage with the service provision process. Further, there must be strong systems in place to support YPLHIV throughout their continuum of care.



4. DISCLOSURE

“ For a young person living with HIV to be empowered and engaged in the HIV response, they must be able to exercise their human rights to the fullest. However in many settings our rights to confidentiality and privacy cannot be realised due to restrictive policies and laws and institutional discrimination. The issue of if, when, how and to whom to disclose our HIV status is a personal decision that must be respected. We must have all the elements necessary to create a safe and conducive environment for these rights to be realised and all the support we need to build our own skills and manage our own disclosure strategies.”

Global YPLHIV Consultation Statement, Amsterdam, June 2010

5. DIVERSITY

“ Being a YPLHIV does not mean that we necessarily share the same needs and desires as each other or our older counterparts. Beyond our age specific diverse needs, YPLHIV represent a diversity in our sexuality, culture, religion, gender and age from a youth perspective. We are not a homogeneous group, nor can we be treated as one.”

Global YPLHIV Consultation Statement, Amsterdam, June 2010

RECOMMENDATIONS

- >> Service providers, including teachers and healthcare providers, care givers and others that provide care and support to YPLHIV must have a greater awareness of the sensitive nature of the disclosure process and be equipped to support the decisions that YPLHIV make.
- >> YPLHIV need to be better informed about their rights and the implications of the laws and policies in their specific country contexts. This would include developing youth friendly information on laws and policies as they relate to disclosure.
- >> YPLHIV must engage and be supported by national, regional and international PLHIV networks to repeal existing legislation that restricts the rights of YPLHIV to choose if and when to disclose and advocate for supportive and non discriminatory laws that protect their right to make decisions around their own HIV status.

RECOMMENDATIONS

- >> Programmers and policy makers need to meet the real needs of YPLHIV according to the diversity of the group – addressing the reality of the epidemic among young people is a critical step to delivering appropriate services.
- >> YPLHIV must start to systematically document and report cases of discrimination, working alongside national, regional and international networks of PLHIV and youth serving organizations to inform their advocacy efforts.
- >> Education providers need to acknowledge the diversity within the community of YPLHIV and within young people in general.

GNP+ RESPONSE

GNP+ is committed to supporting YPLHIV to realise and exercise their rights, in particular around disclosure and confidentiality. Continued work against the criminalisation of HIV transmission and exposure will ultimately create a space where YPLHIV feel able to make informed decisions for themselves around information related to their status. Partnerships remain key to ensuring YPLHIV have this space and have the support from those around them, i.e. friends, parents, family members, service providers, community members and teachers.

GNP+ RESPONSE

GNP+ is committed to ensuring that any response to the needs of YPLHIV reflects the diversity within the community and therefore the different approaches and initiatives that may be necessary. YPLHIV are not an homogenous group and GNP+ will work with partners to guarantee that any programming or policy recognizes this fact and responds appropriately.



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The young people living with HIV programme (Y+ Programme) is an initiative of GNP+, the global network for and by people living with HIV. The Y+ Programme is for and led by young people living with HIV (aged 15-30) and addresses specific gaps and needs of this group in the HIV response.

If you would like to know more about the Y+ Programme join the Y+ list serve by sending a blank email to ypluslistserve+subscribe@googlegroups.com

If you have specific programmes or activities that relate directly to the Y+ Programme please send an email to: yplus@gnpplus.net

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



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