

# POSITIVE HEALTH, DIGNITY AND PREVENTION

What does it mean for networks of people living with HIV?



## **About the Global Network of People Living with HIV (GNP+)**

GNP+ is the global network for and by people living with HIV. We work to improve the quality of life of all people living with HIV. This means we advocate for, and support fair and equal access to treatment, care and support services for people living with HIV around the world.

## **Acknowledgments**

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# WHO IS THIS BOOKLET FOR?

This booklet is designed to be used by networks of people living with HIV, including groups supporting women, young people and other populations. It is one of a series of materials that aims to improve the understanding of Positive Health, Dignity and Prevention. These booklets were written to support organisations to promote the meaningful engagement of people living with HIV in decisions that affect our lives.

The Positive Health, Dignity and Prevention framework was created for and by people living with HIV. It is a living idea that continues to evolve and can be used to support our lives today.





Hi! How was the  
Positive Health,  
Dignity and Prevention  
training?

It was great thanks.  
We need to talk about  
how to use PHDP in  
our network.

Hold on.  
PHDP?  
What is  
that?

It's a way of  
looking at how  
HIV affects all our  
lives.

Positive Health, Dignity and Prevention is a framework or an approach to help improve the lives of people living with HIV.

It builds on the principle of GIPA (the greater involvement of people living with HIV) and starts with us at the centre. But, it is not just about HIV. Positive Health, Dignity and Prevention is about finding a way for us to live full and contented lives with dignity – free from stigma. It gives us a set of standards that we can use to ensure people living with HIV are treated fairly by our families, communities and institutions.



WE ARE  
MORE THAN  
PATIENTS

WE ARE ALL  
RESPONSIBLE  
FOR HIV  
PREVENTION

WE WILL NOT BE  
TREATED AS A  
RISK TO  
OTHERS

WE HAVE  
NEEDS AND  
DESIRES TO BE  
FULFILLED

# WHAT MAKES PHDP DIFFERENT?



Previous initiatives like 'Positive Prevention' and 'Prevention with Positives' often focus on people living with HIV preventing HIV transmission to others. 'Positive Living' supports people living with HIV to stay healthy through taking treatment regularly, getting good nutrition and exercise, as well as practicing safer sex.

'Positive Health, Dignity and Prevention' is different. It includes a focus on the prevention and treatment of HIV, but it is about more than physical, mental and sexual health. It is about the rights, dignity and complete wellbeing of people living with HIV.


## Positive Health, Dignity and Prevention:

- shifts from blaming people living with HIV to the idea of sharing responsibility for preventing HIV in our communities
- moves beyond only focusing on HIV transmission to a more complete view of the health and wellbeing of people living with HIV
- looks at how HIV prevention, treatment and care link together and support each other
- puts the human rights of people living with HIV first.

Policies and programmes that focus on preventing HIV transmission can cause stigma and suggest that people living with HIV are to blame for new HIV infections. Positive Health, Dignity and Prevention looks for solutions not scapegoats and instead promotes a **‘shared responsibility’** for HIV prevention.

People who are aware they are living with HIV know that they have an ethical responsibility to avoid infecting another person, but everyone, no matter what their HIV status, should take responsibility for their own health and take steps to protect it.

Positive Health, Dignity and Prevention also looks beyond individuals. Sexual partners of people living with HIV, families, communities, civil society, the public and private sector, the media, donor and multilateral agencies such as the UN all share responsibility for preventing new HIV infections.

An illustration of a man with dark skin, wearing a green patterned t-shirt and orange trousers, standing with his hands on his hips. A pink speech bubble points to him from the left, containing the text 'What is 'shared responsibility'?'.

What is  
'shared  
responsibility'?

# HISTORY OF PHDP



## 1983, Denver Principles, Denver

A bold charter that refused to see people living with HIV as victims and set out their right to self-empowerment. It led to the creation of the National Association of People with AIDS in the US, the first of similar networks around the world.

## 1994, GIPA Principle, Paris

42 countries agree to support the greater involvement of people living with HIV in design, implementation and monitoring of HIV policies and programmes at all levels “ensuring their full involvement in our common response to the pandemic”.





### **2001, UN Declaration of Commitment, New York**

The world finally pledges concerted action on the AIDS epidemic reaffirming GIPA and setting ambitious targets.



### **2009, Positive Health, Dignity and Prevention, Tunisia**

An approach that calls for a shared responsibility for HIV prevention to counter the stigma and blame attached to HIV transmission and starts with the rights and wellbeing of people with HIV.

