



Patient Advocacy Alliance

Youth Activist and Advocates Scoping Project (YAASP)

Final Project Report (Synopsis)

August 2018

A full version of this report is available



1. INTRODUCTION

The Youth Activist and Advocates Scoping Project (YAASP) is a stand-alone scoping exercise to collate the current global response to engaging Young People Living with HIV (YPLHIV) in activism and advocacy on the global stage.

The project ran over eight months, bringing together a team of six freelance consultants with varied expertise and experience in the adult, youth and paediatric HIV field. The team included three YPLHIV, who were based in Nigeria, the UK and Uganda. The project was funded by ViiV Healthcare, Gilead Sciences and Janson (Johnson & Johnson).

2. OBJECTIVES AND PROCESS

- YAASP reached out to twenty four key global and regional organisations that either support youth activism and advocacy or are youth-led and conducted in-depth one hour long interviews with each.
- YAASP engaged sixty nine YPLHIV who are current or potential activists and advocates and recorded their experiences through an online survey. YAASP also hosted a Twitter Q&A where YPLHIV participated.
- YAASP brought together regional youth representatives from across the globe to a Round Table meeting in London in June 2018. The meeting looked at the results so far and created youth-led recommendations and action plans.
- Round Table representatives and YAASP engaged the wider community of YPLHIV at the International AIDS Conference 2018.

3. KEY RESULTS

From all the activities undertaken, the findings fell under five themes:

Theme 1: ENGAGEMENT & SUPPORT FOR YOUTH ACTIVISTS/ADVOCATES

“...provide them with platforms in meetings and conferences to speak out and be heard and share experiences” Funder and implementer.

Those interviewed reported that the primary engagement of YPLHIV as activists and advocates is through being invited as speakers at events and participating in consultations. The key support offered in this area is training and mentoring, although the experiences of undertaking these activities and the quality of support offered varied significantly.

The survey showed that half of the YPLHIV who are currently active in activism and advocacy reported receiving training. Most highlighted their current training needs are to build their knowledge and capacity in activism and advocacy.

Theme 2: SUPPORT & ENABLING FACTORS FOR YOUTH ACTIVISTS/ADVOCATES

“Organisations that have put young people in decision making positions”
Regional youth-led network

All those engaged shared what they think are the enabling factors for YPLHIV to undertake activism/advocacy. The main areas from the interviews were that YPLHIV need to have ownership and be empowered, have support from staff and have mentoring and training available. It was acknowledged that there is now more active engagement of YPLHIV, which means more opportunities for them, increased funding to support them and in some cases, policy change to enable this.

YPLHIV reported having developed multiple interpersonal skills and better understanding about HIV through being an advocate or activist. They said this has built their confidence, ability to talk more openly about HIV and employability. This was reinforced through the Twitter discussion.

The Round Table participants drew particular attention to self-care being critical to enable and support YPHIV in activism and advocacy. This included ensuring YPLHIV have access to the correct knowledge and information, access to healthcare and supportive organisations that are aware of their self-care needs.

“Wellbeing of the activist has to be taken into account to ensure activism is effective”.

They agreed that mentoring and training were also important factors; building YPLHIV’s capacity to work at all levels, from a local activist through to running a youth-led global organisation.

Theme 3: CHALLENGES FACED BY YOUTH ACTIVISTS/ADVOCATES

“People like quick fixes to sort out issues and yet youth engagement is a process of development over time”. UN

All those spoken to highlight the multiple challenges that YPLHIV face in advocacy and activism. Funding and HIV related stigma were the areas mentioned most frequently by all groups.

Money was specifically raised in different ways. Some felt there was sometimes an over focus on money and YPLHIV seeing activism as a job. Whereas for many YPLHIV, they spoke about how there needs to be some financial compensation. Young people have various priorities in their lives, and these can be a challenge for them and for those supporting them. Some organisations highlighted the culture of volunteerism and how YPLHIV are expected they give their time for free.

