

**Adolescent health series****Engagement with young people as partners in health research: four case studies from Sub-Saharan Africa**

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**Sustainable Development Goals:** Good Health and Wellbeing, Reduced Inequalities

**Abstract**

**Objectives:** Existing health services for young people (10-24 years), which are predominantly designed for but not with young people, often do not meet young people's needs. The 2018 Global Consensus Statement on meaningful adolescent and youth engagement affirms that young people have a fundamental right to actively and meaningfully engage in all matters that affect their lives. We present four case studies from three countries in sub-Saharan Africa as practical examples of the engagement of young people as partners in health research. We critically reflect on best practices to inform and guide the increasing adoption of collaborative approaches.

**Methods:** We developed a narrative summary of each case study through review of study documentation and discussions with research staff and young people. A youth engagement framework was used to describe partnership activities according to the following dimensions: purpose, process, positioning, perspective, power relations, place and protection. We reflected on innovative practices used, overall level of participation achieved, and strategies to address ethical, logistical and/or financial barriers.

**Results:** In all case studies we found evidence of engagement activities that aligned with the Global Consensus Statement on Meaningful Youth Engagement. However, access to participation was often uneven and despite

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efforts, marginalised young people continue to have insufficient opportunities to engage. Furthermore, although young people had some opportunity to influence the research methods, many of the key design decisions had been determined prior to their involvement. In our case studies researchers had built in insufficient opportunities to evaluate the level and impact of youth engagement.

**Conclusions:** We therefore recommend early involvement of young people in the research process so that they can contribute to setting the research agenda, the design of planned studies and thus increase the scope of their engagement from the beginning. Youth engagement activities need to be evaluated from the perspective of all stakeholders including young people themselves with a focus on opportunities to engage, the level of engagement achieved, and impact of engagement. From the beginning, researchers should provide space for learning, and involve young people in encouraging critical reflection of what does not yet work, as well as what does, to enable improvements.

**Keywords:** Adolescence; health; young people; research participation; participatory research; youth engagement; Africa

## Introduction

Existing health services and interventions are not meeting the needs of Young People (YP, 10-24 years) which has deleterious consequences on their health.[1-3] The gap in the provision of services is in part explained by the implementation of interventions that were predominately designed for but not *with* YP. Accompanying the increased prioritisation of YP's health in recent times has been an emerging effort to involve YP as partners in co-designing interventions.[4, 5] This is predicated on the logic that if we can collectively develop youth-centred interventions which are more appealing and acceptable, this should improve the access, uptake, and effectiveness of services and related outcomes. This is supported by a developing global consensus that YP have a fundamental right to actively and meaningfully engage in all matters that affect their lives.[5-8] The principles outlined in the Global Consensus Statement on Meaningful Youth Engagement emphasise that engagement should be rights-based, transparent and informative, voluntary and free from coercion, respectful of young people's views, backgrounds, and identities, and safe.[6]

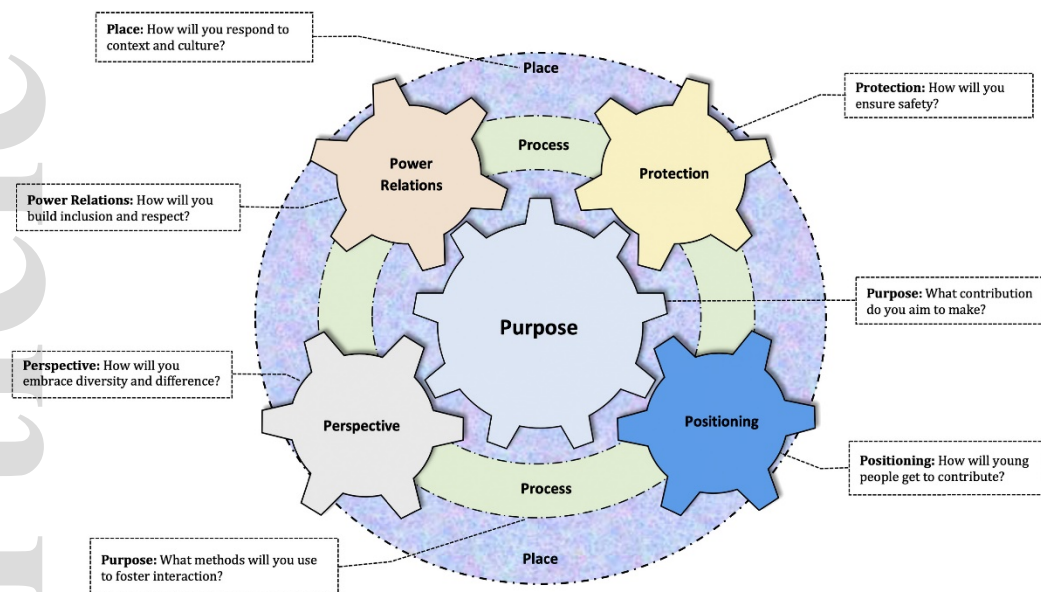
In research, there are multiple opportunities to engage YP including: devising research questions, developing and delivering intervention design, supporting community engagement, data collection, analysis, and interpreting and disseminating findings. Youth engagement can take many forms ranging from consulting and informing YP through to youth-led decision making. Tools that are widely used to describe the different forms of meaningful youth participation include Hart's ladder of participation and the Flower of participation.[9, 10] In these typologies, participation ranges from YP being consulted and informed through to YP leading decision-making. While the principle of inclusion and engagement is increasingly adopted, best practices about when, how and in what ways YP can be meaningfully engaged in the research process has received relatively little attention in the literature.[4] Even in studies where excellent participatory work is done, research outputs which focus on research study findings tend