NOTHING  
ABOUT US,  
WITHOUT US



The principles of HIV-related self-determination are as important and relevant today as they were in Denver almost three decades ago.

Positive Health, Dignity and Prevention builds on these principles at a time when there is concrete evidence of the benefits of early treatment and better medication. These benefit both the health of people living with HIV as well as supporting prevention.

# HOW CAN PHDP SUPPORT OUR WORK?

Positive Health, Dignity and Prevention is important to us because it:

- gives us common values and principles to guide all our work whether we are advocating for the sexual and reproductive rights of women living with HIV, designing youth-friendly services for adolescents, or developing joint actions with sex worker networks
- helps analyse and shape our policy positions on many issues from advances in science to changes in legislation
- brings our focus back to the meaningful engagement of people living with HIV and gives networks like us practical support to demand that we are involved in the design and implementation of policies and programmes
- can inspire our communities and reduce stigma faced by people living with HIV.

PHDP helps us understand what we should all be able to expect from other people.

Our steering group uses PHDP to help shape our policy positions.

PHDP empowers us and our members to lead and guide HIV programmes.

## What does it mean for our work?

As networks, we are a central part of our communities and are engaged in all areas of life, not just issues around HIV. Positive Health, Dignity and Prevention is not a new programme, it is a framework for us to use to guide how we carry out all aspects of our work:

- **Our strategy:** staff, members and governance structures all need to understand and support PHDP as a rights-based and people-centred approach
- **Our programmes:** HIV programmes should respond to all the needs of people living with HIV including the most vulnerable
- **Our advocacy:** we can promote PHDP at every opportunity from district to national level, not as a separate initiative but across all policy-making, including health, education and the economy
- **Our language:** as leaders of the HIV response, we should make our voices heard and be sure that our language does not stigmatise any community or behaviour
- **Our partnerships:** we can ensure that affected communities, including the most marginalised, are empowered to play a part in society



# WHAT DO THE DIFFERENT ELEMENTS OF PHDP MEAN FOR OUR NETWORKS?

**Empowerment**

**Gender equality**

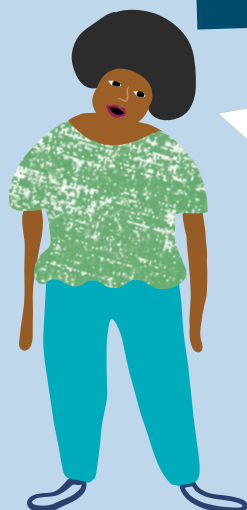
**Human rights**

**Preventing HIV**

**Promoting health for all**

**Sexual and reproductive  
health and rights**

**Social and economic justice**



A more detailed description of these elements can be found in the *Positive, Health, Dignity and Prevention Operational Guidelines* and the *Policy Framework*. The web link is at the end of this booklet.

## Empowerment

Self-empowerment is the foundation of Positive Health, Dignity and Prevention. As people living with HIV, we need to feel empowered to make informed decisions about our health and wellbeing, to support our families and contribute to our communities.

From the Denver Principles to the GIPA principle and onto Positive Health, Dignity and Prevention, HIV activists have repeated time and again how important it is that people and communities affected by HIV are at decision-making tables speaking for themselves.

Networks and groups of people living with HIV have led the HIV effort and helped achieve many remarkable landmarks in the global HIV response. But, we can still do more. We especially need to support the empowerment of women, young people, men who have sex with men, sex workers, transgender people, people who use drugs and other marginalised populations disproportionately affected by HIV.



### HOW CAN NETWORKS DO THIS?

- Encourage the meaningful involvement of people living with HIV in all decisions that affect us
- Through mentorship and other ways, support people living with HIV to develop leadership skills
- Set up and run peer support groups in communities
- Put in place education and literacy programmes on: sexual and reproductive health and rights, comprehensive sexuality education, treatment, prevention, the law and rights, self-esteem and confidence, and healthy living
- Work to build the capacity of our own organisations – by accessing and investing resources for this and partnering with other organisations

## Gender equality

Positive Health, Dignity and Prevention recognises that gender inequalities in our societies make the impact of the HIV epidemic worse. And while the struggle for gender equality goes beyond HIV or health, as HIV activists we can contribute to it. Talking about HIV has helped us realise that gender equality is not just about women and men (whatever their sexual orientation) it must also include transgender and intersex people.

