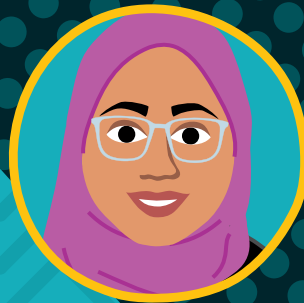


We Matter,

Value Us.

A guideline for organisations on the meaningful and ethical engagement of young people living with HIV in the HIV response



GLOBAL NETWORK OF
YOUNG PEOPLE
LIVING WITH HIV

ACKNOWLEDGEMENTS

The Global Network of Young People Living with HIV (Y+ Global) is immensely grateful to the young people from different parts of the world for contributing to the development of this set of resources. We would like to show appreciation to those who gave their valuable time to be interviewed and take part in focus group discussions and social media platform debates. Our deepest gratitude to our dynamic Steering Committee (SC) members who have given their time to work together to shape the document and its tools and ensured that the voices of young people are at the heart of the work- Georgie Wallis, Anmar Khalid, Eddy Rudram, Joshua Oliyo, Martha Clara Nakato and Beatrix Vas. A special thank you to Mercy Shibemba and Magda Conway for their invaluable contribution to the guideline.

We would like to thank the team who led the project; Cedric Nininahazwe, Daren Paul Katigbak, Tinashe Rufurwadzo, Igor Kuchin and our funder, ViiV Healthcare for their support and guidance. A special thank you to Bakita Kasadha and Renatta Langlais who helped us on the initial stages of the project including the development of the grant proposal. And finally, this piece of work would not have been completed without the technical assistance from our amazing consultants – Kate Iorpenda and Pascal Akahome, and our graphic designer, Garry Robson.



“

I was asked to present in a conference in

Zambia I had only one week's notice,

but I prepared what I was going to say.

When I got there, I saw myself as listed on the

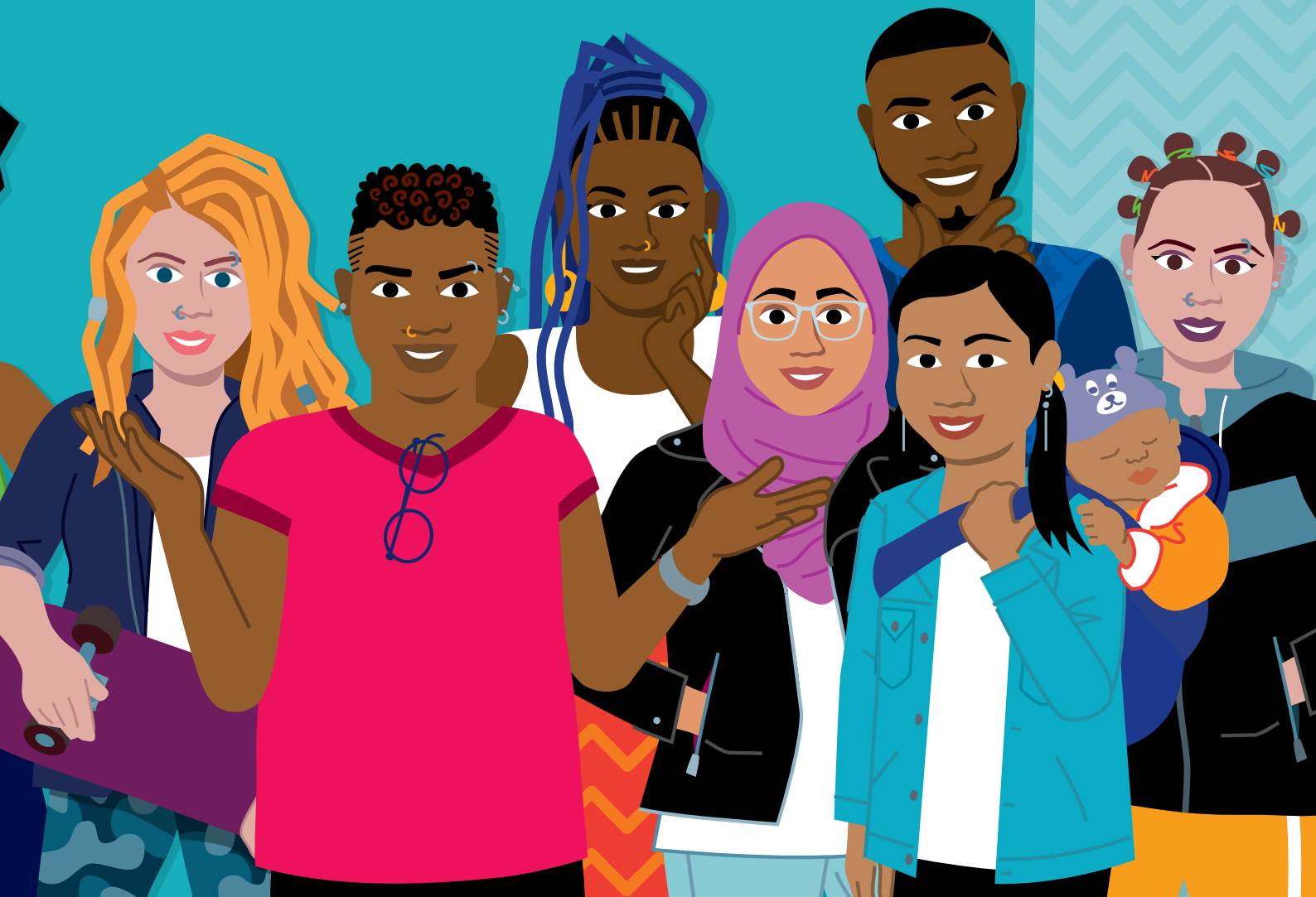
programme as giving a 'testimony' about living with HIV.

I was uncomfortable about it but did it anyway.

I didn't have the power to stand up and say no.

Young person from Zimbabwe

”



ABOUT THE GUIDELINE

What is this guideline?

This guideline has been developed by the Global Network of Young People living with HIV (Y+ Global - www.yplusglobal.org) to support organisations to work more meaningfully and effectively with young people living with HIV (YPLHIV) and to ensure that our contribution really does make a difference and that we are supported during this process. It is for all organisations working with young people living with HIV including donors, international agencies, NGOs, government departments, implementing organisations, advocacy and media organisations.

This guideline sets out:

- The background to this project
- An overview of participation and principles of meaningful and ethical engagement
- Seven key themes for organisations to consider
- A tool for assessing organisational progress

Our stories and experiences are found throughout this guideline. It provides recommended actions for organisations working with young people to ensure our meaningful and ethical engagement and contribution to the HIV response. In addition, as should be at the core of all work with children and vulnerable young people, the processes and procedures to ensure every effort is made to minimise risk of abuse, exploitation or harm when working with YPLHIV.