The capacity of YPLHIV was raised in different ways, highlighting how YPLHIV need skills to be leaders at all levels, including running projects and programmes themselves. Aging out and ageism were noted, with the need for clear transition processes to hand over responsibility but not lose all the knowledge gained.

Many spoke of a lack of transparency and accountability, with clear monitoring needed and YPLHIV being represented at all levels of development and delivery. It was felt that there is a lack of information on how YPLHIV can get involved in advocacy and activism, and that those involved may not always want to share opportunities that come up.

The Round Table meeting specifically talked about the need for the ‘Ethical Engagement’ of YPLHIV in advocacy and activism. This covered associated costs, representation of YPLHIV at all levels of programme and project development and delivery, transparency and accountability.

Theme 4: STRATEGIES FOR IMPROVEMENT

All groups offered similar ways forwards to improve the experience and ability of YPLHIV in advocacy and activism. Partnership working, organisations linking together and building capacity in existing organisations were the key leading factors. It was suggested that current youth-led organisations and networks were mapped as a starting point. Increased funding, and funding specifically to support youth-led programmes that includes capacity building of the young people involved was also seen as a way forward.

The majority of YPLHIV engaged in this scoping exercise highlighted the need to provide more opportunities, paid positions, cover costs, training and skill development, and representation at all levels. They want youth-led programmes locally, regionally and globally, and support for YPLHIV to do this. They felt capacity and skills should be developed through training and mentoring. They saw utilising technology as a future way to mobilise activists and advocates and to provide easy routes in for those who want to get involved.

Theme 5: ACTION PLANS

The final theme was around the structure of action plans. It was felt this should be a facilitated process covering accountability, action and results, using and supporting existing structures, building partnerships, mentoring and that this needs to include buy-in from funders. All parties involved need to be engaged and best practice should be agreed, with clear processes of engagement, activities, building leadership and capacity of existing organisations. There needs to be a strong protection and rights ethos running throughout.

The plan itself needs to be accessible to young people, clear, jargon-free, inclusive, practical, realistic, strategic and standards driven. The YPLHIV also included they want action that develops their skills and capacity to be activists, advocates and run their own programmes and projects.

4. YOUTH-LED RECOMMENDATIONS

As part of the Round Table meeting, participants produced recommendations for five areas that are currently active in the YPLHIV activism and advocacy field.

1. Adult Networks/Civil Society
2. Funders
3. Service Providers and Implementers
4. UN, Bilateral & Government
5. Youth Organisations

These recommendations are set out in full in Annex One.

5. DEVELOPING ACTION PLANS

The final activity for the Round Table was to work in groups to develop Action Plans. The groups were asked to think up creative solutions and develop a plan that they would then pitch to the group as a whole (see YAASP Full Report Section 4 for details of this and the pitches the representatives made). Each pitch was then discussed, and these are the key themes that came out:

- **Youth-led or partnered work**
That there needs to be a culture of youth-led activities, projects and organisations. Where something is stakeholder-led, youth-led organisations need to be equal partners and there needs to be YPLHIV present at all levels, including decision making, in a non-tokenistic way.

- **Agreed and implemented global ‘ethical guidelines’**
These should cover how to engage, support and treat YPLHIV who are advocates and activists and include meeting associated costs, representation of YPLHIV at all levels of programme and project development and delivery, transparency and accountability.
- **Training and mentorship programmes**
YPLHIV who are advocates and activists need to be skilled up in all areas, from activism through to running organisations, fundraising and governance. This should be done through training and mentoring.

6. CONSULTATION AT AIDS2018

At the International AIDS Conference (AIDS2018), Round Table representatives and the YAASP team facilitated a feedback session with youth activists and advocates. This provided the opportunity to involve more YPLHIV in shaping the action plan and to continue to involve youth activists in every stage of this process. This was an open call with eleven YPLHIV attending.

The group were given information about YAASP and presented with the project results so far. The group resonated with the themes identified and supported the action plans created. For most of the consultation the group was split into three smaller groups to focus on one of the three action plans and their feedback was recorded. All groups emphasised the importance of the action plans being youth-led, with technical assistance from key stakeholders.