We can see that harmful gender norms and gender-based violence increase vulnerability to HIV. We also know that being diagnosed with HIV can further increase the risk of gender-based violence. These problems need to be addressed together.



### HOW CAN NETWORKS DO THIS?

- Raise awareness and challenge negative attitudes on sexual orientation and gender identity among our communities
- Ensure people living with HIV, including the most marginalised, fully participate in our organisations and setting priorities
- Contribute to other social justice movements to challenge harmful gender norms, policies and laws
- Help design and deliver gender-responsive services and gender-transformative programmes\*
- Join initiatives to stop gender-based violence – including training healthcare workers and advocating for laws and policies to protect people from gender-based violence



\***Gender-responsive** services are based on an understanding of how gender affects a person's ability to access services and the type of services that they need, **Gender-transformative** programmes actively promote gender equality and the empowerment of women.

## Human rights

Fear and ignorance about HIV have fuelled high levels of stigma, discrimination and human rights violations against people living with HIV. Today, after 30 years of progress, stigma is still one of our main concerns. This is despite the fact that HIV is no longer a death sentence and that understanding of how to avoid transmission and protect ourselves from HIV has increased dramatically.

The starting point for Positive Health, Dignity and Prevention is that the rights of people living with HIV, whoever they are, should be respected, protected and fulfilled.

Sadly, human rights violations against people living with HIV are common. In some countries, laws violate human rights such as those that criminalise HIV transmission. In other cases, policies and practices are to blame, such as the forced sterilisation of women living with HIV. And, almost everywhere, we face human rights abuses from the people we encounter in our day to day lives – from the police to healthcare workers and even our neighbours.

People living with HIV from key populations (such as sex workers, people who use drugs, migrants and others) are often discriminated against by society and then face the added stigma of their HIV status. Our networks are best placed to understand and champion the rights of all people living with HIV.



### HOW CAN NETWORKS DO THIS?

- Raise awareness and understanding of human rights among communities, service providers and policy-makers
- Document, monitor and respond to stigma, discrimination and human rights abuses, using tools like the Stigma Index
- Roll out community-led programmes to reduce stigma
- Challenge laws, policies and practices that criminalise or discriminate against people vulnerable to or living with HIV

## Preventing HIV

The Positive Health, Dignity and Prevention framework moves away from approaches that focus on stopping transmission of HIV or see people living with HIV as responsible for HIV prevention. Instead, PHDP encourages us all to share responsibility for transmission and exposure. Everyone is responsible for his or her health and should try to protect it. We all have a part to play in preventing new infections – our sexual partners, families, communities, civil society, the public and private sector, the media, donor and multilateral agencies such as the UN.

PHDP starts with the wellbeing of people living with HIV – treatment and care to improve their health are the priority. Science has now clearly shown that the sooner a person starts antiretroviral treatment, the better their health will be in the long term. It has also shown that people living with HIV who take their treatment correctly and have an undetectable viral load are unlikely to transmit HIV to others.

Undiagnosed and diagnosed people, along with their partners and communities, all need to be included in HIV prevention programmes.

We need many different **approaches to prevention** including:

comprehensive sexuality education

non-judgmental, voluntary counselling and testing services

support for sero-discordant couples

access to prevention methods including clean needles

contraception and new prevention technologies

support for women living with HIV  
who want to have a child and/or breastfeed

universal access to treatment



## HOW CAN NETWORKS DO THIS?

- Focus on shared responsibility for preventing new HIV infections
- Support programmes, policies and laws that create shared responsibility for preventing new HIV infections among everyone whatever their HIV status
- Raise understanding of HIV prevention through education and literacy programmes
- Advocate for improved access to tools and technologies that prevent sexual HIV transmission and vertical transmission
- Call for improved access to HIV treatment
- Advocate for and help to design and implement programmes to support people with specific risks, such as counselling and peer support for sero-discordant couples or harm reduction programmes