to be prioritised over methodologically reflective papers describing participatory activities and so opportunities for research practice to learn and further develop are missed. There is a need to create a legitimate space for critical reflection about what underpins successful engagement of YP as partners in research. In this paper we present four case studies to provide practical examples of engagement of YP in health research in Sub-Saharan Africa and to generate critical reflective learning to inform the development of best practice going forward.

## **Methods**

We used a case study approach[11] to describe four examples of engagement of YP (Table 1). The case studies were purposively selected from our existing research networks, which predominantly focus on sexual and reproductive health (SRH), with the aim of presenting a range of engagement approaches and including examples of YP's contribution across the research process. SRH research is a pertinent topic to explore both the suitability and feasibility of partnership research to support the development of acceptable youth interventions.

Information and reflections on the partnership approach in each case study was collected in three stages. The first was that each research team, constituted of academics, public engagement practitioners, and YP (co-authors of this paper), described their activities in relation to the seven interconnected domains of the Cahill and Dadvand P7 model on youth participation (Figure 1). [12] The second stage was to provide reflections on the following topics: innovative practices used, overall level of participation achieved, and strategies to address ethical, logistical and/or financial barriers. The third stage involved assessments conducted by each study with YP to understand YP's experiences of the research process and obtain their recommendations to support involvement of YP. For example, a focus group discussion (FGD) was held with Youth Research Academy participants after the initial week of training, and interviews and FGDs were held with the YP who led the Healthy Adolescents and Young Adults (HAYA) dissemination. In addition, research teams were also asked to characterise the perceived effect of youth participation on the YP themselves, including the skills that they obtained through the process. The initial findings on YP's experiences are summarised in this paper, however, more detailed analysis and interpretation is ongoing and will be reported on separately by each individual study. Through this reflective learning process, we have formulated recommendations for researchers who would like to more actively engage YP in their work.



**Figure 1.** Cahill and Dadvand (2018) The P7 Model: A thinking tool for visioning, planning, enacting and evaluating youth participation.[12] Reprinted from Children and Youth Services Review, Volume 95, Cahill and Dadvand, Reconceptualising youth participation: A framework to inform action, Pages 243-253, Copyright (2018), with permission from Elsevier

## Results

We present below the characteristics of each case study mapped against the domains of the P7 Model with further details in supplementary tables (Tables S1-S4).[12]

### **Case study 1: P-ART-Y, Zambia (PopART)**

HIV prevention trials network (HPTN) 071/PopART (Clinical Trials registration number NCT01900977) is a community-based trial to assess the effects of a test and treat strategy on HIV incidence. [13]

*Purpose:* The PopART for Youth (P-ART-Y) study, nested within the PopART study, aimed to engage YP aged 15-24 years in HIV testing and treatment services in 12 communities in Zambia and 9 in South Africa. The PopART intervention was primarily implemented at household level by trained community HIV Care Providers (CHiPs). P-ART-Y had a broader community-level youth engagement with additional community and school-based activities. Youth engagement activities were developed jointly by the newly formed adolescent community advisory board (ACAB) and other stakeholders. This case study focuses on the 12 Zambian communities.