Engagement Action Plan

The group felt this Action Plan lacked the routes and structures to protect young people and reduce tokenism and said it needed to include an ‘Accountability Framework’ and defined responsibilities to facilitate transparency and ensure participation is diverse.

They want this all managed by YPLHIV but said they would need some guidance from stakeholders’ who are experienced in this field and who could skill up YPLHIV to deliver the programmes.

Funding Action Plan

This lacked information on where youth organisations can source funding for specific activism and advocacy work, and specifically asked funders to put mechanisms in place to help YPLHIV to apply for this, with funding programmes that include training to gain the skills in project and programme management.

They felt that building stronger networks on a local and regional level to increase opportunities to access needs must be included. They also highlighted the ‘English bias’, that they felt funders could address to ensure equal access to potential funding sources for all YPLHIV, not just those fluent in English. This sub-group specifically named the Y+ networks as who they felt should lead this action plan.

Training Action Plan

The group wanted local considerations to be present in the final action plan. They suggested a structure be in place where there are identified training frameworks developed globally/regionally, that have the capacity to be delivered locally, reflecting and addressing local considerations. They wanted the training to incorporate annual impact reviews that are measured against key indicators.

The group were clear that they wanted this developed and led by YPLHIV with the training delivered by “*knowledgeable/passionate trainers*”, who are young people themselves. They want the youth trainers to be supported and mentored to develop the training programme and their skills by experienced trainers.

7. THE ACTION PLANS

| Youth Action Plan | | | | | |
|--|---|---|-----------------|---|------|
| <p>Prior to the Action Plan’s implementation, it is critical that key Youth-led organisations have the support and internal abilities to manage the development and delivery of these large global projects.</p> <p>Pre-Action plan activities:</p> <ol style="list-style-type: none"> 1. Mapping and skills assessment of local, regional and global youth-led organisations 2. Where needed, develop country or regional youth-led networks to lead on these developments 3. Where needed, capacity-build in key leading youth-led organisations to develop organisational infrastructures and skills to be able to manage global projects. | | | | | |
| What | Why | Lead | Target audience | How | When |
| Youth- Led Funding Position Paper | Improve funding access and transparency to youth-led projects and organisations | Youth led-organisations in partnership with stakeholder organisations | Funders | Connect with ICSS on their position paper | |
| | | | | Identify YAASP working group | |
| | | | | Provide content ideas including funding recommendations and available resources | |
| | | | | Participate interviews with ICSS | |
| | | | | Review position paper | |
| | | | | Be part of launch at [Event] | |
| | | | | Disseminate | |

| | | | | | |
|--|---|---|--|---|-------------------|
| Youth leadership, advocacy and engagement in the HIV response: Guidance youth-led movements/networks and stakeholders | To build capacity and confidence | Youth led-organisations in partnership with stakeholder organisations | Youth-led organisation, funders, implementer, researchers, pharmaceutical, media, governments and other key stakeholders | Present the idea at YAASP AIDS2018 action plan workshop, review YAASP ethical guideline objectives, brainstorm scope and content ideas (and what to include), decide on next steps and establish a youth project team | 22nd July |
| | Facilitating the ethical engagement | | | Engage a consultant to support grant proposal | |
| | To facilitate agency and leadership | | | Submit for funding | |
| | To empower young leaders | | | Create and post content outline for youth led networks to review | Funding dependent |
| | To set norms and standards on how youth-led networks engage | | | Call for best practice examples from youth-led networks | Funding dependent |
| | To provide clear expectations on how stakeholders ethically engage | | | Online review process/meeting | Funding dependent |
| | To provide a practical guide based on experiences and best practice | | | Complete guidelines | Funding dependent |
| | | | | Publish, Launch, and disseminate the guidelines (translation into major languages) | Funding dependent |

