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Youth participation in HIV and sexual and reproductive health decision-making, policies, programmes: perspectives from the field

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ABSTRACT

The purpose of this article was to present the current state of evidence and experience of youth participation approaches in HIV and sexual and reproductive health decision-making, policies and programmes. By combining a literature review of evaluation evidence with in-depth interviews and a global survey targeting young people with the experience of participation, this study opens a new window into the support needs for meaningful youth participation globally. Limited available evidence indicates that youth participation has positive effects on programme, self-efficacy and empowerment outcomes for the young people engaged in policies and programmes. Young people who have participated in decision-making reflected on improvements in outreach and representation of young members of key affected populations, but also expressed concerns about tokenism, age-based hierarchies and access for younger adolescents, women and marginalized groups. Overall, evidence indicates a need for further investments in capacity building, training, inclusive participation spaces and research on meaningful youth participation.

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KEYWORDS

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Introduction

In 2015, young people aged 15–24 years accounted for an estimated 35% of new HIV infections among adults 15+ years (UNAIDS HIV estimates, 2016). Older adolescents (ages 15–19) were the only age group among which AIDS-related deaths were not declining in 2015 (UNAIDS HIV estimates, 2016). While, young people are disproportionately vulnerable and affected by HIV, spaces for meaningful participation are limited. Some key affected populations (KAPs), such as young women, transgender young people, or young people who sell sex or use drugs, are still the minority in spaces reserved for young people in the global HIV response.

This study seeks to consolidate and understand evidence of the effectiveness of youth participation on HIV and sexual and reproductive health (SRH) decision-making, policies and programmes as well as the experience of youth participation globally, incorporating the voices of young people.

Background

In order to improve access to and quality of HIV and SRH information and services, there is a growing interest in ‘youth participation’ approaches particularly in the era of the Sustainable Development Goals. In particular, youth advocates and allies have engaged in international policy discussions in

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recent years to establish a need for and encourage investment in youth participation in development programmes and funding. Increasingly, initiatives recognize the need for youth engagement in policy design and delivery, and it is hypothesized that youth engagement will improve effectiveness of services, programmes and policies.

A systematic literature review found that, while research on the effect of youth participation on programmatic outcomes is scant, there is more evidence to suggest that youth participation has significant and positive outcomes for young people themselves. In Ashcraft's (2008) study, self-efficacy improved for peer leaders, while Fongkaew, Fongkaew, and Suchaxaya (2007) showed that a peer-designed and peer-led sexual health programme was effective in improving young leaders' ability to share SRH knowledge, and in promoting positive attitudes towards themselves. Pearlman, Cambert, Wallace, Symons, and Finison (2002) demonstrated a positive effect of a peer-design and peer-led education programme on both young people's knowledge and their self-efficacy. Of the hundreds of studies identified in the literature review, few involved young people in the design or conduct of the research. The literature review also demonstrated that youth participation was most effective when adults took an active role in providing the opportunities, assistance and guidance so that young people could develop their leadership capacity in an atmosphere of trust and respect.

The goal of this study is to better understand the quality of youth participation in HIV and SRH policy and programmes, including gaps, as perceived by young people.

Methodology

To explore the perceptions of youth participation, the study assessed the experienced quality and impact of young people's participation on a policy or decision-making body.¹ The study focused on: (1) in-depth interviews were conducted with young advocates who have participated or are currently participating in policy or decision-making bodies related to HIV and SRH and (2) a global survey reaching young people who identify as involved in HIV and SRH. This study offers an unprecedented window into young people's experience with the participation opportunities afforded by governments, civil society, and other actors in the HIV and SRH field. The study is exempt for approval by any Institutional Review Board.

In-depth interviews

UNAIDS Regional Youth Officers interviewed a total of 51 respondents between the ages of 18 and 29 who currently participate or have participated in HIV and SRH-related decision-making bodies at national level for at least one year. Interviews were conducted using a standardized interview format via phone or face-to-face; transcriptions were then synthesized and analysed using Survey Monkey.