Over the years, there has been a commitment to increase youth engagement in shaping the global HIV response. Two out of every seven new HIV infections globally in 2019 were among young people (15–24 years)¹. Therefore, our engagement is crucial to reducing HIV transmission rates and improving the quality of life and access to treatment for YPLHIV, with models of care informed by the experiences and preferences of YPLHIV. As young people directly affected by the HIV epidemic, we have experience and ideas to help guide the

1. UNAIDS (2021) *Young People and HIV*

response, to identify priority issues and to understand how best to reach and engage other young people. We have energy and passion for this work but how organisations partner with us and the way in which we are treated is critical to getting the best results.

This guideline focuses on work with young people living with HIV aged 18-24 who are engaged as advocates, activists, researchers and implementers within programmes. A global group of young people have developed this guideline, but we recognise that young people are diverse, and their experiences will vary depending on age, gender identity, sexual orientation, country of origin and circumstances and there are more stories and experience to learn from as we move forward.

Who is it for?

This guideline is for all organisations who work with YPLHIV in supporting their advocacy and activism; as partners in research; implementation within programmes and as speakers in meetings.

It has been developed to support organisations to reflect on their work with young people and support them to change their practice to create more meaningful and ethical partnerships and collaborations.

This guideline is also relevant to any organisation that is working with YPLHIV and wants to learn from their experiences, support them with projects or interventions or to work with them to define policy. This might be international agencies, non-governmental organisations, government, donor organisations or youth-serving and youth-led organisations.



The global context:

'Nothing about us, without us'

There is growing expectation that any organisation working to improve the uptake of HIV services and support for young people living with HIV should be listening to young people's experiences to help define, design and implement services. As a result, several guidance documents and recommendations have been developed to advise how this should be done. However, few of these publications reflect the experiences of young people themselves and, despite being engaged more regularly, too often we report feeling unsupported, exploited, or used.

Despite large numbers of organisations signing on to global statements or endorsing models of 'meaningful youth engagement', there is still work to be done to ensure organisations are fulfilling their duty of care in safeguarding young people and working in ways to ensure young people can participate fully.

The phrase 'nothing about us, without us' continues to be a powerful call used by many youth activists to ensure that young people are involved in the decision-making processes that affect our lives. Y+ Global hopes that this guidance will encourage organisations to reflect on their work with young people living with HIV and provide clear, specific, and practical suggestions and recommendations, based on our experience. The guideline presents the practices we want to see and the processes that must be in place to ensure work with young people living with HIV is ethical and meaningful - work that is important to young people, has a purpose and tangible impacts, demonstrates the highest standards of respect, safeguarding and collaboration to ensure young people living with HIV are supported and engaged appropriately.



How was the guideline developed?

This guideline has been developed in consultation with YPLHIV from around the world, who have offered advice and recommendations on the issues that matter most to them. It has been developed through speaking directly to over 30 YPLHIV, as well as collecting experiences from many more through our social media channels. The structure and themes of the guideline have been shaped by the ideas and recommendations of a youth steering committee of 8 YPLHIV who have overseen the project.

The need for this guidance was initially identified in 2018, when a group of youth activists came together in London to explore the key global concerns for YPLHIV. Those attending the Youth Activists and Advocates Scoping Project (YAASP) were representatives from all regions of the globe, were all living with HIV and representatives of regional networks or organisations. This diverse group included those born with HIV, members of the LGBTIQ+ community, young people who use drugs, young people who sell sex and young people with disabilities.

The meeting led to a call to change the way in which YPLHIV are engaged locally, regionally and globally, and the need to ensure we are safe, respected and valued. The report* from this meeting provided a core recommendation that guidelines need to be drawn up by and for YPLHIV on our meaningful and ethical engagement.

* www.yplusglobal.org/resources/we-matter-value-us



The foundations of meaningful and ethical engagement

Through our consultation work, seven key themes emerged which together we believe form the foundation of a meaningful and ethical framework for engaging young people living with HIV.

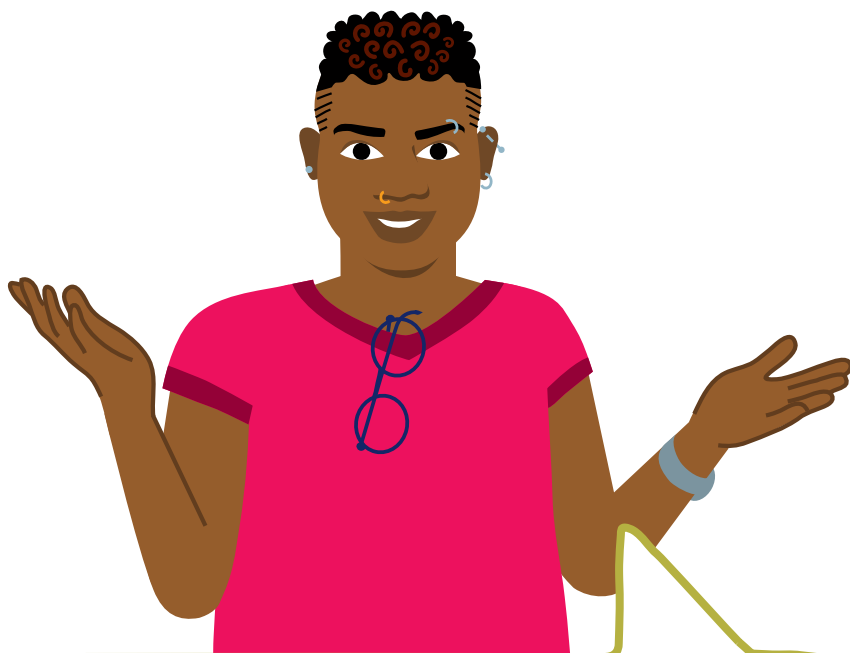
- 1** KEEPING YOUNG PEOPLE SAFE
- 2** VALUING THE CONTRIBUTION OF YOUNG PEOPLE
- 3** ENSURING DIVERSE REPRESENTATION OF YOUNG PEOPLE
- 4** PROVIDING SUPPORT
- 5** BUILDING POSITIVE YOUTH PARTNERSHIPS
- 6** INVESTING IN YOUNG PEOPLE AND THE SUSTAINABILITY OF YOUTH-LED ORGANISATIONS
- 7** PROMOTING GREATER ACCOUNTABILITY TO YOUNG PEOPLE

This framework will be followed in our guideline, accompanied by short case studies from young people that illustrate both good and poor practice. We hope that these examples and the checklists for each section can promote specific actions for organisations to take when working with young people. The checklists in this guide have been turned into a scorecard that organisations can use to assess themselves and there is one for young people to use to score organisations.

The guideline is accompanied by a set of resources for organisations and young people found on the Y+ website (www.yplusglobal.org/resources/we-matter-value-us) that include;

- Guidance for young people on what to expect from organisations
- Scorecards to assess how well organisations work with young people
- A summary of participation

We see this greater accountability as key to ensuring safe, sustained and effective partnerships with young people and youth-led organisations.



