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# Nothing About Us Without RIGHTS—Meaningful Engagement of Children and Youth: From Research Prioritization to Clinical Trials, Implementation Science, and Policy

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**Abstract:** This article presents a new agenda for the meaningful engagement of youth in guiding research and policy. It has been codeveloped with youth, adolescents, and children who are living with and affected by HIV. We set out 6 basic requirements (we call them RIGHTS) that hold across clinical trials, observational studies, implementation science, service delivery, and policy development. These requirements are based on a literature review and in-depth consultations with children, adolescents, and youth, which have taken place over a decade in the HIV/AIDS epidemic. Youth engagement must be adequately Resourced with time, training, technical support, and funds. It must be Impactful, with youth informed of how their inputs have been directly used in research, policy, and programming. It must be Genuine, with youth understanding the intentions of the project and choosing to take part. It is essential that we ensure that participation is Harmless, and that it is responsive to the emotional and mental health needs of youth. Processes of participation should be Teen friendly, designed to be enjoyable and relevant to youth priorities. Finally, regarding Skills building, participation should allow for the competencies and skills developed to be recognized in youth education and career experience (without advertising the HIV aspect if this is inappropriate for young people). We propose that these 6 basic requirements be endorsed by all research organizations, and that they become a core component of research in the HIV response.

**Key Words:** youth, HIV, adolescents, meaningful engagement, human rights, treatment, global, young people

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## INTRODUCTION

The fight against HIV has been groundbreaking in bringing together advocacy, research, and civil society with a set of common goals. This unique alliance has accelerated progress from evidence to policy, with treatment development and access as a primary example, but children, adolescents, and youth still lag behind in the HIV/AIDS response.<sup>1</sup> We are failing to reach targets on the treatment cascade—only 43% of HIV-infected children and 36% of adolescents have access to antiretroviral therapy (ART).<sup>2</sup> Adolescents are the age group with the lowest ART adherence.<sup>3</sup> AIDS remains the leading cause of death among adolescents in Africa.<sup>4</sup> Eastern Europe has seen a 21% increase in HIV infections among adolescents since 2010.<sup>5</sup> According to the report of the Commission on AIDS in Asia, nearly all new HIV infections (95%) among young people in Asia occur in key populations.

For children, adolescents, and youth in the epidemic, there remains an urgent need for a unified response. Although HIV-affected adults have increasingly become involved with research, service delivery, and policy making, in particular through required community advisory boards or steering groups, there is a major lag in such participation of children, adolescents, and youth. The maxim, “nothing about us without us,” does not yet apply to the age groups most affected by the epidemic.

There are a range of barriers to participation—in particular for adolescents and youth from key populations. These include: the complexities of consent procedures that are often located in disconnected legal and policy frameworks of broader consent; researchers being deterred from including adolescents younger than 18 years because of concerns about institutional review board requirements; and researchers, service providers, and policy makers being uncomfortable with methods that are youth-friendly rather than adult-focused. Such challenges are often exacerbated for young people who are particularly vulnerable or whose behavior is stigmatized or criminalized.<sup>6</sup>

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Where youth participation happens, it can have major and positive impacts for research, programming, and policy, and for young people themselves. Adolescents and youth have clearly articulated their desire to be involved in the science and decision-making that affect the HIV/AIDS response.<sup>7</sup> This article sets an agenda for meaningful and equitable participation for young people, with a focus on engagement in research and policy making. We aim to establish a set of minimum requirements for all studies, from qualitative work to clinical trials, and from the stages of research prioritization to impact on policy.

## METHODS

The conclusions of this article are based on literature review and in-depth consultations with children, adolescents, and youth over a decade in the HIV/AIDS epidemic. We use inputs from 4 initiatives in which children, adolescents, and youth have discussed their participation in research. These initiatives are based in Africa (the Teen Advisory Group and the Global Network of Young People Living with HIV—Y+) and globally (the Adolescent Treatment Coalition). We do not report on this as a preplanned research exercise or consultation, although these are of enormous value. Instead, these are the contributions and inputs of vulnerable young people, which have been shared over a period of many years, and through the process of building understanding of advocacy, involvement in research, and trust with the authors of this article. These young people were not random population samples or representative of particular countries. However, their views and experiences provide an unprecedented opportunity for a research field that is led by adults to gain insights into the needs and values of the youth we seek to engage.

Oxford University and the University of Cape Town established the Teen Advisory Group in 2008. The study by Mzantsi Wakho has advised a series of Southern African studies, including a longitudinal survey of adolescents affected by parental HIV,<sup>8</sup> randomized trials,<sup>9</sup> and a cohort of adolescents living with HIV (ALHIV).<sup>10</sup> Every year, 20–30 adolescents, youth and their younger siblings, and children attend a weekend camp. These include a range of sports, games, and fun activities to engage with planning, enacting, and disseminating the results of research studies.