Global survey

A total of 615 respondents, predominately young people or youth advocates, completed a global online survey to assess:

- Knowledge of and access to decision-making bodies and processes at the local, national, regional and global levels;
- The current perceived representation of young people and specifically young members of Key Affected Populations (KAPs) in decision-making bodies and processes; and²
- Young people's perception of the quality and impact of their participation in decision-making bodies and processes at all levels.

The survey was disseminated online via Survey Monkey in English, Spanish, French, Russian and Arabic. It was promoted using UNAIDS networks and partner organizations. Survey responses were analysed in Microsoft Excel for global trends in representation, perceived access and impact.

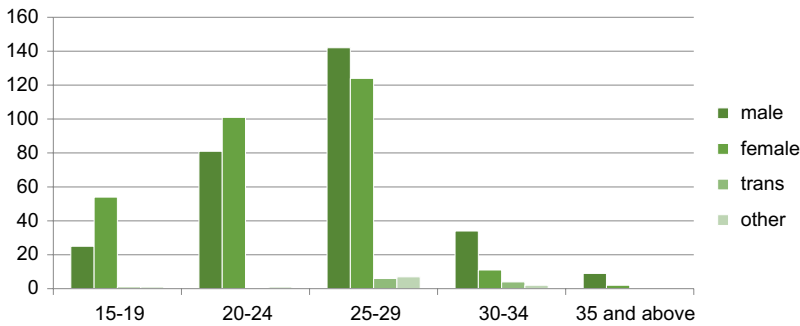


Figure 1. Global survey respondents by age and gender.

Findings

Demographics

Out of the 51 interviewees, 56.9% ($n = 29$) were male and 41.2% female ($n = 22$), 2% ($n = 1$) self-identified as 'other' and there were no respondents who identified as transgender or intersex. About 2% ($n = 1$) were between 18 and 20 years of age, 8% ($n = 4$) between 21 and 23, 40% ($n = 20$) between 24 and 26 and 52% ($n = 26$) between 27 and 29 years.

A total of 615 people participated in the online survey. Survey participants were given five options for gender self-identification: male, female, transgender, intersex, and other (Figure 1).

Survey respondents covered 102 countries. The average number of participants per country was 6; 29 countries only had one participant, while the maximum number of participants in a single country was 54. Eastern Europe and Central Asia (EECA) and Latin America and the Caribbean (LAC) had the greatest number of participants with 22% of global respondents each ($n = 137$ and $n = 135$, respectively), while East and Southern Africa (ESA) had 15% ($n = 93$), West and Central Africa (WCA) had 12% ($n = 71$), Asia and the Pacific (AP) had 11% ($n = 69$), the Middle East and Northern Africa (MENA) had 10% ($n = 64$), and 'Other', encompassing North American and Northern and Western European countries, had 7% of respondents.

For the in-depth interviews, UNAIDS offices recruited the participants in their respective regions. About 4% ($n = 2$) of responses were from participants in ESA, 16% ($n = 8$) from WCA, 20% ($n = 10$) from AP, 27% ($n = 14$) from LAC, 14% ($n = 7$) from MENA and 20% ($n = 10$) from EECA.

Representation among key affected populations

Among interviewees, 81.6% self-identify or work with any of the KAPs, 82% of male respondents and 80% female respondents. In ESA and AP, all interviewees represent or work with KAPs. This is slightly lower in MENA with 85.7%, and LAC and WCA, both with 71.4%. In EECA only 60% of interviewees self-identified or worked with key affected populations.

For the survey, 91.9% of respondents said that they worked with either a KAP or 'young people in general'. Of these, 63% ($n = 390$) worked with YPLWH, 38% with young gay men or MSM, 30% each with YPWUD and young people selling sex and 24% with young transgendered populations. Of those respondents to the global survey working with select KAPs, between 14 and 51% also self-identified as a member of that population (Table 1).

While, all of the interviewees ($n = 51$) were currently participating or had formerly participated in decision-making bodies or processes, only 20% ($n = 121$) of survey respondents had formerly participated or were currently doing so. Survey respondents who were participating were 54% male, 42% female and 2% trans, and 79% of participants were between the ages of 20 and 29 (49% 25–29, 30% 20–24).

