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Youth engagement in developing an implementation science research agenda on adolescent HIV testing and care linkages in sub-Saharan Africa

Julie A. Denison[a], Audrey Pettifor[b], Lynne M. Mofenson[c], Susan Kasedde[d], Rebecca Marcus[e], Katongo J. Konayuma[g], Katlego Koboto[g], Mmangaliso Luyanda Ngcobo[e], Nokuthula Ndleleni[e], Julie Pulerwitz[f] and Deanna Kerrigan[a]

Background: The importance of youth engagement in designing, implementing and evaluating programs has garnered more attention as international initiatives seek to address the HIV crisis among this population. Adolescents, however, are not often included in HIV implementation science research and have not had opportunities to contribute to the development of HIV-related research agendas. Project Supporting Operational AIDS Research (SOAR), a United States Agency for International Development-funded global operations research project, involved youth living with HIV in a meeting to develop a strategic implementation science research agenda to improve adolescent HIV care continuum outcomes, including HIV testing and counseling (HTC) and linkage to care.

Methods: Project SOAR convened a 2-day meeting of 50 experts, including four youth living with HIV. Participants examined the literature, developed research questions, and voted to prioritize these questions for the implementation science research agenda. This article presents the process of involving youth, how they shaped the course of discussions, and the resulting priority research gaps identified at the meeting.

Results: Youth participation influenced working group discussions and the development of the implementation science agenda. Research gaps identified included how to engage vulnerable adolescents, determining the role that stigma, peers, and self-testing have in shaping adolescent HTC behaviors, and examining the costs of different HTC and linkage to care strategies.

Conclusion: The meeting participants developed the research agenda to guide future implementation science research to improve HIV outcomes among adolescents in sub-Saharan Africa. This process highlighted the importance of youth in shaping implementation science research agendas and the need for greater youth engagement.

AIDS 2017, **31** (Suppl 3):S195–S201

Keywords: adolescent, HIV linkages to care, HIV seropositivity/diagnosis, HIV testing and counseling, sub-Saharan Africa

[a]Johns Hopkins Bloomberg School of Public Health, Baltimore, Maryland, [b]University of North Carolina Gillings School of Global Public Health, Chapel Hill, North Carolina, [c]Elizabeth Glaser Pediatric AIDS Foundation, Washington, District of Columbia, [d]United Nations Children's Fund, New York, New York, USA, [e]The Desmond Tutu HIV Centre, Institute of Infectious Disease and Molecular Medicine, University of Cape Town, Cape Town, South Africa, [f]The Population Council, Washington DC, and [g]Youth Advocate, Zambia and Youth Advocate, Botswana.

Correspondence to Julie A. Denison, PhD, Assistant Professor, Department of International Health, The Johns Hopkins Bloomberg School of Public Health, 615 N. Wolfe Street E5032, Baltimore, MD 21205, USA.

Tel: +1 443 287 2704; fax: +1 410 502 6733; e-mail: jdenison@jhu.edu
Received: 7 April 2017; accepted: 10 April 2017.

DOI:10.1097/QAD.0000000000001509

Introduction

Youth engagement is the involvement and leadership of adolescents and young adults in developing, implementing, and evaluating research and programs that impact their health and wellbeing [1–3]. The need to engage youth is particularly pressing for HIV prevention, care, and treatment in sub-Saharan Africa (SSA), where 23% of the population consists of adolescents [4]. SSA is also where 85% of the estimated 1.8 million of the world's adolescents living with HIV (ALHIV) live [5]. HIV-related deaths are declining in every age group except 10–19-year-olds, and AIDS is the leading cause of death among adolescents in SSA and among 10–14-year-olds globally [6].

Several initiatives have been formed to respond to the HIV crisis among adolescents including the 'All In' initiative led by the Joint United Nations Program on HIV/AIDS and the United Nations Children's Fund (UNICEF), with partners such as the President's Emergency Plan for AIDS Relief. As more attention and resources are focused on ALHIV, it is critical that a strategic implementation science research agenda parallels these efforts. It is equally important that such agendas are created and implemented in partnership with adolescents.