Finally, we are still collating stories, feedback and examples to learn from and positive examples where young people have felt valued, supported and heard. If you would like to share your stories, please send these to: youthengagement@yplusglobal.org

How to meaningfully and ethically engage YPLHIV: The seven things that matter

“ We had the opportunity to design and change things not just fight against things that had already been decided ”

This section focuses on what we found through our consultations and the outcomes and actions we believe organisations need to put in place to ensure the ethical and meaningful engagement of YPLHIV.

Participation theories and models have been a foundation of good community development for many years, ensuring individuals and communities can access information and influence the decisions that affect their lives. Models of participation have been developed and debated at length but commonly promote the ownership and commitment of communities, and the active participation by local citizens, in programmes and policy development.



When working and engaging YPLHIV, organisations must understand these principles.

PARTICIPATION IS A RIGHT AND MUST BE:



Transparent and informative - young people are informed about the process and its purpose.



Voluntary - young people understand that it is their choice to participate, and they are free to stop or withdraw at any point. Voluntary does not mean unpaid.



Respectful - young people are listened to and contributions are valued.



Relevant - the content is important to the lives of young people.



Inclusive - the process respects diversity and seeks different ways to engage and gather views from a wide range of young people.



Supported by training - organisations are trained to work with young people and young people are offered support and training as part of the process.



Accountable - the views of young people are taken seriously and can impact on decisions. Young people receive feedback of outcomes, decisions, and next steps.

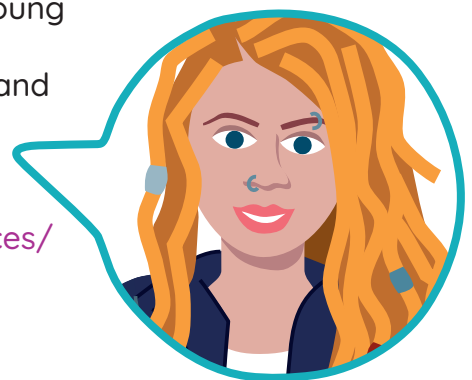


Safe and sensitive to risk - the process takes account of any risk to young people by assessing processes and ensuring spaces are safe, confidential and offer support to young people.

These principles² are important in how we work with all young people and are critical across each of the 7 key themes identified in this project as the foundation of meaningful and ethical engagement.

For more detailed discussion on participation read the [summary on participation \(www.yplusglobal.org/resources/we-matter-value-us\)](http://www.yplusglobal.org/resources/we-matter-value-us).

2. UN (2009) *Convention on the Rights of the Child: General Comment No 12 - The right to be heard*





KEEPING YOUNG PEOPLE SAFE



It was the first time I had travelled to a conference;

I was left in a city with no support and no accommodation.



Young person, Uganda

The most important responsibility of an organisation when working with young people is your ‘duty of care’ to keep children and young people safe from harm. Engaging young people in your programmes, policy and advocacy work can increase their exposure to risk and it is your responsibility to:

- Ensure you have assessed and taken actions to prevent or mitigate risk
- Train and educate your staff on keeping young people safe and what actions to take should an incident or allegation occur
- Ensure the young people involved understand that they should not be harmed and what to do should something happen or concern them.

Your organisation needs to have a safeguarding policy which is the key tool in the training and preparation of staff. You can see a sample policy here: www.yplusglobal.org/resources/we-matter-value-us.

For us safeguarding is about protecting a young person’s health and wellbeing to prevent harm, abuse and neglect. It is part of an organisation’s duty of care when working with young people and something everyone should be responsible for.

What young people said:

Feeling safe

As young people we have found ourselves at events where safeguarding was inadequately done, we are expected to arrive in new places late at night with no money and limited information about where we are. At times we are not provided with information of potential risks in a certain context such as unsafe areas, local laws or attitudes towards specific groups and we are not given information on how to get support.

Some of us have felt coerced or under pressure during events or meetings to do things we are not comfortable with, such as sharing personal information publicly or having images or information about us shared without permission. We can even find ourselves in discussions where people press us for personal details, experiences of trauma, violence or exploitation with no expertise in counselling and no adequate support provided.



CASE STUDY:

A young advocate was invited to a conference in Glasgow, Scotland. The organisation arranged to pay her flight, but they did not think of things like travelling to the airport, or from the airport to the venue. She was young and had no experience with traveling. She had no idea how to find her way around and there was no one to take her through the airport.

“It happens a lot where young people are invited to be part of the “furniture” for the event but are not really looked after at all.”



CASE STUDY:



A young advocate from Dominica reported a situation where a regional network was designing a project for self-testing. They had a stakeholder meeting to discuss this issue and her network was invited. During the call, one of the organisers said that only the people living with HIV should speak on this issue and they should identify themselves on the call.

I felt extremely uncomfortable with this, as I didn't want my status shared. So, I had to leave the meeting in protest at that point.



Having a policy and protocols that assess risk before engaging with young people is so important. It allows you to mitigate risk, speak to the young person about possible risks to prepare them and ensure the support they need is provided.

Staff working with young people should be trained properly, have had the appropriate vetting and be made aware of their responsibility under the safeguarding policy around their interactions with young people. They need to be thinking about potential areas of risk or vulnerability such as travel but also issues of interactions with others, opportunities for abuse of power to coerce, force, abuse a young person physically, mentally or emotionally.

An organisation's duty of care when engaging YPLHIV should also include possible impacts on young people participating in events or meetings where they are asked to present personal stories or asked questions about their HIV status, family bereavement, and experiences of abuse and trauma. This can cause distress or re-traumatise young people, particularly those speaking or sharing for the first time. It is important that organisations prepare support and are aware of potential instances or triggers that might have an impact on a young person and are ready to offer personal and psychological support.

CHECKLIST



Have a **safeguarding policy**, and if you already have one, ensure it directly references work with young people and it is reviewed annually and updated.



Consider your duty of care and issues of safety and security of the young person.



Ensure staff working directly with young people are vetted - carry out background checks, police checks, references.



Train staff on working with young people and safeguarding - introduce the safeguarding policy, reporting procedures, staff responsibilities.



Carry out a risk assessment that looks at safe working practices, travel, accompaniment, safe accommodation, financial and personal support. You can look at a sample risk assessment here: www.yplusglobal.org/resources/well-matter-value-us



Put in place identified actions to safeguard each young person to ensure they are secure, and not vulnerable to risk, exploitation or abuse while working with your organisation.



Provide information to young people as you would for staff on travelling and representing the organisation. This should include the safeguarding policy and a named person responsible for safeguarding and how they should report any concerns.



Ensure you request full consent around the participation of young people. Be clear about the use of material, who might see it, what they are being invited to do and the information they are expected to share. Continue to ensure consent over time for the use of a young person's words or images as their circumstances may change.



Provide information about personal support and advice that they can access, information on mentors, counselling and other support.