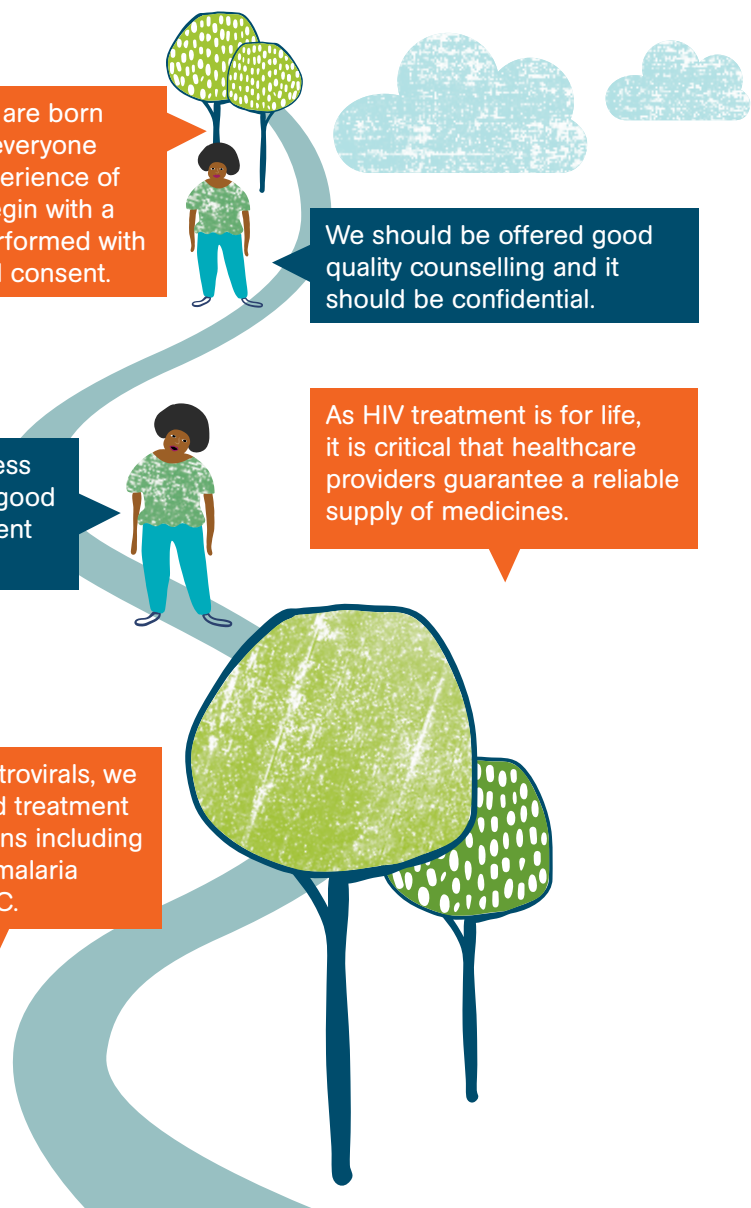


PHDP is about sharing responsibility for preventing HIV in our communities.

And that means everyone, not just people with HIV.

## Promoting health for all

Our health and wellbeing are at the heart of Positive Health, Dignity and Prevention. We have the right to choose whether and when to start treatment and no cultural or religious practices should prevent us. PHDP not only aims to support access to effective HIV treatment but also comprehensive healthcare services that address all our physical, sexual and emotional health needs.



Some people are born with HIV. For everyone else, their experience of HIV should begin with a test that is performed with their informed consent.

We should be offered good quality counselling and it should be confidential.

We need access to a range of good quality treatment and care.

As HIV treatment is for life, it is critical that healthcare providers guarantee a reliable supply of medicines.

Beyond antiretrovirals, we may also need treatment for co-infections including tuberculosis, malaria and hepatitis C.

The Positive Health, Dignity and Prevention framework sees everybody as equal. Healthcare systems and providers should not judge or exclude anyone seeking medical help, including people who are often marginalised by society such as members of key populations.



## HOW CAN NETWORKS DO THIS?

- Support the provision of community-based counselling and testing services
- Set up support groups to promote psychosocial wellbeing
- Offer to take up roles ourselves to support healthcare provision – as people living with HIV we can share our expertise as community healthcare workers, treatment supporters, peer educators, etc.
- Encourage the sensitisation and training of healthcare providers



## Sexual and reproductive health and rights (SRHR)

One of the goals of Positive Health, Dignity and Prevention is to ensure the sexual and reproductive health and rights of people living with HIV. Often, people living with HIV are made to feel that they should abstain from sex. PHDP recognises that we all have the right to a satisfying and healthy sex life.

It can be difficult to understand how to best protect our own health and the health of our sexual partners. Comprehensive sexuality education that is age-appropriate, culturally-appropriate and gender-transformative is critical. It is not just young people who need education, adults also need full, accurate information about all the issues relating to their sexual and reproductive health. We also need access to non-judgmental sexual health services including ones that screen for and treat STIs and ones that provide advice on fertility and contraception.