Implementation science studies rarely include adolescents as participants, especially those under 18-years of age. These studies are essential in addressing continuum of care outcomes among this population, including low levels of HIV testing and counseling (HTC) and linkage to care (LTC). Though HTC is the entry point to care and treatment, only an estimated 14% of women and 9% of men aged 15–19 years in SSA have undergone HTC and received their results in the previous 12 months [5]. Many countries have policies and laws restricting adolescent access to testing in clinic settings [7,8]. Of 90 countries with available data, 58 required parental consent for young people to access HTC [9]. These data highlight the unique legal, policy, and environmental challenges adolescents face in accessing HTC services. These challenges, together with issues of autonomy and vulnerability, have historically limited adolescent participation in HIV research as beneficiaries or as partners. Although there have been increasing efforts to engage communities in biomedical adolescent HIV research [10], less is known about the active inclusion and leadership of adolescents and young adults in developing youth-specific HIV research agendas.

To develop an implementation science research agenda addressing the care continuum outcomes among ALHIV in SSA, Project SOAR (Supporting Operational AIDS Research) prepared a background article and held a 2-day expert meeting in 2016. Project SOAR is a United States Agency for International Development (USAID)-supported global operations research project, implemented by a multipartner consortium of expert institutions. Youth living with HIV from SSA participated in this meeting to work with funders, researchers, and programers to strategize and recommend priority implementation science research questions. This article details youth participation in the agenda setting process, and the resulting implementation science research questions identified to improve adolescent outcomes across the care continuum, including the uptake of HTC and their subsequent LTC.

Two-day implementation science research agenda setting meeting

Project SOAR convened a 2-day implementation science research agenda setting meeting in February 2016. The main objective of this meeting was to reach consensus on a set of priority implementation science research questions to develop, evaluate, and scale up intervention models to improve HIV outcomes within each component of the care continuum among ALHIV. Participants included four youth living with HIV from southern Africa. Other participants represented US government agencies (Centers for Disease Control and Prevention, Health Resources and Services Administration, National Institutes of Health, and USAID), international agencies (UNICEF, WHO), nongovernmental organizations (Clinton Health Access Initiative, Elizabeth Glaser Pediatric AIDS Foundation, FHI360, Gates Foundation, John Snow, Population Council, Zambart), researchers from US universities (Baylor University, Columbia University, Indiana University, Johns Hopkins Bloomberg School of Public Health, University of North Carolina, University of Pennsylvania, Yale University), and international researchers (from Mozambique, South Africa, Uganda, Zambia, South Africa, Tanzania). The meeting started with young people sharing their experiences living with HIV, followed by a review of a background article and presentations from expert policy-makers, researchers, and programers. The remainder of the meeting centered on four working group discussions on the following topics: HIV testing and linking ALHIV to care; retaining ALHIV in HIV care; ALHIV adhering to antiretroviral therapy (ART) and achieving viral suppression, and ALHIV transitioning to adult care and HIV self-management.

The objectives of the working groups were to identify research questions for the group's care continuum topic and select six priority research questions. Working groups evaluated potential research questions based on their ability to inform the development, evaluation, or scale-up of an intervention along the care continuum, and their feasibility and regional and global relevance.

After working groups reported back to the larger meeting, every participant selected their three priority questions within each topic through a silent voting process. The meeting then concluded with a final youth panel in which the young participants shared their experiences in the working group meetings and their views on the selected priority research questions.

Identifying adolescents and youth

The planning team for the implementation science meeting determined early in the process that involvement of ALHIV from SSA was essential. The team also realized that minors would need to have chaperones to travel, providing logistical and financial challenges. In response, the group sought the engagement of older adolescents and youth from SSA who were 18–24 years of age, who could share their experiences living with HIV as adolescents, and would feel comfortable talking and participating in a meeting in the United States. The team first asked Project SOAR consortium partners to recommend youth to contact. One partner identified a young woman from Botswana who had previous experience participating in International AIDS meetings and was a peer educator for youth. Another partner identified a young woman from Zambia who had never attended an international meeting before but who had started youth groups for young people living with HIV in Lusaka. We then reached out to invited adult participants from SSA who identified two more young people from South Africa, one of whom was a peer navigator for fellow youth.

Meeting preparation

Three of the youth had never before traveled out of their home countries and needed to obtain their first passports. Two of the youth had never previously traveled by plane. The two youth from South Africa flew to Washington, District of Columbia, with another meeting participant who was a researcher and also happened to be one of their medical doctors. The other two participants traveled alone. None of the youth had participated in a research meeting before this event.