Ensure practical support provided to young people travelling on communication, insurance, finances, logistics, visas, accommodation to ensure they can carry out their work safely.



Offer mentoring to ensure young people can make the most of the learning opportunity.



‘ARE YOU LISTENING?’ VALUING THE CONTRIBUTION OF YOUNG PEOPLE

“ Value me for what I bring, not my HIV status ”

Young person Zimbabwe

Sadly, as young people we are often not listened to, we are asked for opinions but see little action based on those ideas. As young people we have a right to be heard and to participate in decisions that affect our lives. But this should not be the only reason that organisations work with young people. Young people bring unique perspectives, understanding of the things that matter most to ourselves and our peers, as well as passion, enthusiasm, and determination to make change. Young people can recognise challenges, identify opportunities, and create relevant solutions.

We know better than anyone how to reach the young people who are missing from the work, how to make things interesting and fun to ensure young people are engaged, and to describe the kinds of partnerships we want to forge with organisations. It is critical that organisations working within the sexual and reproductive health and HIV sector recognise and value the contribution YPLHIV make.

What young people said:

Are you listening?

As young people our abilities are often underestimated, and our qualifications and skills ignored. We are presented with work that is already designed and ready to be implemented and we are asked to take the plans and deliver them the way other people want. We are invited to meetings to share stories, but end up feeling ignored, or undervalued with invitations being sent late; and being given words to speak, on behalf of organisations and if we refuse, we are unlikely to be invited again.



CASE STUDY:



A young advocate from Nigeria said that he had a positive experience working with a state government department and NGO partnership. They were both highly receptive to young key populations. In addition, they valued his skills and opinions, provided stipends for attendees at their meetings and more importantly, provided a safe space for the LGBTIQ+ community in the state to engage freely.



I most valued the fact that I had a great learning opportunity,

and my skills were valued

and put to use.

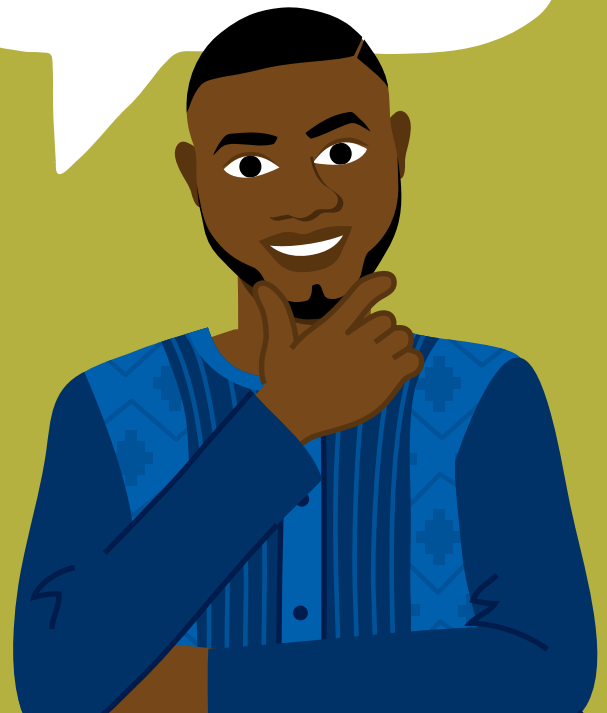


CASE STUDY:



A youth advocate from Uganda, said that in his experience, some donor institutions and international organisations did not value the skills of young people. They would rather pay other organisations to engage youth-led organisations. He described how an organisation was funded with a large sum for the youth engagement component, but they engaged young people as volunteers and gave the youth organisation a fraction of the money.

Give us the hundred thousand directly and monitor us and help support our systems and structures then watch us grow.



CHECKLIST



Take time to listen – young people often come with a unique perspective or something you may not have thought about before, we understand young people and we have ideas.



Be honest and transparent about what young people will be involved in and the level of influence we will have. Be clear about where there are opportunities to make decisions that are meaningful and ensure we are not being used in a tokenistic way.



Involve us from the beginning – we have skills and experiences to help design something effective and sustainable. Bring us in early so we can help shape the process.



Plan for our engagement – identify a budget for the work and discuss with us about our time and remuneration in advance as you would do with other partners.



Recognise our diverse and rich skills and experience – we can do more than social media campaigns – we have skills in strategy development, facilitation, advocacy, writing, research, analysis, and organisational skills. Remember we understand and can comment on things beyond the issues of young people living with HIV – we are also citizens, family and community members and we have opinions and ideas about so many other areas of the world.



Provide opportunities for young people to make decisions that can influence change. Collaborate and engage with young people at every level.

3

‘ARE WE ALL HERE?’ ENSURING DIVERSE REPRESENTATION OF YOUNG PEOPLE

“ It was hard to be treated so badly, but I needed to stay involved with them as they are focused on sex work and SRHR. Removing myself would remove the opportunity for the whole community of sex workers to be heard there. ”

Young person, South Africa

We are seeing many more YPLHIV representing their peers at events, contributing to programme materials and contributing to media work, but we often see the same faces and hear the same voices. YPLHIV are diverse and though we may share many similar challenges, we have unique experiences that vary across locations and circumstances. It may seem easier to work with the same person each time as you know their capacity, they know your organisation and you have a relationship. However, it is important that you have thought about:

- Who the right person is to represent the issues
- Your responsibility to equality of opportunity to all YPLHIV
- That those engaged actually have the lived experience they are representing.

This is particularly important when recognising the lived experience of young people with disabilities, young people living with HIV, young lesbian, gay, bisexual, transgender and queer people, young people who use drugs, and young people who sell sex.



What young people said:

Diverse representation

You need to be sure you are recognising and including us all and that you have young people who understand and have relevant experience on the issues you have chosen. No young person can represent all other young people. Organisations need to work to find young people from all communities that represent diverse identities.

It is also important to support our youth-led organisations so we can build our capacity and mentor new young people from diverse backgrounds as advocates and activists and invest in the next generation.





CASE STUDY:



A young Russian advocate identified that one organisation had a large number of older staff leading work. They designed projects for older people and this led to young people not wanting to participate.



Many of the people in charge

were older, and young people

did not relate freely with them.



CASE STUDY:



A young Vietnamese advocate said that in his early career, he had an opportunity to establish an organisation for the men who are having sex with men (MSM) and the transgender community, who were not recognised in Viet Nam. A key donor worked hard to support this organisation and the community it served, providing training and capacity building as well as support to attend meetings and workshops to ensure those so often excluded were represented.

Young people from the LGBTIQ+ community are more engaged in HIV programmes – they are interested. Ten years ago, very few were engaged. There are now a lot more programmes in the community and young people are more visible and getting involved.



CHECKLIST



Ensure you work with a diverse range of young people who can share lived experience on specific issues.



Be inclusive and think about how to support other people to engage who may face barriers to participating such as young people living with a disability, marginalised and stigmatised groups. Reach out to these communities and talk to them about what would facilitate their engagement.