*Process/positioning:* Each participating community formed its own local ACAB comprising of at least 10 members at the start of the study. YP were identified through youth organisations and potential ACAB members were interviewed by a panel that included study staff, health facility staff and adult CAB members. The ACAB members contributed to the development of tools (including revising language to align with locally acceptable terms); decision-making on intervention content (e.g. broadening the range of community activities); implementation of the intervention; and the interpretation and dissemination of findings. They were particularly influential in shaping the

study recruitment approaches, including accompanying study staff during sensitisation activities (sporting and community events and announcements in school assemblies), successfully advocating with the study team for submission of a request to the ethical review boards for a waiver of parental consent during the study's cross-sectional survey, and revising terminology in the intervention format. Some YP were later enrolled as research assistants on the recommendation of the ACABs. Their input was enabled through their involvement in monthly study local update meetings, as well as through their representation at national Advisory Group and ACAB meetings.

*Perspective/power relations:* The guidance and criteria for the selection process were developed in consultation with YP, youth organisations and adult CABS. The selection criteria reflected the diversity of the target population, for example, age, gender, knowledge of HIV and TB, experience with voluntarism etc. The group comprised 120 members (10 from each community) with 52% being female and the age range was 14 to 24 years.

*Place/protection:* The ACAB fora were designed to maximise the engagement of YP. This involved the provision of transport to attend meetings and refreshments; communicating in the vernacular in line with the preferences of YP; using creative participatory methods; and providing training opportunities to extend their SRH and research literacy, including research ethics, research protocols, and facilitation skills. To fit in with the routines of YP, meetings were held on Saturdays or during school breaks. Study staff sought guardian permission for ACAB members who were younger than 16 years on the occasions when they needed to attend ACAB meetings late or travel for national meetings.

The overall level of *engagement* achieved could be considered '*YP are consulted and informed*' with some aspects of shared decisions.[9]

There were challenges with obtaining guardian permission for younger ACAB members and arranging meetings to accommodate the mobility and transient routines of YP. Although there was a monthly ACAB budget of approximately \$500 this was insufficient to implement all the suggestions made by the ACAB such as making their meetings and training sessions more youth-friendly and providing more skill-building activities.

The researchers and YP observed positive impacts of ACAB participation on the YP. Some YP were later employed as research assistants for a few months and during this time were asked to relinquish their membership of the ACAB due to potential conflict of interest. Some members went on to get employment on other research studies as data collectors. To ensure sustainability of their ongoing participatory influence and knowledge, at the end of the P-ART-Y study the ACABs transitioned into advising other studies being conducted within their communities. Formal evaluation of the ACAB is underway and will be published separately.

### **Case study 2: CHIEDZA, Zimbabwe**

*Purpose:* CHIEDZA is a trial of a community based SRH service delivery for 16-24-year olds in Harare, Bulawayo and Mashonaland East, Zimbabwe.

*Process/ positioning:* YP contributed to the design of the intervention. An initial intervention design was developed through extensive formative research, which included 90+ in-depth interviews (IDIs) with several stakeholders including 51 YP (aged 16-24). These YP were recruited through youth organisations and a purposive sampling

approach was adopted reflecting the CHIEDZA target population. 45 YP then participated in a series of co-design workshops to further develop and revise the proposed outline into an intervention plan.

A smaller cohort of these YP, who had participated in the workshops and similarly reflected the target population, formed the study's Youth Advisory Group (YAG). The YAG provided further input into intervention design and implementation on an ongoing basis through study meetings and activities. Following the design phase, the YAG was disbanded and YP from intervention areas were selected as mobilisers and champions to help with community engagement and mobilisation.

*Perspective/power relations:* To enhance the inclusivity of participation, 16-17-year olds did not need parental consent. Considerations around HIV status and gender influenced the composition of groups. For example, separate workshops were held for HIV+ and HIV- YP so as to not accidentally facilitate disclosure, and to foster a safe space to discuss sensitive issues. Some sessions within the workshops included males and females, but others, such as the session discussing aspects of the intervention that should be tailored to each sex, were conducted separately. To foster interaction researchers implemented creative and interactive session with facilitators trained to re-direct or rephrase questions that did not elicit immediate or enough response and less responsive participants were given extra encouragement to contribute. There was no formal skill-building but participating YP may have improved their knowledge of research, health issues, and gained some additional communication and teamwork skills. Throughout care was taken to transparently explain that considerations of feasibility may mean that not all suggestions could be incorporated and may be subject to adaptation. These decisions were taken in collaboration with YP.

**Place/ protection:** YP developed a workshop "rules list" that would allow for respectful conduct, dialogue, and discussion. The refinement process in the co-design workshops involved identifying areas of majority consensus. In most instances, the suggestions of YP were incorporated into the design. For example, the use of youth mobilisers within intervention communities to sensitise youth, facilitate linkage and enhance uptake, the idea of distributing information in the study communities and raising awareness of the study to increase service uptake. Some ideas were not feasible and required adaptation in order to be incorporated. For example, suggestions to increase the number of operation days per site could not be resourced, so YP instead proposed the days and times of operation that would be most suitable.