Prior to the 2-day implementation science meeting, the youth and members of the planning team spent a day together. The purpose of this premeeting included giving the youth time to get to know each other and the planning committee in an informal setting, reviewing the meeting objectives and familiarizing the youth with the public health and research terminology they would hear during the meeting, listening to what youth had prepared to discuss at the opening of the meeting, and listening to youths' questions and experiences traveling to the meeting. The youth also toured the monuments and mall in Washington, District of Columbia, providing them with further opportunities to socialize together. This premeeting created a supportive environment and a chance to build the youths' public speaking and participation skills and their knowledge regarding implementation science research.

Youth engagement

The youth attendees started the meeting by sharing key parts of their own stories that they deemed critical for understanding the needs of ALHIV, including how each had learned his or her own HIV status, and as adolescents, how they navigated HIV care, disclosure to others, stigma and school. The meeting then allocated a significant amount of time for a discussion among the youth with the adult researchers, funders, and implementers. Meeting participants used this time to ask a variety of questions of the youth, such as how they handle relationships and their transition into adulthood. One youth emphasized how their needs extended beyond achieving viral suppression to also include skill development for negotiating jobs and navigating relationships while living with HIV.

All four youth then selected to participate in the transitioning to adulthood working group for the 2 days and voted on the priority research questions across all working group topics. The meeting concluded with a youth panel in which the young people shared their views and experiences with the meeting and the research questions. The adult programers, researchers, and funders also used this time to ask follow-up questions of the youth participants, such as what transitioning to adult care and HIV self-management meant to them.

Implementation science questions

The working group on HTC and LTC discussed several themes highlighted by the youth at the start of the meeting, including the role of stigma on testing and coping with a positive result. This working group also discussed the need to evaluate the impact and cost of community, facility, and peer-based HTC approaches, how best to reach adolescents at greatest risk for testing HIV-positive and how to identify HIV-positive adolescents at risk of not LTC. Based on these discussions, the group developed six implementation science research questions to address HTC and LTC that were later voted on and prioritized by all meeting participants. The top two questions were about the effects and costs of both a stigma reduction intervention on HTC and LTC uptake, as well as a peer navigator model in improving LTC rates in the context of community-based or mobile testing programs. The third priority question was about identifying adolescents at risk of not linking to care and the effective strategies to address barriers they confront. Table 1 presents the prioritized implementation science questions for HTC/LTC as well as for the other care

Table 1. Implementation science research agenda: key questions to answer to improve HIV care continuum outcomes among adolescents living with HIV in sub-Saharan Africa.

HIV testing/linkages to care	Order based on number of votes
What are the effects and costs of a stigma reduction intervention on uptake of HIV testing and linkage to care among adolescents?	Tied for first
What is the effectiveness and costs of a peer navigator model in improving linkage to care rates in the context of a community-based or mobile testing program?	
How do you identify those ALHIV who are at high risk of not linking to care? (Phase 1) What strategies are effective in addressing barriers to linking to care? (Phase 2)	Second
Do adolescents who self-test, including members of key populations, get linked to care and if so, how?	Third
What are effective testing strategies and their costs in identifying ALHIV in low prevalence versus high prevalence contexts?	Fourth
How can an enabling environment be created that supports adolescents to test? What are best practices for consenting adolescents for HIV testing?	Fifth
What are the effective messages/tools/apps to get high-risk adolescents to test, and those testing positive, to link to care?	Sixth
Retention in HIV care	
Can providers' enhanced capacity to deliver adolescent services improve retention?	First
What peer intervention models are effective in improving retention?	Second
What is an appropriate differentiated care model for adolescents?	Third
What are the effects of test and start on retention?	Fourth
What is the effect of incentives (provider, client, and/or both) on retention?	Fifth
Adherence to ART	
How can we best identify adolescents in need of adherence interventions before treatment failure occurs?	First
What modalities of treatment simplification (regimen and delivery) can improve adherence among adolescents?	Second
What mental health interventions (targeting depression, anxiety, PTSD, and ADHD) in the context of adolescent HIV services can improve adherence?	Third
How can mHealth and social network interventions effectively support adherence in adolescents?	Fourth
Can essential components of treatment literacy training/assessment and autonomy development be effectively standardized using technological solutions?	Fifth
How do we scale up existing successful social support and resilience-enhancing models?	Sixth
Transitioning to self-management/adult care	
What are the key predictors of a successful transition for adolescents who are in HIV care?	First
What are existing models of delivery of care that facilitate transition for ALHIV?	Second
Can providers monitor adolescents on modified adult care schedules (e.g. that align with their educational/school schedules)?	Third
Can schools provide a platform to help young people transition to self-care? Are there existing models for strengthening school-based health services to support young people in transitioning?	Fourth
What are the comparative effects of the different transition models identified in question 2 on the outcomes below? HIV-related outcomes: viral suppression, adherence, transition and retention in adult care, and disclosure of HIV status to the adolescent. Non-HIV (wellbeing outcomes): quality of life, future orientation, life skills, autonomy, mental health, and economic stability	Fifth
Can we use mHealth technology to achieve a successful transition?	Sixth

ART, antiretroviral therapy; ADHD, attention deficit hyperactivity disorder; ALHIV, adolescents living with HIV; PTSD, post traumatic stress disorder.

continuum topics of retention to care, adherence to ART, and transition to adult care.