Some healthcare providers still discourage women living with HIV from getting pregnant. Women living with HIV should now feel confident that, with the right treatment, they can have children with very little risk of vertical transmission.



### HOW CAN NETWORKS DO THIS?

- Help to design and deliver comprehensive sexuality education
- Work to support programmes that address the SRHR needs of adolescents and young people living with HIV and other key populations
- Advocate for laws and policies that allow everyone to enjoy their full sexual and reproductive health and rights
- Support behavioural change programmes that empower women to make decisions about their sexual and reproductive lives

## Social and economic justice

Positive Health, Dignity and Prevention speaks to all aspects of life. People living with HIV should have the same opportunities as others to participate fully and meaningfully in their communities.

We all have the right to a standard of living that is adequate for the health and wellbeing of ourselves and our family. This includes:

- access to enough food and water
- a safe place to live
- access to education and training – including specific training and education for young people and women living with HIV
- employment opportunities.

In some cases, people living with HIV, their families or people who help to care for them may need extra financial, social or emotional support. Often this is because they are unable to earn an income (for example, if they are sick or are caregivers). Children and adolescents living with HIV have their own specific needs and we need systems that support their protection and wellbeing.



### HOW CAN NETWORKS DO THIS?

- Advocate to ensure that workplace policies and laws respect the rights of people living with HIV
- Support social protection programmes for people living with HIV, in particular children and adolescents and their caregivers
- Support local initiatives and innovation
- Put in place systems to record, monitor and support individuals who experience rights violations



# HOW CAN WE PUT PHDP INTO PRACTICE?

## Five key steps for networks

### 1. Promote PHDP to our members and communities

PHDP is for individuals and communities. For most people, it is an ideal to strive towards, we can help our members understand it and feel empowered to use it. This is where networks have a big part to play. The infographic on pages 22 and 23 can be used to show people what PHDP can mean for them.

### 2. Build evidence

This includes assessing the situation in our own countries, carrying out research, analysing policies and monitoring progress. People living with HIV should be involved and engaged in research both as participants and researchers – in setting research priorities, developing research tools, data collection and analysis, and drafting recommendations and conclusions.



### 3. Advocate for Positive Health, Dignity and Prevention

Understand and promote PHDP to different stakeholders whether it is policy-makers (National Strategic Plans, national policy forums, Country Coordinating Mechanisms, technical working groups) or healthcare workers and other service providers.

### 4. Ensure integration into programmes and strategies

Make a political commitment to integrate the principles of Positive Health, Dignity and Prevention into all our existing work and programmes – from sexual and reproductive health to programmes targeted at specific groups such as youth or other key populations. This includes ensuring that all our work is grounded in respect for human rights and contributes to gender equality.

### 5. Monitor progress and impact

We should be aware of the impact of our work and any changes in practices, policies and programmes. We can use anything from focus groups to evaluation forms, surveys or community meetings to monitor our work. The results of our monitoring can then be used to adapt our work and approaches.