Don't rely on the same people all the time – there is a risk of burn out but also limitations on them being able to represent other young people.



Support translation and don't use the need for translation as a reason not to include someone. It requires time and money but it is an important part of creating equal opportunity to participate.



Build relationships with youth-led organisations to widen your understanding of the diverse needs of young people and to achieve wider representation of young people in your work.

4

‘ARE WE GETTING PAID FOR THIS?’ PROVIDING SUPPORT-LOGISTICAL, FINANCIAL, EMOTIONAL

“

They booked me into a terrible hotel. Hygiene wise, it was filthy and lacked amenities. I also had to share a room. I delivered 3 presentations for that organisation, no one else on that panel was treated like that.

”

Young person, Lebanon

Some of the most concerning behaviours identified by YPLHIV are around the lack of personal and welfare support offered to them. Part of a duty of care is to ensure there is no exploitation of young people. This includes ensuring that young people do not face financial hardship or loss of earnings due to their work with an organisation.

The experiences of young people are critical to the discussions about our lives and the work to support us. As a result, we are often asked to attend meetings in person or online to provide the perspective of a young person. However, this opportunity is often offered without any acknowledgement of the loss of earnings to the young person or the full financial support needed to attend or participate.

We face challenges with taking part due to lack of support to travel, or to access data or equipment to participate online. We are often expected to use personal phones and precious credit to participate in working groups, steering committees, and webinars – we are paying just to have the opportunity to engage.

Opportunities to travel far from home to attend meetings and conferences, often come with little support and we are expected to feel grateful for the opportunity to travel.



What young people said:

Are we being paid for this?



As young people representing organisations at meetings, we are rarely offered per diems like other staff. We were expected to pay up front and invoice organisations or use bank cards many of us don't have. We can be sent on complicated travel routes, late night flights, connecting flights crossing multiple continents which require additional visas and time, all to save costs.

Too many of us arrive in foreign places with no knowledge of how to get around or are placed in basic hotels, sharing with strangers while other panellists relax at comfortable hotels.

We are placed in meetings with limited preparation and often not supported to understand the processes of organisations or the terminology being used. At times we are not provided with translation and end up feeling excluded through a lack of understanding of the system or the language.





CASE STUDY:



An advocate from Dominica described when she attended an international conference as a rapporteur. She was not paid for her work nor given per diems by the organisers. She was only given a meal voucher to get meals at the conference venue. On most days, she had to leave the conference centre late at night, due to the volume of work and there were significant safety and security issues in the city at the time.

“ I was disappointed because it was a global network, and they should have known better. ”

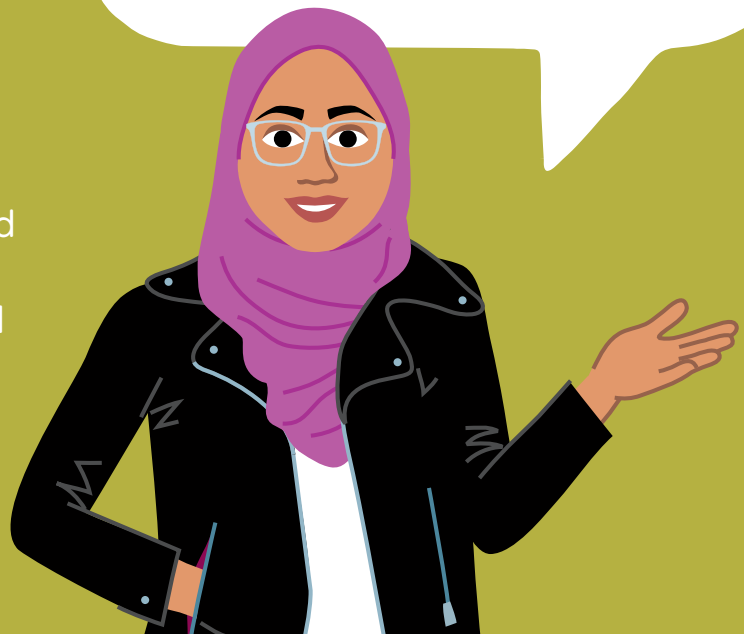


CASE STUDY:



A young activist living in the UK described her work with an international organisation as highly rewarding. She described how she was paid as a consultant on the project, and she was supported by four members of staff. Throughout the project they had regular conversations about how they could help her strengthen her skills to be more useful in her next project, and to get future jobs.

They paid me! They actually came to me and asked me what it would cost for me to do the work. Rather than limiting me with a budget. I was not exploited in this role. It was a positive sign that I was going to be taken seriously on this project.



Not being paid can have multiple impacts on YPLHIV. All engagement should not only be cost neutral, but also acknowledge that most young people work in employment where we are paid for what we do, and if we take time off of work, we do not get paid.

Saving money with complicated travel plans not only puts YPLHIV at risk of potential harm and stress, it can also create health and well-being challenges, having to manage medication across time zones and a lack of rest and preparation before speaking.

CHECKLIST



Discuss our needs around travel and accommodation well in advance.



Ask us if we will miss work, and if that means we will lose money.



Respect the health and wellbeing of young people and consider how to make trips efficient, safe, and straight forward.



Ensure appropriate involvement of parents and caregivers to gain their support for engaging young people.



Provide financial support in advance. Per diems are much easier for young people to manage and provide the option of saving to take something home.



Pay for our time, support us with stipends or contracts- our time is precious, and we have responsibilities too. Don't expect young people to volunteer their time for free, ensure you pay them an appropriate rate that recognises their contribution not just the 'minimum'.

5

‘WORKING TOGETHER’ BUILDING POSITIVE YOUTH PARTNERSHIPS

“

When I became known in the field, and when I was taking global positions, the local organisation I worked with were unhappy with the fact that I was going places, they were afraid that I would form an organisation and that would compete with them.

”

Young person, Lebanon

Working with young people can lead to issues around an imbalance of power. People make assumptions about young people lacking capacity or experience and this can lead to older people dominating young people and youth spaces or underestimating their capacity.

Young people can find themselves being directed or instructed in what to do, with little room for their own suggestions or decisions. In some situations, this power imbalance can lead to us to feel we are being manipulated into doing things that are uncomfortable or being used for menial tasks that don't reflect our skills and capacity.

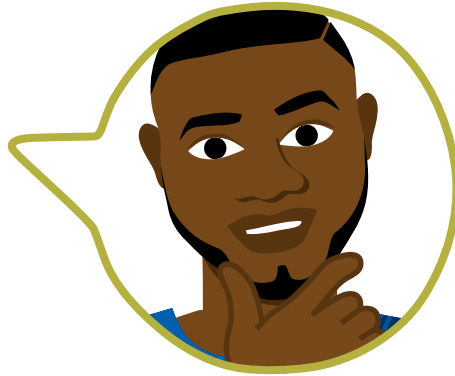
What young people said:

Working together



As we work with some organisations, they can become paternalistic and want to control our activities when they should be empowering and supporting us. At times organisations become territorial and actively or passively block interactions, opportunities, and partnerships for young people outside of their organisation.