Discussion

Given the growing adolescent HIV epidemic, rigorous implementation science research has a clear role in moving the HTC and LTC field forward for adolescents, especially as countries adopt WHO HIV testing and universal treatment guidance [11]. The Project SOAR 2-day meeting provided a case study of the importance and challenges of engaging youth in setting an implementation science research agenda. Based on this process, we put forth the following lessons learned and key recommendations regarding youth engagement.

Youth engagement is valuable to both the research agenda setting process and youth capacity building

Throughout the meeting, the three young women and one young man kept the discussion focused on issues relevant to ALHIV and shaped the subsequent implementation science questions developed. For example, youth emphasized issues of stigma during the opening panel sessions by sharing salient challenges they confronted as children and then as ALHIV. This topic shaped discussions throughout the working group sessions in which each group independently discussed the

pervasiveness and types of HIV-related stigma, including internalized, experienced, affiliated, and perceived stigma [12–14]. Although research among adults relates concepts of self-identity and social integration to one's ability to manage HIV [15,16], less is known about the impact of stigma on adolescents who are still forming their identity as they transition into adulthood [17]. The HTC and LTC priority research question about stigma reduction interventions (Table 1) highlights the importance of stigma as a barrier to accessing HIV testing and treatment. This issue illustrates the need to understand the community, family, and school context within which adolescents manage HIV-related information, services, and behaviors.

The youth also reminded the researchers, policy-makers, and donors that public health terminology, often viewed as well defined, may have different meanings to adolescents, and that to engage youth in the development of an implementation science research agenda, researchers need to communicate in a manner accessible to young people. Over the intense 2-day experience, researchers and youth were able to develop collaborative relationships that fostered understanding through opportunities for listening, questions, and feedback.

The meeting also presented the first opportunity for these youth to actively engage in setting a research agenda about the issues they identified as important. One young woman emphasized how 'meetings about adolescents are usually held without adolescent participation', and that the meeting gave her 'the opportunity to be heard by others from around the world'. Another youth attendee reported that participating in the meeting made her 'feel important, smart, and even proud to be representing South African adolescents'. She went on to emphasize how important it was to feel listened to and not judged, particularly when surrounded by 'big people like doctors and psychologists who work in the HIV field'. After the Project SOAR meeting, two of the young people facilitated and spoke at the 2016 International AIDS Conference satellite session 'Adolescent HIV Care and Treatment: From Dialogue to Action' held in Durban South Africa. When describing how she was able to talk in front of a large audience, one young woman described how the 'meeting in Washington really gave me confidence in public speaking, and the courage to talk to fellow youth in my situation', providing further evidence of capacity building and enhanced self-esteem resulting from youth participation. She went on to say that she used her trip to Washington, District of Columbia, to encourage girls and young women in Zambia that their voices matter and that they should 'stand to fight this condition together'. Youth attendees who subsequently were in the audience at the AIDS satellite session reemphasized how important and affirming it was to see their peers representing their concerns at an international HIV conference and commented 'if only there were more youth' at such events in the future.

Direct involvement of key populations

Given the challenges and costs of minors traveling internationally, holding future research meetings in SSA will allow more adolescents to shape a research agenda relevant to their communities. Working within the regional setting will also offer more opportunities for capacity building with youth across different developmental stages. Even the 1-day premeeting with youth proved invaluable support and training that enhanced the meaningful involvement of youth in the implementation science agenda setting meeting.

There is also a critical need to engage and support adolescents who are members of key populations. The vulnerability of key populations of youth, such as men who have sex with men, transgender youth, young people who sell sex, and youth who inject drugs, is well established with their risks for poorer health outcomes related to HIV, sexually transmitted infections, and reproductive health exceeding their adult counterparts [18]. Researchers, programers, and donors need to employ innovative strategies to involve these populations in research agenda setting efforts, while being cognizant of potential vulnerabilities, safety, consent, and ethical considerations.