Table 1. Percentage of respondents working with a key population whom self-identify with the same key population.

Key pop	Global (%)	ESA (%)	WCA (%)	AP (%)	EECA (%)	LAC (%)	MENA (%)	Other (%)
YPWUD	27	50	33	36	15	18	33	33
CSWs	19	21	45	28	0	12	27	16
MSM	51	50	63	60	53	53	47	23
Transgender	14	27	20	22	14	6	14	12
YPLWHA	37	57	45	29	29	36	28	27

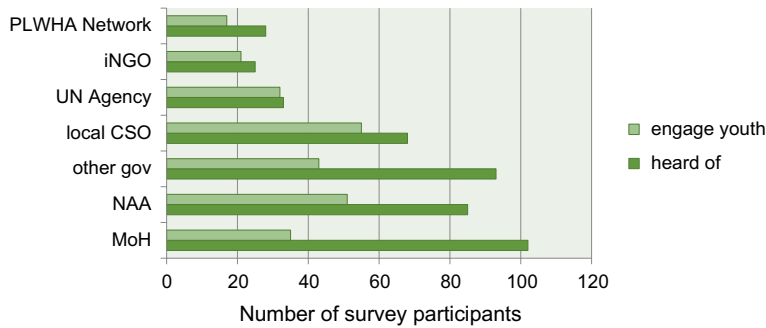


Figure 2. Knowledge of youth engagement on decision-making bodies/processes at national level.

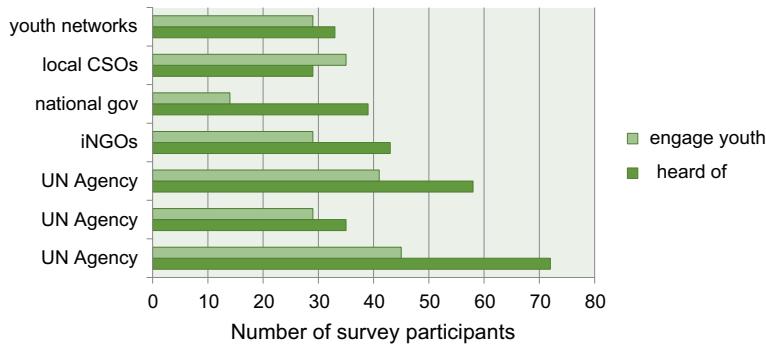


Figure 3. Knowledge of youth engagement on decision-making bodies/processes at global level.

Note. United Nations Agency is defined as UN technical agency, joint programmes, funds, global Member State-decision making spaces.

Knowledge of decision-making bodies and processes

Survey participants were asked to name decision-making bodies or processes related to HIV and SRH at the national (Figure 2) and global levels (Figure 3), and, of those, identify which involved the participation of young people.

Survey respondents were also asked which KAPs, in their experience, were represented in HIV and SRH decision-making processes at the national, regional and global levels, which was compared to the KAP self-identification of those respondents who reported that they were participating in decision-making (Figure 4).

Access to institutional decision-making

Among the 41.2% ($n = 21$) of interviewees who indicated occupying a 'leadership position', 25% ($n = 1$) were between 21 and 23 years old; 50% ($n = 10$) were 24–26 years old and 25% were 27–29 years old. About 37% ($n = 19$) of interviewees had spent 1–2 years and 2–4 years, respectively, and 28% ($n = 14$) had spent five or more years in leadership positions (Figure 4).