Strong and positive youth partnerships where young people feel safe, valued and can participate fully, are so important in countering this.



CASE STUDY:



A Ugandan advocate said that an organisation he was once engaged with behaved unethically towards young people. Young people did not receive salaries for work done, and they were engaged as volunteers. Tokenism was rife, and they did not listen to the voices of young people when making decisions. This organisation once sponsored a young advocate to attend an event, but then prevented him from interacting with any representative of other organisations, denying them the opportunity to network.



For me, I have enough experience

to push back on this kind of

situation, however, what about young

people who do not have the ability

or the experience to push back?





CASE STUDY:



An activist from Uganda described a positive experience while attending a summit meeting where organisers allowed him to engage effectively with the participants who attended and supported him to network with people.



There was a space for me to

make conversation, open up and

make sure there were no barriers

between me and the participants.



CASE STUDY:



A young advocate from Cameroon described her work with a youth coalition. She was asked to work on designing a concept note for the project and to design the baseline. Working with other young people she collected information and worked on the design together. Young people gave ideas about how to implement and who to include.

Normally in the past the organisation would come and give a project for us to implement. In this we had the opportunity to change things and give ideas on how we could make things better.



CHECKLIST



Ensure young people are given space to express opinions and make decisions that are meaningful – if our input can't influence change why are you including us?



Do not try to control what young people say or do, we are not there to amplify your voice, we are there to use our own.



Think about how to allow young people greater autonomy and be aware of the power dynamics in relationships when you engage with young people. How can you create greater balance and equality in the partnership?



Trust youth-led organisations to do the work and manage the money. If you have selected them to work with you, give them the same autonomy you give others. If they need additional support offer that too.



Don't create competition or restrict young people's interactions with other organisations. Create space and opportunities for young people to learn and develop.



Equip your own organisation on how to work with young people, explore issues around communication, responsibility, autonomy, voice, and challenge social norms that limit the participation of young people within your own organisation and beyond.



Don't assume that 'young' means inexperienced – assess and recognise the qualifications skills and experience of young people as you would others. And where we don't have skills, offer mentoring to build them.



Build strong relationships that are two-way. It is the responsibility of young people and organisations to create and maintain strong partnerships. Identifying where we can lead processes, make decisions and where we need more guidance and support.

6

‘LOOKING TO THE FUTURE.’ INVESTING IN THE SUSTAINABILITY OF YOUTH-LED ORGANISATIONS

“Mentorship is key, a ripple effect of cascading down information is the first thing. Once an organisation identifies me, I should be able to identify other young people who are potentially key to drive the same agenda in the different forums.”

Young person, Zimbabwe

The last few years have seen significant progress in the commitment to youth engagement and the meaningful engagement of YPLHIV, but commitment is just the start. There is still much to do to improve the practice more widely and to sustain this work. We need to maintain the flow of high calibre young people within the HIV and wider health sector who work as advocates and activists and that means investing in their development.

For there to be a commitment to sustainability by organisations there must be an understanding of the value of young people and recognition of the support and opportunities we need to thrive in the sector.

What young people said:

Sustainability

Sustainability requires investment in partnerships with youth-led organisations, in training and skills development and in preparing and mentoring the next generation of advocates. As young advocates we should be supported to attend entire meetings or conferences, and not be in situations where we are sent home from meetings early to save on costs.

We also need to see pathways and opportunities created as people move out of the youth space and support provided for young people taking on new roles in organisations.



CASE STUDY:

A youth advocate from Uganda highlighted an INGO that worked well with young people. The organisation provided per diems, listened to criticism, and adjusted accordingly, provided timely communication to young people, and always took their needs into account when setting up trip itineraries.

In addition, the organisation provided support for advocates ageing out, and provided opportunities for growth for activists who work with them.

“

My knowledge base

has increased, I love to learn,

getting these opportunities to

tap into brains and collect resources.

”



CASE STUDY:



An activist from Lesotho described how funds directed to youth-led organisations are not sustainable. Donors often specify the use for funding, for example, requiring the organisation to hire rather than buy vehicles. Usually, the projects are short term and when the project terminates, the organisation retains no assets and dies.

“ I think donors should allow organisations to buy assets so they can run even after the project ends. ”



CASE STUDY:



An activist from Zimbabwe said that she had a positive experience working with an international network of advocates. She was trained on how to tell stories and make them impactful, and how to link stories to the issues at the national level where donors understand the impact they make. The organisation was intentional about their training objectives and organised a three-day training in the technical and non-technical aspects of storytelling for the young advocates in their network. In addition, the organisation provided personal support to its members to ensure they stayed safe and well during the period of the global COVID-19 crisis.

It was one of the best models I had seen of an organisation supporting young people in advocacy.



Donors are critical in sustainability, they can support and sustain this work by expecting to see funded components of programmes that support youth engagement and to evaluate this as part of their grant management work.

This means encouraging applications which include youth partnership and contribute to building the capacity of young people living with HIV as programmers, advocates, researchers and advocates.



CHECKLIST FOR ORGANISATIONS



Consider longer term relationships and partnerships with youth organisation and how you can get the most out of the engagement of YPLHIV. Avoid planning one off events.



Consider how your organisation could develop pathways for young people within your organisation. Are there employment pathways that can be mapped - for example, internships, junior posts, and secondments.



Consciously plan for young people who are aging out of the sector. Don't just look at the next set coming through but consider the pathways for those who are moving onto the next stage.



Support further training or scholarships to invest in young people for the sector not just your organisation.



Recognise that the energy and enthusiasm of young people is not limitless. In a desire to learn and impress and to maximise every opportunity, young people are at risk of burn out – be aware of the support you should offer and not overburdening individuals.

CHECKLIST FOR DONORS



Support and fund skills development as part of the work with YPLHIV – help build capacity through mentoring, training, and investment in youth-led organisations.



Make plans and invest in the next generation of advocates – provide longer term support and assistance to youth-led organisations to support the training and mentoring of young advocates.



Advocate for greater investment in youth-led organisations over the longer term – this means supporting their organisational capacity not just their restricted programmes.



Invest in young people long-term and beyond the specific piece of work – support them to build connections and networks so that the young person is more established regardless of whether they stay with you.



Require organisations to demonstrate more sustained and effective partnerships for youth engagement from grantees. Evaluate an organisation's ability to engage young people in meaningful and ethical ways.



Promote sustainable financial support to initiatives for young people. Too often the funding to support youth organisations is limited and short term. There needs to be secured funding in the HIV sector to sustain support to youth-led organisations to ensure they can be effective.