Build opportunities for leadership roles

It is also important to reflect on the role of youth in the implementation science agenda setting meeting and the extent of their engagement. Youth were active participants in the meeting as experts. This process not only increased the youths' comfort and confidence to actively engage in public discourse on the experiences and needs of adolescents but also familiarized adults with strategies for working with youth and maximizing youth involvement. Youth, however, were not involved in the development and design of the implementation science 2-day meeting. One young participant did take on a leadership role in designing and preparing for the subsequent IAS satellite session mentioned above. With growing requirements for user involvement in research, it is essential to ensure that young people's participation is not merely a tick-box exercise, but one that meaningfully involves youth from planning to implementation and evaluation. This meeting represents a first step in youth engagement.

There is a body of literature that defines components and characteristics of effective youth engagement. The UK Department of International Development's Guide on Youth Participation in Development identified three aspects of youth engagement: 'working for youth as beneficiaries, engaging with youth as partners, and supporting youth as leaders' [1]. This guide defines these three components as ranging from targeting and

informing youth as beneficiaries to conducting 'collaborative' interventions with youth as leaders. There is also a body of literature on youth participatory action research that emphases youth's role both as beneficiaries but also as leaders and implementers [19–21]. Fox *et al.* [19] detail five 'threshold commitments' that must be achieved for critical youth engagement in projects: recognizing young people as sources of knowledge and power; critical consciousness of history, privilege, and power; youth leadership in partnership with adults; recognizing the intersectionality of different sectors of life (e.g., health, education, housing); and research linking to collective action for social change. A primary element of this participatory action research model is its intention to equalize power between researchers and target youth groups.

Community engagement and good participatory practice (GPP) has also garnered increasing attention within the field of HIV biomedical trials with an emphasis on the role of youth, their parents and families, and communities [10]. Ellen *et al.* [10] describe the benefits of community and youth engagement not only in terms of individual capacity building but also for the 'improvement of the ethical and scientific integrity of trials, increased transparency and accountability of the research to the community, the increase of benefits and decrease of risks for participants and the surrounding community, and the improvement of local capacity and infrastructure'.

As adolescent HIV implementation science research progresses, it will be critical to draw upon such frameworks and approaches to more fully engage adolescents and young adults not only as beneficiaries but as partners and leaders. Systematic efforts are needed to understand best practices for adolescent and youth involvement, especially as adolescents represent a heterogeneous population that encompasses a wide array of developmental stages and growth [17].

Conclusion

The current research agenda was developed to guide future implementation science research to strengthen the engagement of ALHIV to improve care continuum outcomes, including HTC and LTC, and is available to funders and researchers worldwide [22]. The process highlighted the importance of youth involvement in shaping research agendas. It also illustrated the effectiveness of bringing together 50 experts, including youth living with HIV, who dedicated their time and attention for two full days to brainstorm, develop, and prioritize an implementation science research agenda. Research conducted in collaboration with adolescents and youth to address the implementation science research questions identified through this process will result in much needed evidence and insight into improving adolescent HTC and LTC, and other care continuum outcomes, in SSA.

Acknowledgements

J.A.D., D.K., and J.P. designed the methods. J.A.D., A.P., L.M.M., R.M. and D.K. wrote the first draft of the article. S.K., K.K., K.K., L.N., N.N. contributed critical revisions to the analysis and interpretation. All authors contributed to the writing of the final draft.

Project SOAR (Supporting Operational AIDS Research), Cooperative Agreement AID-OAA-A-14-00060, is made possible by the generous support of the American people through the President's Emergency Plan for AIDS Relief (PEPFAR) and the United States Agency for International Development (USAID). However, the contents of this article are the sole responsibility of Project SOAR, the Population Council, and the authors and do not necessarily reflect the views of PEPFAR, USAID, or the United States Government. The writing of this manuscript was also supported by the National Center for Complementary and Integrative Health (5K01AT009049-02).

The authors gratefully acknowledge the youth who shared their experiences and perspectives living with HIV during the Project SOAR Technical Advisory Network meeting. We also acknowledge the expertise and commitment of the other meeting participants who dedicated 2 days debating and developing implementation science questions to address the needs of young people living with HIV in sub-Saharan Africa. We thank the USAID Project SOAR Management Team, Technical Advisors, and other colleagues who contributed to the conceptualization of the meeting.

Conflicts of interest

There are no conflicts of interest.

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