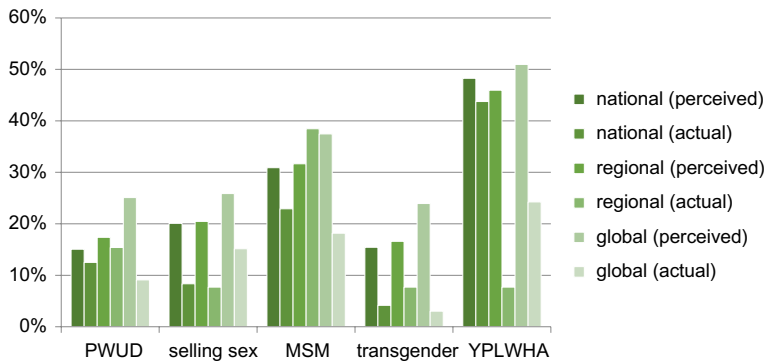


Figure 4. Young KAPs' engagement on decision-making bodies/processes, perceived and actual.

Of the 121 survey respondents who were currently or had previously taken part in decision-making bodies or processes ($n = 22$) had been engaged for fewer than 6 months, 10% ($n = 11$) for between 6 and 12 months, 27% ($n = 29$) for 1 year, none for 2 years, 26% ($n = 28$) for 3 years, 6% ($n = 6$) for 4 years, 3% ($n = 3$) for 5 years and 9% ($n = 10$) for more than 5 years. The bulk of respondents who identified as participants (71%) were active at the national level, 10% at the regional level and 19% at the global level. About 60% of participants at national level ($n = 42$) were male compared to 41% female ($n = 29$), while the gender split at the global level was 47% ($n = 9$) male and 53% ($n = 10$) female. About 98% of respondents currently or having previously taken part in decision-making were self-identified with one or more of the KAPs.

Perceived quality and effect of participation

Interviewees and survey respondents had positive responses when asked about the quality of their participation in decision-making. 54.9% of interviewees rated their participation 'good' ($n = 28$), 27.5% 'excellent' ($n = 14$), 15.7% 'below average' ($n = 8$) and only 2% rated it as 'poor' ($n = 1$). About 89% of interviewees believe their leadership has had a lasting impact (three or more years). Furthermore, the great majority of respondents (98%) believe that youth engagement empowers young people within their own communities. In addition, young people have expressed that it allows them to have a voice in matters that affect their lives; therefore, issues that affect young people are more represented and expressed genuinely by young people themselves.

Survey participants overall graded the meaningfulness of their role quite highly: 47% ($n = 51$) responded 'very meaningful', 32% ($n = 35$) 'fairly meaningful', and 18% ($n = 20$) 'neutral', while only 3% ($n = 3$) marked their role 'not very meaningful' and none marked 'not at all meaningful'. Respondents followed a similar trend in grading their ability to influence the process: 27% ($n = 29$) marked 'very good', 49% ($n = 53$) 'fairly good', 21% ($n = 23$) 'neutral', and only 2% ($n = 2$) each 'not very good' or 'not good at all'.

Survey responses from young people who answered yes when asked if they were currently participating or had previously participated were markedly more positive from the overall survey respondents': overall respondents expressed a generally negative view of current participation, with 48% ($n = 111$) reporting spaces were 'slightly good' and 18% ($n = 46$) 'not at all good', with 22% ($n = 58$) 'moderately good' and only 9% ($n = 24$) and 8% ($n = 20$) responding 'extremely good' and 'very good', respectively. When asked to explain their ranking, many respondents who responded 'slightly good' or 'not at all good' reflected issues related to age discrimination, tokenism or failed spaces for participation, as reflected in the quotes from narrative survey responses below:

Youth are not engaged particularly in the AIDS councils in the national and local levels. Other instruments for youth engagements were discontinued. Even the young people's council is at a limbo whether or not the country would continue with its implementation.

There is no representation for young people themselves. There are those who sit and speak on their behalf, most of the time.

While there is evidence of effort to allow young people space to actively participate and get involved in the HIV response, in some cases we are invited partially or at the end of a process that has already been carried out for example to validate a plan which is not likely going to be changed even after young people make their contribution and this becomes empty participation.

Areas for further support

Many respondents mentioned that, while spaces for participation were opening up and that governments and organizations were putting more effort into engaging young people, those spaces were only open to young people from privileged socioeconomic status, or who already have more access to education and other opportunities. Others said they were only informed or consulted and not actually allowed to make decisions, or that the young people who were participating weren't heard or given any authority.