| | | | | | |
|--|---|---|-----------------------------|---|---|
| | | | | Monitor the progress of the guideline's awareness and application of the guidelines | Funding dependent |
| Develop a global youth leaders and advocacy training and mentorship programme | To support personal development and increase the capacity of young people in the field of activism and advocacy | Youth led-organisations in partnership with stakeholder organisations | Youth activists and leaders | Present the idea at YAASP AIDS2018 action plan workshop, brainstorm scope and decide on next steps and establish a youth project team | 22nd July |
| | To increase young people's ability to train other young leaders and advocates in the global HIV response | | | Engage a consultant to support grant proposal to develop training a mentorship programme | TBC - can be done simultaneously with ethical guidelines action or after this |
| | To ensure young leaders have access to guidance and mentorship to increase impact | | | Submit for funding | |
| | To promote self-care and prevent burnout | | | Mapping exercise to identify current HIV activism and leader and youth leadership training programmes | |
| | To support the ethical engagement guidelines | | | Disseminate draft ideas for consultation and review | |
| | To provide on-going support for young leaders | | | Develop a youth HIV training and mentoring programme | |

| | | | | | |
|--|---|--|--|---|--|
| | To learn from leaders and advocates of experience | | | Write grant proposal for implementing training and mentorship programme | |
|--|---|--|--|---|--|

8. CONCLUSION

There are some clear conclusions that can be drawn from this scoping project. YPLHIV, and the organisations that work with them, in general agree that there is scope to improve the experience of YPLHIV in this area. Although there is training, support and opportunity available, there are many gaps and YPLHIV have distinctly varied experiences.

The lack of YPLHIV at a decision-making level locally, regionally and globally, and a lack of transparency in how decisions about YPLHIV are made, needs to be addressed with non-tokenistic representation at all levels.

Many YPLHIV want to participate in activism and advocacy, but the routes are not always clear, and the opportunities not always given through an open process.

This scoping project recommends:

- That the Youth-led Recommendations in Annex One are rolled out and instigated by Adult Networks/Civil Society, Funders, Service Providers and Implementers; the UN, Bilateral & Governments and Youth Organisations. This should see a significant change in the experience of YPLHIV and address the power imbalance when YPLHIV are interacting and providing feedback within these environments.
- That youth-led organisations are supported to build their capacity to develop and manage global programmes and projects. Support should be offered through advice, mentoring and skills developing.
- That youth-led organisations lead on instigating the key elements of the action plans.

Once infrastructures and foundations are developed to ensure youth-led organisations have the capacity and ability to lead on developing the global, regional and national programmes they need, then there is no reason why future projects and programmes about YPLHIV who are advocates and activists cannot either be run by youth-led organisations, in equal partnership with youth-led organisations or have YPLHIV in active and influencing positions at all levels of the work.

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The funders (ViiV Healthcare, Gilead Sciences and Janssen)

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Annex one: RECOMMENDATIONS

1. ADULT NETWORKS/CIVIL SOCIETY RECOMMENDATIONS

These recommendations are set out in order of priority

YAASP recommends that every organisation that host youth lead networks or have separate youth members/elected representatives should have a separate, autonomous budget or sub-budget that is managed by the young people to ensure transparency and build skills.

YAASP recommends that every organisation working with and supporting YPLHIV as activists and advocates should have a structured mentor programme with a set curriculum, specific aims and purpose and a regular, recorded review process.

YAASP recommends that every organisation working with and supporting YPLHIV as activists and advocates writes and implements a policy within one year that focuses on youth-centred publicity and events

YAASP recommends that every adult network or civil society organisation working with and supporting YPLHIV as activists and advocates has a youth wing or youth representation at the top level.

2. FUNDERS RECOMMENDATIONS

These recommendations are set out in order of priority

YAASP recommends that there needs to be a separate 'youth fund' specifically to support youth-led organisations, projects and researchers, implemented by young people for young people.

Successful grants given through this 'youth fund' offer additional support to develop young people's technical skills through training and mentoring.

YAASP recommends that there is specific technical assistance and skills development offered by funders to youth-led organisations on grant writing and developing and implementing monitoring and evaluation

YAASP recommends that all budgets submitted by organisations, which include engaging YPLHIV in advocacy, must include some form of payment (wage, stipend, per diem etc) for those young people involved.