Overall a high level of youth participation was reported by the research team. The overall level of *engagement* achieved could be considered 'Adult-led, shared decisions with youth'.<sup>[9]</sup> There was a dedicated budget for the YAG of approximately \$1000 to cover meetings (cost of refreshments and \$10 per meeting for each YAG member to cover their transport). Some YP faced logistical challenges getting to the engagement activities and researchers attempted to mitigate these barriers by organizing transport at convenient points in the community.

### *Case study 3: Youth Research Academy, Zimbabwe*

*Purpose:* The Youth Research Academy led by the Biomedical Research and Training Institute (BRTI) in Harare, Zimbabwe aimed to train youth researchers to design and conduct their own research projects.

*Process/positioning:* YP attended a one-week residential training on research methodologies. They were assigned a

research topic (e.g. technology, menstrual hygiene management, and mapping) in groups and matched with mentors. Over a 3-month period mentors guided groups through the process of identifying research questions, developing study designs, collecting and analysing data and disseminating their findings. The YP met with mentors at least once a week over a 3-month period and received ongoing supervision. YP presented their preliminary research plans at a stakeholder ceremony at the end of the training week. At the end of the research period a dissemination meeting was held at which the YP presented their findings and some YP travelled to Uganda to present at a regional meeting. There was no plan or expectation that the youth researchers would then continue on to work in research, however all reported having advanced their skills and some were later employed on research projects.

*Perspective/power relations:* Advertisements to apply for the Youth Research Academy were distributed by a community-based organisation working with YP. Mentors shortlisted applicants for interviews based on the responses within their one-page applications, with particular attention paid to their experience/ motivation for working with other YP and their future career plans. The interview involved a short face-to-face discussion with the mentors and a 10-minute piece of group work to show the interviewee's ability to work as part of a team and interact with peers. There was an attempt to include a diverse range of YP, however, some groups such as YP living with disabilities or those with low levels of schooling were not represented. During the mentorship phase youth researchers were encouraged to engage openly with mentors as research projects were to be led by the youth researchers.

*Place/ Protection:* In addition to covering methods, the one-week residential included activities to foster a safe and collaborative working space and aimed to adequately prepare the YP to navigate difficult or sensitive issues they may encounter through their research, including, given their proximity in age to participants, any potentially distressing triggers. This was done through role plays and interactive teaching on the sensitive topics.

Overall, the Youth Research Academy was successful with a mutual benefit for the YR and BRTI. Research projects included the mapping of 'social hotspots' where YP meet and congregate, developing tools to support female engagement and participation in a menstrual health management intervention, describing the use of technology by YP, and identifying barriers and facilitators to young men's engagement with health services. The overall level of *engagement* achieved could be considered 'Youth-led, shared decisions with adults'.<sup>[9]</sup> A FGD at the end of the residential prior to the conduct of their research projects provided largely positive feedback on the programme with YP expressing a feeling of empowerment and support. However, some YP worried that their participation could lead to them being marginalised from peers and/or described apprehension and fears about being inadequate but felt supported by the approachable and friendly Youth Research Academy staff. Limited challenges existed in related to supporting the YP to navigate their position within their research projects. This was ameliorated by including them within intervention briefing meetings which allowed them to integrate more effectively into the broader research team.

Key factors which contributed to the Academy's success were appropriate resourcing (approx. \$40,000) which allowed an initial one-week residential training and payment of YRs during the 3 months of the research. This was supplemented by staffing costs of mentors being absorbed within their existing research on BRTI projects.

#### **Case study 4: Healthy Adolescents and Young Adults (HAYA), South Africa**

*Purpose:* Youth in rural KwaZulu-Natal were recruited to transform the research findings of the Healthy Adolescents and Young Adults (HAYA) package of research projects on the health and well-being of YP into accessible materials which would be appealing for youth.

*Process/positioning:* A group of 30 school going YP (15 males, 15 females), from five local schools, were selected by their teachers to participate in a dissemination design workshop. Having developed an understanding of the key research messages, they wrote, created and performed five hip-hop songs and made 3 short films (2-3 minutes) to convey the research to YP. They were supported by professional music producers. While the main messages for the films had been pre-specified, YP were left to use their creativity in portraying the message across to their peers. The schools were selected due to their proximity to the research institution, Africa Health Research Institute, which eased logistical challenges, and their connections and involvement in previous research. Not all schools in the area were involved, but adopting this selective approach was necessary for feasibility. Three male and three female out-of-school YP, who had previously participated in a peer-navigator programme, were nominated by their study coordinator.