Because we start wanting to involve young people; that previously did not exist! But we are still at the beginning.

In my personal experience these platforms are simply tokenistic engagements. Youth participation needs to be translated as meaningful youth participation which gives young people the same rights/privileges as other members on that board, being a mere observer/participant would not empower youth.

When asked for ways to increase meaningful youth participation, interviewees mentioned more spaces for young people to engage (31%), more consultation (23%), more support and training (15% each). About 35% of survey respondents wanted more economic/financial support, 26% wanted help in opening new and more spaces for youth participation, 17% wanted peer mentorship and 11% more training/information before engaging with a decision-making body or process.

Discussion

Representation

Findings from both the interviews and the survey reflected common assumptions about participation in decision-making spaces related to HIV and SRHR: young men have more opportunity than young women, spaces for participation are more accessible to young people in their mid- to late twenties than younger advocates, and participation spaces are more accessible for YPLWH and young gay men or MSM in some contexts. Because this study was promoted and conducted primarily through UNAIDS networks, more respondents were engaging in decision-making related to HIV than SRHR, and this imbalance towards YPLWH and young gay men and MSM is reflective of the HIV field as a whole. Young people who identified or worked directly with one or more of the KAPs were the majority of those currently participating in decision-making in both the global survey and the in-depth interviews, a trend which shows investment in creating representative spaces.

Access to participation

Young people's knowledge of decision-making bodies and processes was varied and comprehensive. Respondents thought that UN agencies and civil society organizations were attempting to engage young people in decision-making, and that many were making a concerted effort to engage young people from KAPs. However, a significant number of respondents felt that access was still restricted to adults, to young people 'in general' and not necessarily those representing KAPs, or to professionalized advocates and NGO workers from all age groups.

Participation quality

Based on interview and survey responses, age, gender and the length of time on a decision-making body may play a role in perceived quality of participation. A common theme expressed by the interviewees was that young people feel some impact from their participation, although the effect is not lasting (no more than a year). Participants expressed that they feel more can be done to better equip them and their peers to engage global HIV and SRHR decision-making bodies.

Spaces for participation are not neutral, people will feel more free to participate in spaces where they feel empowered to define and shape the space of participation.

Survey respondents held varying views about the quality of young people's participation depending on their own level of access. Respondents who were currently or had previously participated in a decision-making body or process were more inclined to positively rate both the quality and the impact of their own participation. Survey respondents as a whole were more pessimistic about the quality of these spaces, regardless of whether or not they have participated. This may be indicative of a larger issue – young people who have been able to make it past the participation barrier are having positive experiences, but young people as a whole aren't seeing a vast improvement in access to participation as a result.

Additional support needed

Some ways young people identified that they can be supported on decision-making bodies include more consultations with youth constituencies (outside of the decision-making bodies) and generally more spaces for young people to engage outside of the formalized setting. Survey participants and several interviewees also called for greater financial support and investment in empowerment tools and mechanisms to improve the quality of youth participation, including capacity building training.

Interviewees also suggested creating quotas or a mandate for youth participation. Notably, some respondents suggested increasing the level of influence young people have by enlisting leadership of decision-making bodies to make changes to overcome age-biased internal decision-making mechanisms, or to promote the need to create neutral spaces for youth participation.

In addition, more attention could be paid to equitable access to opportunities with fair and transparent selection processes. According to survey respondents, spaces available for participation, particularly at the global level, remain limited in quantity and scope and are more frequently occupied by older youth (aged 25–29) and to male-identified young people. Adolescents (ages 10–19) are rarely, if at all engaged.

Limitations and biases

Both the interviews and the survey were susceptible to selection bias. Because the survey was only available online, there was also bias towards those with regular access to the internet and those with stronger written literacy skills. Some participants in the global survey indicated trouble with understanding the translated questions, which may have led to unclear or incomplete responses. In addition, while a vast range of countries are represented in survey responses, many countries have five or fewer responses, and some regions are heavily weighted to a few countries with more responses.