7

‘ACCOUNTABILITY BREEDS RESPONSIBILITY’ – PROMOTING GREATER ACCOUNTABILITY TO YOUNG PEOPLE

“ Provide a platform to be able to share personal experiences and have accountability. Hear our voices and our frustrations about the lack of opportunities. ”

Young person, Uganda

While an increasing number of organisations aspire to engage young people more in their work, there is still a gap in the accountability of organisations, firstly to young people themselves but also to their own organisation and to their funders.

It is not enough to ‘tick a box’ to say you have worked with young people. The work needs to be valuable, have impact and be carried out meaningfully and ethically.

Working with young people needs specific skills and knowledge, and this needs to be acknowledged and reflected in the people that undertake this in organisations.



What young people said:

Accountability



As young people we need to know how organisations are using our experiences, data, and ideas in their work. Organisations must be able to demonstrate what they have done, what they have learnt and how they can improve. To improve practice, young people need to be involved in assessing and measuring the quality of the work. And this does not just mean an evaluation form at the end of an event.



CASE STUDY:



One activist from Zimbabwe described how important it is that organisations are accountable to young people. She emphasised that they should be able to see how they have been working in documentation and reflect on how young people found working with them.



Organisations need to evaluate the process and ask a set of questions every year to provide a transparent and accountable report of young people's experiences.



CASE STUDY:



An advocate described how he looked at the activities an organisation had done and conducted 'undercover' research on the involvement of young people, as too often a young person is a volunteer and not part of the Secretariat.

I am personally not ok with how we young people are statistics, just on paper and yet not physically involved.



CHECKLIST



Ensure young people who participate in surveys, focus groups, advocacy events, meetings, programme design research are provided with feedback on the outcomes of the work, how decisions were made and what influenced decisions. Young people understand that not every idea, experience or call for action will lead to direct change, but we have a right to understand how our opinions and voices were used and what change came about.



Engage young people in processes they can influence – asking us to participate in processes where there is no room for change is tokenistic and doesn't respect the time and contribution of young people.



Ensure you have a fair and transparent selection process when selecting young people for activities and ensure you remunerate young people fairly.



Find ways to measure the effectiveness of your work with young people. Ask young people to evaluate how you have done and what we value about working with you.



Be transparent when you engage young people about what the work entails so young people can make informed choices and can hold you accountable within the partnership.



Be accountable to young people around meaningful and ethical engagement – demonstrate your commitment and how you would like to be measured on your success.



As donors expect to see evidence of quality youth engagement – ask for feedback from young people and request reporting around the engagement of young people against the checklist of issues.



Encourage young people to use the tool in this guide to assess your organisation.

MEASURING OUR PROGRESS

Throughout this guideline we have highlighted the practice and actions we believe organisations should adopt to ensure their work with young people living with HIV is done in a more meaningful and ethical way. In this section you will find a tool that you can use to assess your organisation against the seven areas and identify where there is a need for you to improve your approach.

The tool below contains all the checklists to use to score yourself against 1-5. After completing the scoring, you can read a summary linked to your score and consider what actions you could take.



We have developed a scoring tool for young people to use when they work with organisations, and this can also provide you with additional feedback to help you make improvements.

MEASURING OUR ORGANISATION'S WORK WITH YOUNG PEOPLE

1 = poor **2** = below average **3** = average **4** = good **5** = excellent

Read through each of the statements and score the organisation from 1-5.

3

Add up the totals and read a summary at the end of the tool.

KEEPING YOUNG PEOPLE SAFE



1	We have a safeguarding policy which provides clear information on working with young people and vulnerable adults and procedures for reporting any incident.	1	2	3	4	5
2	We train staff on working with young people and the importance of the safeguarding policy and our duty of care.	1	2	3	4	5
3	We carry out a risk assessment for activities where we work directly with young people to identify potential risks and actions to mitigate risk and harm.	1	2	3	4	5
4	We put in place identified actions to prevent or mitigate risk and harm to young people working with us.	1	2	3	4	5
5	We provide young people with information and training on our safeguarding policy, safety and security for travelling and reporting procedures.	1	2	3	4	5
6	We handle young people's information and data safely and ensure we have consent for all activities.	1	2	3	4	5
7	We offer practical and personal support to young people working with us to safeguard their health and wellbeing through mentoring, counselling, communication or accompaniment.	1	2	3	4	5

VALUING THE CONTRIBUTION OF YOUNG PEOPLE



8	We contact youth organisations and understand who they are, what they do and how we can work together.	1	2	3	4	5
9	We allocate budget to support youth engagement either through a grant or support to an organisation or to provide stipends, per diems or scholarships to young people.	1	2	3	4	5
10	We demonstrate clear commitment to working with young people at every level and are explicit about the value the organisation sees from meaningful and ethical involvement of young people.	1	2	3	4	5
11	We engage young people at every stage of the project.	1	2	3	4	5
12	We give space for young people to lead the work and make decisions that have impact and create change.	1	2	3	4	5
13	We ensure we appreciate the efforts of young people and make them feel involved.	1	2	3	4	5



ENSURING DIVERSE REPRESENTATION OF YOUNG PEOPLE

14	We ensure we work with a diverse range of young people, increasing wider representation by removing barriers to participation of young people- such as access, location, criminalisation, language.	1	2	3	4	5
15	We allocate time and funding to reach young people from more diverse communities for more genuine representation.	1	2	3	4	5
16	We ensure requests for young people to take part in policy, advocacy or programme activities are transparently advertised.	1	2	3	4	5
17	We explore creative ways to engage other young people who we don't normally work with. We use online platforms, digital tools.	1	2	3	4	5
18	We build partnerships with youth-led organisations to support wider representation of young people.	1	2	3	4	5

PROVIDING SUPPORT

































19	We discuss with young people about an event or piece of work in advance. We discuss payment, travelling and logistics before asking them to accept.	1	2	3	4	5
20	We support all travel costs – visas, travel to embassies, insurance, vaccines, connecting flights, per diems and prepare well in advance.	1	2	3	4	5
21	We remunerate young people through per diems, stipends, data and phone credit, and funding to organisations. We discuss and explore what they need to work effectively.	1	2	3	4	5
22	We provide money in advance, so young people have money to travel with and are not expected to pay up front.	1	2	3	4	5
23	We provide information on a new country, on safety, culture, language, money and ensure the young person has insurance and details about security.	1	2	3	4	5
24	We offer accompaniment to meetings and events and translation to allow young people to participate fully in events.	1	2	3	4	5
25	We recognise the wellbeing of young people. We don't overburden the same people and risk burn out.	1	2	3	4	5































BUILDING POSITIVE YOUTH-ADULT PARTNERSHIPS

26	We provide training to staff on how to work effectively with young people. We explore attitudes and values, and challenge power dynamics to create more equal partnerships.	1	2	3	4	5
27	We provide space and mechanisms for young people to feedback and challenge the organisation without fear of rejection or exclusion.	1	2	3	4	5
28	We allow young people to speak their own words and bring their own ideas, we do not coerce young people to talk about things they are not comfortable with.	1	2	3	4	5
29	We support youth-led organisations to lead the work with young people, we trust in their ability to do the work with the right support.	1	2	3	4	5
30	We facilitate connections for young people with different organisations and networks. We don't create competition or become territorial about our relationships with young people.	1	2	3	4	5

INVESTING IN THE SUSTAINABILITY OF YOUTH-LED ORGANISATIONS

31	We think long term when working with young people. We don't plan one-off events.					
32	We design pathways for young people within our organisation. We identify roles and points of progression.					
33	We invest in skills building and mentoring of young people to prepare them for current and future work.					
34	We plan for 'aging out' when young people move out of the youth sector, and we invest in the next generation of young people.					
35	We ensure our expectations of young people are realistic and that we are not at risk of overburdening them.					
36	We document and promote the value of our work with young people. We report to donors and advocate for greater investment in youth-adult partnerships.					