The Teen Advisory Group has codesigned research questions, questionnaires, and researcher training programs. It has been engaged in the sharing of findings with policy makers, including writing letters to the Deputy Director-General of the South African National Department of Health, Yogan Pillay, who responded to each letter individually and sent 2 senior officials to the next camp weekend to participate directly. Group members also spoke at the UNAIDS Planning Coordination Board in 2015. The Teen Advisory Group has had major impacts on policy, including cowriting the South African National Adolescent and Youth Health Policy,<sup>11</sup> and inclusion in UNAIDS and UNICEF guidelines for social protection, care, and support.<sup>12,13</sup>

In 2014, the Global Network of People Living with HIV and Y+ held a series of workshops in 4 African countries

with 84 participants. At the same time, an online survey was disseminated in 5 languages across both organizations' global networks. A total of 386 respondents completed the survey; a total of 117 respondents from 30 countries were eligible for inclusion. The workshops and survey focused on understanding adolescents' everyday lives on antiretrovirals (ARVs), challenges and benefits of ART, missing and stopping ART, information and support for adherence, and services. The data from the workshops and survey were analyzed using qualitative content analysis. Participants emphasized that, despite knowing the benefits of ART, they still faced treatment challenges in adhering to treatment; the major challenge was including ARVs in daily activities. In all, 84% of survey participants reported missing ARVs at least once.

Suggestions for improving ARV services for adolescents included changing provider attitudes, supporting youth-led interventions, and finding ways to allow adolescents to live their everyday lives uninterrupted by their medication. A key to improving conditions is maximizing opportunities to enhance youth participation in the design and implementation of programs that affect their lives.

The Adolescent HIV Treatment Coalition (ATC), hosted by the International AIDS Society, is a diverse network that advocates for accessible quality HIV treatment and care for ALHIV. The ATC comprised a diverse group of stakeholders, including global and regional networks of people living with HIV, international and national nongovernmental organizations, community-based organizations, researchers, research cohorts, treatment advocacy organizations, and young people living with HIV (YPLHIV).

As part of the coalition's efforts to increase adolescent and youth participation through the HIV response, the ATC created the Intergenerational Summit (IS) for Positive Youth Leadership. The IS is aimed at fostering a dialogue among HIV-positive youth leaders and other stakeholders in the HIV response to understand the status of the global regional and national spaces that impact and engage YPLHIV and leverage solidarity and action to improve the engagement and development of ALHIV and YPLHIV networks across the world.

Discussions about the engagement of young people in the HIV response have taken place for quite some time. However, the space to understand how youth-led networks and organizations operate, as well as to see firsthand the challenges that YPLHIV face in mobilizing enough resources to sustain their organizations, was absent. As a response, the IS brought together 23 global, regional, and national networks to discuss governance, human resources, financial management, transition, and program development within the existing spaces led by young people themselves. As a result, some key aspects were highlighted that are crucial to responsibly and meaningfully engage YPLHIV.

Understanding how practices of engagement affect the livelihood of young people, particularly those living with HIV and/or those from key populations, is crucial. Tokenism, as well as exploiting emerging leaders, can result in burnout and an overall sensation of fatigue. Because a large number of youth are engaged with the response on a voluntary basis, it is crucial to ensure that their engagement is responsible, and that their contributions are remunerated and accounted for. Also,

managing expectations from funders and other partners about how they envision youth-led spaces and networks and about the importance of mentoring and supporting leaders as they go through the youth HIV response has resulted in important discussions through the IS. Equipping young people with the tools to enable them to respond to the demanding environment of funders, grants, proposal, and organization development is vital to have sustainable youth organizations.

## RESULTS

Using the lessons that have arisen from the activities described, adolescents, youth, and children have identified 6 basic requirements—or RIGHTS—for their meaningful participation in research, from prioritization to clinical trials, implementation science, and policy. These requirements are universal principles that should be applied to improve the quality of adolescents' and young people's engagement in research both as participants themselves and as advisors within the research process. In short, participation is essential, and should be Resourced, Impactful, Genuine, Harmless, Teen friendly, and Skills building (RIGHTS).

### Resourced

If the potential of adolescents and youth participation in research is to be maximized, it will have to be always adequately supported. We cannot presume that we can rely on enthusiasm alone to ensure sustained and effective participation. This includes allowing sufficient time for young people to engage at their own pace, and training and technical support for unfamiliar activities such as public speaking. It is also essential to recognize that adolescent and youth affected by HIV are often also deeply affected by poverty. Youth should be adequately compensated for their contributions—eg, with transport money and refreshments—as a part of the ethical principles of conducting research. For many youth, the per diems they receive for attending conferences or meetings are their only form of income. Because many young people engage in the response to HIV as volunteers to impact their peers and effect change, failing to recognize the importance of supporting adolescents and young people in their livelihoods should be a priority in order for responsible engagement to take place. In many instances, youth are not adequately compensated for their participation and instead their participation is seen as good will. Therefore, understanding the needs of the youth engaged, as well as compensating them for their time and commitment, is important. Compensation does not always mean using financial resources; creativity and understanding the needs of young people can help develop other types of compensation that might ultimately be better for young people themselves. We cannot continue expecting young people to always volunteer their time; by doing so, we might be negatively affecting their development.