Conclusion

Given the limited evidence available on the effects of youth engagement on policy processes, significant investments in research and evaluation are needed to ensure adequate evidence to identify gaps, recommendations and measure the impact of meaningful youth participation. Stronger investment in M&E of existing programmes and efforts as well as new research by and with young people themselves can establish best practices.

Increased research is needed on the effects of youth participation at every level in order to better understand the linkages between youth participation, outcomes related to empowerment and self-efficacy, programme and policy outcomes and public health indicators. Available evidence points towards potentially positive outcomes for youth engagement, on young people's empowerment and self-efficacy. In order to be effective, though, these investments need to clearly consider both the sustainability of spaces for youth participation in policy, programmes and decision-making, and increased training and capacity building not only for young people but also for adult members of policy and decision-making bodies.

More work is needed on cross-generational dialogues and approaches to meaningful participation, both to improve the spaces available to young people in policy and decision-making, and to ensure that participation mechanisms are better able to take on young people's contributions and benefit from their expertise. Investments in capacity-building for youth participation cannot be solely targeted at young people but must also engage adult decision-makers and senior staff. In addition, further support is needed for young people who participate in decision-making bodies and processes to better network with and engage other young people in their communities, to improve communications mechanisms for increased representation, and to report back and facilitate ongoing consultations. Investment in supporting youth to better engage their peers and youth networks could help relieve some of the disparities among communities of young people who participate more in decision-making bodies, as well as improving the quality of representation within existing mechanisms and access to information regarding decision-making processes.

Investments in outreach to young members of KAPs must be sustained and scaled up to ensure access for all young people, including the most marginalized, at all levels of decision-making. More attention should be paid to outreach to adolescents and to young women and girls to maintain gender and age parity among those with access to decision-making at all levels.

Authors' contribution

Tyler Spencer, Adriana Hewson, Aram Barra, Paska Kinuthia, Rupa Bhadra, Felix Mugumya, Aries Valeriano, Elena Kiryushina and Alicia Sanchez.

Notes

1. A policy or decision-making body is defined as an entity having power of decision which influences policies or programs related to SRH or HIV at the local, national, regional, or global level. A policy or decision-making process is defined as the process of making important decisions on policies and programmes related to SRH or HIV at the local, national, regional or global level.
2. UNAIDS considers gay men and other men who have sex with men, sex workers and their clients, transgender people, people who inject drugs and prisoners and other incarcerated people as the main key population groups. These populations often suffer from punitive laws or stigmatizing policies, and they are among the most likely to be exposed to HIV. Their engagement is critical to a successful HIV response everywhere – they are key to the epidemic and key to the response. Countries should define the specific populations that are key to their epidemic and response based on the epidemiological and social context (UNAIDS HIV estimates, 2016).

Disclosure statement

No potential conflict of interest was reported by the authors.

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Meheret O. Melles is a consultant for the Partnership for Maternal, Newborn and Child Health, housed in the World Health Organisation. She holds a master's of Public Health with a specialisation in Health Policy and Project Management at EHESP French School of Public Health. She formerly served as UNAIDS Youth Programme Officer and Acting Youth Programme Coordinator, when this research was conducted. Her interests cover the spectrum of sexual, reproductive, maternal, newborn, child and adolescent health, including HIV/AIDS. Her work focuses on gender equality, community engagement, human rights and access to education and health for communities and particularly for young people, women and key affected populations. She has published and contributed to articles, guidance documents and tools on related issues with The British Medical Journal, Advocates for Youth, International Planned Parenthood Federation, UNFPA, UNAIDS and the World Health Organisation.

Chelsea L. Ricker is an independent consultant and a founding member of The Torchlight Collective. She holds an MA in Education, Health Promotion, and International Development from the Institute of Education in London. Her work focuses on international sexual and reproductive rights, youth organizing and advocacy, sexual and reproductive health services delivery, comprehensive sexuality education, sexual orientation and gender identity and expression, and gender equality. She has written guidance materials and toolkits for the International Planned Parenthood Federation, Amnesty International, Georgetown University's Institute for Reproductive Health, and the International Women's Health Coalition.

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