PROMOTING GREATER ACCOUNTABILITY TO YOUNG PEOPLE

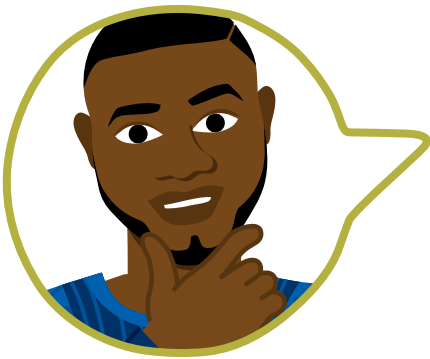
37	We collect consent from young people after they are informed of the activities they will be involved in and where appropriate ensure parents and caregivers are informed about the work and seek their permission.					
38	We design mechanisms to get feedback from young people on their engagement and participation, evaluating how well they were supported and how valued they felt.					
39	We ensure young people engaged in work are provided with feedback on the outcomes and the contribution they made.					
40	We provide young people with references, commendations, letters of support for their work with us.					
41	We ensure that young people working with our organisation are engaged in ongoing learning and development.					
42	We ensure we appreciate the efforts of young people and make them feel involved.					

HOW DID YOU DO?



Below 90

Your organisation is not considering how to work with young people in a 'meaningful and ethical' way. You need improve your approach before you engage any young people.



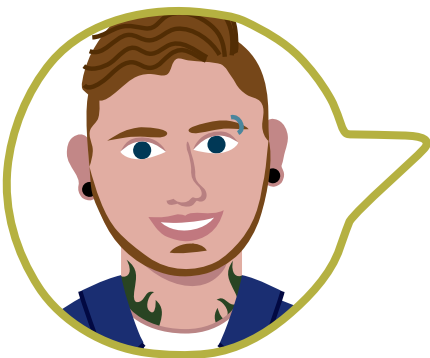
90 - 130

Your organisation is demonstrating some measures to support young people in a 'meaningful and ethical' way. You should review your scores in specific areas and identify where you still need to make improvements. Use the actions in the guideline to support you.



130 - 170

Your organisation is doing well with engaging young people in a 'meaningful and ethical' way but there is still more you can do. Consider the areas where you can improve your scores and use the actions in the guideline.



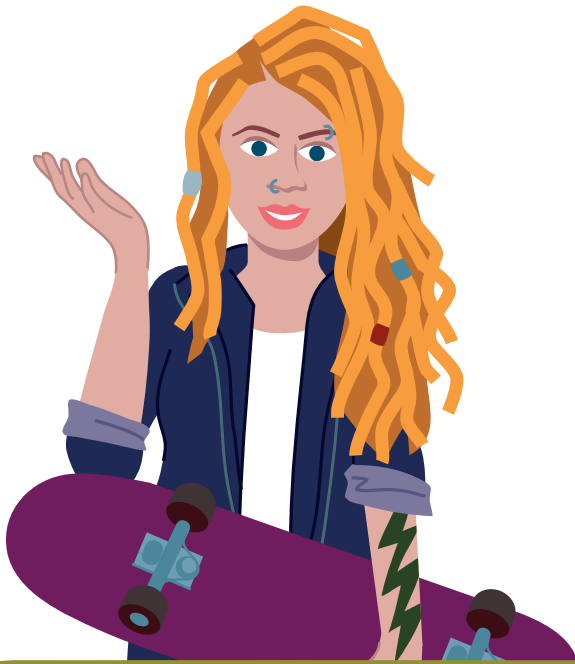
170 - 210

Your organisation is thinking carefully about how to work with young people in a 'meaningful and ethical' way and you have shown that you have things in place to ensure young people are supported, valued and respected. Young people will enjoy working with you but make sure you regularly review your work to ensure you are maintaining the standards and remember there is always room to improve!

SUMMARY

Listening to young people from across the world tells of a deepening commitment by organisations to work with young people living with HIV in programmes, policy and advocacy. However, it is clear there is still so much that can be improved in the way that engagement is done to ensure that all young people feel safe and valued for the work they do and the contributions they make.

For organisations we hope this guideline will help you plan your work more carefully and ensure that your staff are trained and prepared to work alongside young people in order to benefit from their experience, their ideas, their skills and their talents. We also hope that you see the importance of investing time and money in engaging young people and that you work with donors and other investors to support us as young people and as leaders of organisations, to participate fully.



As Y+ Global and as young people we know what works, we know what is relevant and engaging and we are ready to collaborate to promote meaningful and ethical engagement of young people living with HIV in programmes, policy and advocacy. This is a key action for us to deliver on in our strategy – to raise and amplify our voice and advocate for our right to live healthy and fulfilling lives.

USEFUL RESOURCES

- CHOICE (no date) *Meaningful youth participation: a position paper*. CHOICE
<https://www.youthdoit.org/assets/Uploads/MYPpositionpaper.pdf>
- Frontline AIDS (2016) *Aiming High: 10 strategies for meaningful youth engagement*. LINK UP Project.
https://frontlineaids.org/wp-content/uploads/old_site/aiming_high_10_strategies_for_meaningful_youth_engagement_english_original.pdf?1464863631
- PMNCH (2018) *Global consensus statement on meaningful adolescent & youth engagement*
<https://www.who.int/pmnch/mye-statement.pdf>
- Women Deliver (2016) *Engage Youth: A discussion paper on meaningful youth engagement*
https://womendeliver.org/wp-content/uploads/2016/04/Meaningful_Youth_Engagement_Discussion-Paper.pdf
- Women Deliver (2018) *Meaningful Youth Engagement: Sharing Power, Advancing Progress, Driving Change*.
https://womendeliver.org/wp-content/uploads/2019/05/WD_YouthPositionPaper.pdf
- Y+ Global (2016) *Ready to Advocate*.
<https://www.yplusglobal.org/resources-ready-to-advocate>

Global Network of Young People Living With HIV
Eerste Helmersstraat 17 B3
1054 CX Amsterdam, Netherlands
T: +31 (20) 423 4114
E: info@yplusglobal.org

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Living with HIV (Y+ Global)
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We Matter, Value Us resources:
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