YAASP recommends that on youth programme funding streams, there are a minimum of two young people acting as key decision makers on funding boards.

YAASP recommends that there is secured funding for capacity building and training for young people and that this training is accredited and proven to be effective.

3. SERVICE PROVIDERS AND IMPLEMENTING ORGANISATIONS RECOMMENDATIONS

These recommendations are set out in order of priority

YAASP recommends that by 2019 comprehensive and ethical youth engagement policies and guidelines be developed on the public and private engagement of YPLHIV who are activists and advocates.

This should include:

- YPLHIV as partners at all levels, from policy development through to service development and delivery.
- The role of YPLHIV in research and their representation at all levels, from the development of trials and research about YPLHIV, through to the research itself and its dissemination
- The knowledge development of YPLHIV who are advocates and activists, building their skills in multiple areas, including monitoring and evaluating.

YAASP recommends that more youth-focused HIV services and programmes that include counselling, treatment and prevention should be developed, but these need to be youth driven and include a transparent review process to ensure they are meeting the needs of youth

YAASP recommends that a counselling, treatment and prevention guideline and manual should be developed with 25% of the development team being YPLHIV, and which includes indicators that can be annually reviewed.

YAASP recommends that organisations working with YPLHIV have a minimum of 10% of their boards/committees be young people.

YAASP recommends that organisations working with YPLHIV ensure they have YPLHIV as part of monitoring and evaluation teams, to ensure transparency and develop skills.

YAASP recommends that all research relating to children and young people living with HIV should include a pre and post research/trial briefing written with young people for young people.

4. UN, Bilateral & Government RECOMMENDATIONS

These recommendations are set out in order of priority

YAASP recommends that governments should develop guidelines on youth leadership and advocacy

YAASP recommends that 25%* of those involved in high level meetings about children and young people living with HIV are young people themselves

YAASP recommends that when national and global consultations are run with YPLHIV, those consulted are given youth-friendly feedback before reports are released, detailing the learning from the consultation and how it will shape future work

YAASP recommends that Technical Working Groups (TWGs) about children and young people living with HIV need to have 25%* of those present being YPLHIV, which includes having decision making positions. YPLHIV should be supported and trained to engage within these group to ensure that YPLHIV can fully participate and understand the necessary structures.

YAASP recommends that governments should develop tools and outcome indicators to measure YPLHIV involvement which are reviewed annually.

YAASP recommends that YPLHIV are always provided with a minimum of a stipend to cover all their costs (from door to door) including the 1st and last mile of the journey to ensure they are not out of pocket.

YAASP recommends that governments and bilateral organisations provide disaggregated programmatic data for adolescents and young people living with HIV make this accessible to youth organisations.

YAASP recommends that there are allocated, fixed resources for youth organisations at country and global levels.

YAASP recommends that there are ring-fenced budgets set aside that covers YPLHIV costs.

YAASP recommends that governments have specific time and staff to support YPLHIV who are advocates and activists and offer mentorship to develop their skills at this level of decision making.

YAASP recommends that there is equal access to opportunities for all YPLHIV who are involved in activism and advocacy to ensure all experiences and varied views are included at this level

** These youth representatives are chosen either through a democratic process or through application to ensure opportunity for all and that they are representative of their community.*

5. YOUTH ORGANISATIONS RECOMMENDATIONS

These recommendations are set out in order of priority:

YAASP recommends that youth networks have publicly available, clear policies/documentation that outlines roles, responsibilities, and terms of reference of boards/steering committee members.

YAASP recommends that youth organisations create diverse, accessible opportunities for young people to become involved as volunteers, paid staff and at the management and board level.

YAASP recommends that youth organisations establish clear mentorship structures within organisations to support/raise-up young leaders, that include targets set by the young person and a transparent review process.

YAASP recommends that youth organisations have a document/policy that outlines how youth representatives are engaged in advocacy meetings and global opportunities:

- Opportunities are shared
- How young people are selected when opportunities arise
- How young people are engaged and given the opportunity to provide feedback
- How this feedback is shared within an organisation, with the young people and where appropriate, to the public.