### Impactful

If adolescents and youth are to engage in the research process, it is essential that their inputs are not decorative, but

are directly used in the development of recommendations, policy, and programming or are presented in policy decision spaces. Furthermore, many young people have no idea of what happens to their contributions. Children, adolescents, and youth should be given information—presented in a way that they can understand and in their language of choice<sup>14</sup>—so that they know how their inputs have been used and taken up. A commitment to communicating with young people throughout the research process is vital to make this effective. Too often, researchers' dissemination strategies fail to include young people themselves, and researchers then miss out on engaging them as users and influencers of research findings, intervention uptake, and policy impact.

### Genuine

Guidelines on participatory involvement emphasize that child, adolescent, and youth engagement must be meaningful and informed.<sup>15</sup> Young people in the HIV/AIDS response take this a step further to demand that they have leadership roles. Young people need to understand the intentions of the project and choose whether they need to take part.<sup>16</sup> They need to know who made decisions about their involvement, and they must have a core role in decision-making. The International AIDS Alliance guidelines suggest describing clear roles and responsibilities for young people and partners in a written agreement for working together.<sup>14</sup>

### Harmless

As with our research studies, participation must have an overriding principle of “do no harm.” It is important to consider potential causes of harm that may be unique to young people's engagement and may exist despite best intentions. For example, ATC members explained that they would miss school or education to prioritize their advocacy work. We cannot expect young people to attend meetings without recognizing their need for livelihoods, education, and careers. In the end, many young people have had to drop out of their advocacy work due to burnout or not being able to sustain themselves because the work is not remunerated. Allocating resources within research proposals that go beyond providing refreshments to actually investing in the development of the young people engaged is a step toward equity and responsible engagement. Another particularly important consideration for children, adolescents, and youth affected by HIV is hidden mental health distress associated with their daily lives and the potential for further emotional stress from engagement. This is a complex and ongoing challenge—and raises issues of our responsibility toward our civil society partners in the wider fight against HIV/AIDS. A step further than “do no harm” is to consider the possibilities for providing additional support for our young participants. This includes recognizing and investing in support for youth champions, who may be both positively and negatively affected by the responsibility they take on to advocate for their peers.

## Teen Friendly

Children, adolescents, and youth engage in different ways to adults, and this may be particularly true for the most vulnerable. For example, in the formal context of a focus group, young people may be largely silent, intimidated by the direct questions and public nature of responses. The Teen Advisory Group in South Africa has codeveloped activities that help members feel comfortable in sharing their wishes, views, and suggestions. The group also highlights the importance of members understanding what they are contributing to, as well as the relevance of fun (not usually a first priority in HIV research). Games and activities—such as a teen-run parliament—can be a way to make engagement relevant and enjoyable for young people. It is imperative to evaluate how the settings where research takes place and the appropriateness of methods and/or activities affect the involvement of young people. Being teen friendly goes beyond having colorful spaces; it means that we need to deepen the linkage between our work and teens' daily lives.

## Skills Building

Youth participants are also young people who are at the beginning of building their education and careers. Unlike the researchers working with them, many will not want to focus their careers around HIV. Youth participation processes should conceptualize ways to find and use opportunities to ensure that the competencies and skills that they develop can be recognized in their education and career experience.<sup>17</sup> Part of ensuring that the needs of young participants are met is facilitating the recognition of what they are doing outside the HIV research field. This may require finding innovative ways to do this without advertising the HIV element if this is inappropriate or unhelpful for youth.

## DISCUSSION

There are increasing examples of participation of HIV-positive youth in research that has been instrumental in policy recommendations and programming. The research prioritization process described in this special issue engaged with the engagement with the ATC. As part of the working group for the prioritization process, the ATC supported the dissemination of the research questions and solicited feedback from young people at the IS. Furthermore, the ATC is looking to develop a youth-friendly version of the agendas that can be used by young advocates worldwide.

Apart from the ATC, Link Up was established in 2013 as a 5-country initiative to improve sexual and reproductive health of young people affected by HIV aged 10–24 years. The Global Youth Coalition on HIV/AIDS and ATHENA network led a consultation of 800 young people in a global online survey and of 400 young people in a series of community dialogues and focus groups in Bangladesh, Burundi, Ethiopia, Myanmar, and Uganda.<sup>7</sup> Follow-up participatory exercises with young people living with and most affected by HIV (including key populations) provided input on pre-exposure prophylaxis, self-testing, and HIV treatment and care.<sup>18</sup>

Youth Rise and UNAIDS conducted a series of community consultations in 14 countries focused on adolescents who inject drugs.<sup>19</sup> In the Breather study, a recent clinical trial of treatment breaks for HIV-positive adolescents, adolescents codeveloped outcome measures.<sup>20</sup> The Youth Trials Board is a project with a related clinical trial, Odyssey, which is aimed at developing a model for young people to influence the governance, delivery, and dissemination of pediatric clinical trial research.

## CONCLUSIONS

This article sets out 6 basic requirements for youth participation in research. They have relevance across both low-income and high-income settings and may also be of value beyond the field of HIV. But, as with all advocacy messages, the needs of youth participants will remain unmet without high-level support. We call on institutional review boards and thought-leading organizations to demand the participation of children, adolescents, and youth in all research that is about them and to do so in a way that respects and promotes their RIGHTS.

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