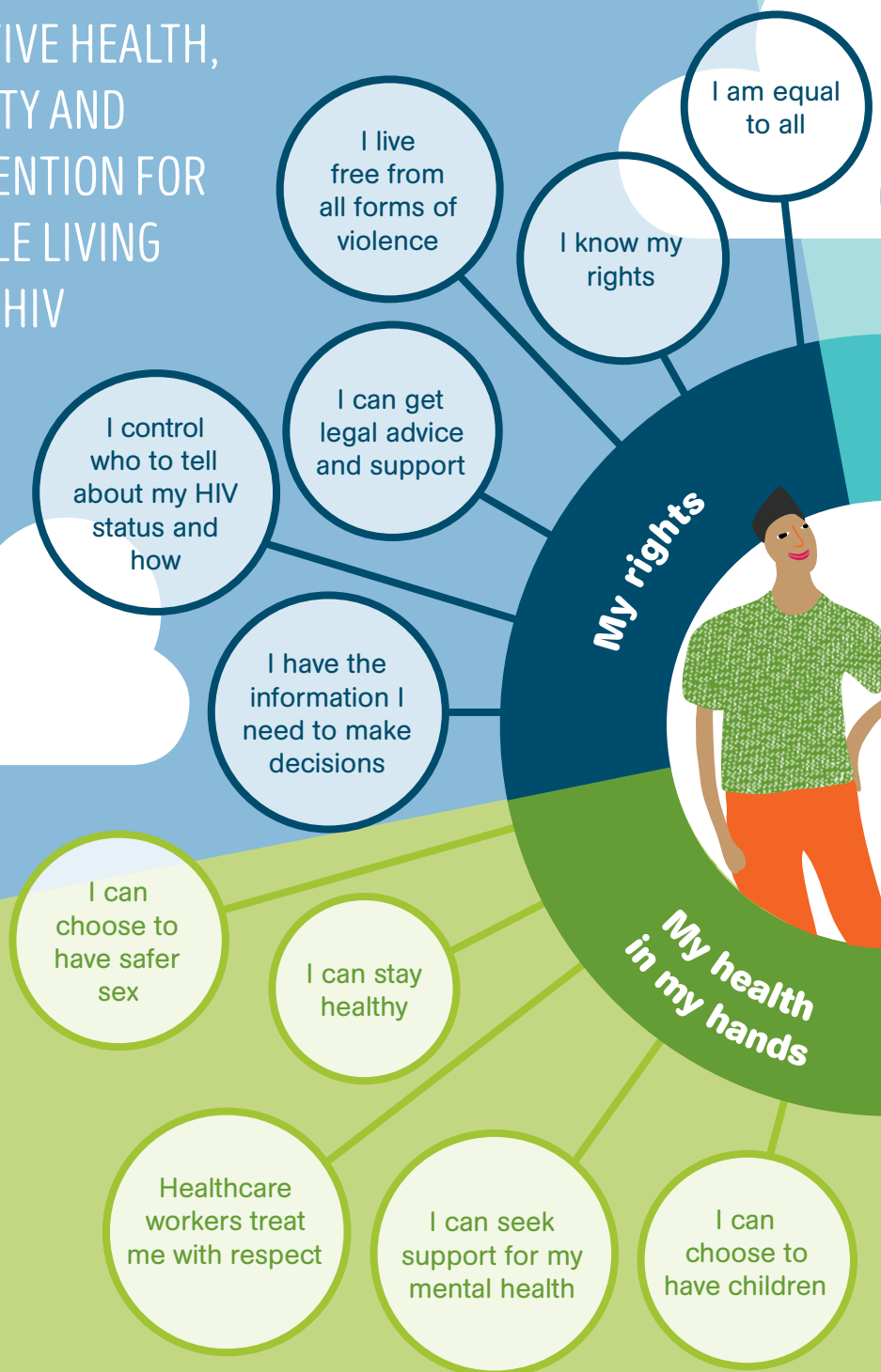


## DEMAND THAT OTHERS SUPPORT PHDP TOO

Our networks need others to commit to play their part in making PHDP a reality too. We will need support, especially:

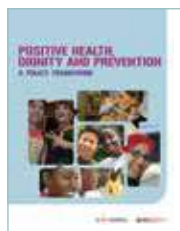
- **Sustained investment**, including political and financial support for all networks and groups led by and working with people living with HIV
- **Ongoing capacity-strengthening** for our networks so that we have all the skills and resources needed to carry out our work
- **Meaningful involvement** in programmes and policies that are part of the HIV response

# POSITIVE HEALTH, DIGNITY AND PREVENTION FOR PEOPLE LIVING WITH HIV





# RESOURCES TO SUPPORT PHDP WORK



*Positive Health, Dignity and Prevention: A Policy Framework* lays out the history, values and the broad concepts to help with the development, implementation and monitoring of policies and programmes to improve the health and dignity of people living with HIV. It can be used by networks of people living with HIV to help to develop advocacy strategies and to encourage the involvement of people living with HIV in the formation and implementation of these policies and programmes.

Available in English, French, Spanish and Portuguese



*Positive Health, Dignity and Prevention: Operational Guidelines* were developed to support stakeholders to put PHDP into practice at a national level. They are designed for use by networks of people living with HIV and other non-governmental and community-based organisations working with people living with HIV as well as other bodies, including national governments, international organisations and donors.

Available in English, French and Spanish



*Positive Health, Dignity and Prevention: What does it mean for me?* is a booklet in the same series as this one, specifically designed for use by individuals. It can be used to help to explain PHDP to people living with HIV and their communities.

You can access PHDP resources at:  
[www.gnpplus.net/positive-health-dignity-and-prevention-phdp/](http://www.gnpplus.net/positive-health-dignity-and-prevention-phdp/)



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