*Perspective/power relations:* To foster engagement and to get a better understanding of the various studies, YP were given the opportunity to interview the scientists on the related studies. No major barriers to participation were reported. However, as selection relied on the teachers, inclusivity could not be guaranteed. The YP were chosen for their interest in science as well as performing arts and music.

*Place/protection:* All meetings, workshops and the live music performance were at Africa Health Research Institute premises. Transport was provided to and from the venue to ensure the safety of YP. Guardians were required to provide their consent for the YP to participate. A mixture of English and IsiZulu, a local vernacular language, was used.

Overall participation could be described as 'Adult-led, shared decisions with youth'.<sup>[9]</sup> The songs and films were played at the live concert,<sup>[14]</sup> as well as on a local community radio station and have been widely shared within their community and discussed at school-based events. These activities have fed into a broader range of community engagement activities at the African Health Research Institute. For example, YP (Peer Navigators) are now part of the drama production on health issues; and the songs that were created by the school learners will be part of this production too.

#### **Discussion**

In all four case studies we found evidence of engagement activities that aligned with the Global Consensus Statement on Meaningful Youth Engagement.<sup>[6]</sup> Each case study engaged with young people as partners in research through different activities illustrating the wide diversity in engagement approaches. Each study aimed to give YP the opportunity to lead some of the decision making. In three of the four case studies (CS1, CS2 and CS4), the engagement was largely 'adult-led' with key decisions such as intervention structure or messages to be disseminated



determined prior to the involvement of YP. The role of YP was to influence the shape of the intervention and/ or messaging to best fit the needs of the target population and to enhance acceptability. The one exception is the Youth Research Academy (CS3), where the research was led by YP with the support of mentors. However, the broad study topics were also pre-defined.

### ***The process of engagement and implications for best practice guidelines***

- When should engagement begin?

To achieve more equitable partnerships and greater degree of youth participation, YP need to be more formally included at the earliest stage. YP should be involved in determining critical early decisions on study focus and design. This could be achieved by integrating sustained youth participation into broad research programmes where they can exert an influence in conceiving ideas and the development of study proposals, prior to funding being secured, when plans tend to be more malleable.

- Which young people?

As noted within these case studies, adopting appropriate and inclusive strategies to identify and invite YP to participate in research engagement activities is commonly very challenging. In three out of the four case studies YP's participation was brokered by adults who acted as gatekeepers and invited selected YP (CS1, CS2, CS4). However, the self-selection through responding to an advertisement for the Youth Research Academy (CS3) was relatively transparent involving a competitive application and selection process. However, self-selection during the application stage could have been influenced by where the advertisements were placed. Also, applicants may still have been influenced by being encouraged to apply by community mentors. This may have inadvertently favoured less vulnerable YP.

Across the case studies, efforts were made to include YP who were representative of their target population and diversity was observed across age and genders. Nevertheless, given the small target numbers of YP, it became less feasible to have all sub-groups of YP represented. It is worth noting that no specific attempts were made to include participants from under-represented groups, such as YP with disabilities or with non-heteronormative sexual orientation. The Youth Research Academy had wanted to specifically include YP with a disability but the additional logistic support and related resources that might have been required were not available. The recruitment process was commonly facilitated through local youth organisations, and this may have favoured the inclusion of YP who had prior exposure to youth-focused services. Although recognising the value of enthusiasm will continue to be influential in recruitment processes, widening the recruitment net to bring in YP who are not visible in the community and who may not normally access health programmes could be very beneficial for programmes and YP.

- Modes of participation

A variety of modes, pre-defined by the researchers, was used to engage young people including design workshops, advisory committees/panels, and small group mentoring sessions. Young people also played an active role in the

delivery of interventions e.g. leading community mobilisation activities. The relative impact and cost of these modes was not explored and is an important area for further research. The involvement of young people in the planning of research studies would allow their input into the selection of the modes of participation.

- Responding to local context, and power dynamics

Society's view of YP can enhance or impede their meaningful participation as citizens in community affairs. YP may not be able to make autonomous decisions, including decisions about choosing to participate in research. In Zimbabwe 16-17 year-olds could provide consent to participate in the CHIEDZA intervention design, but in other settings in the region and globally, adolescents in this age group may indirectly be precluded from participating in engaging in the design of SRH research as having to rely on their parents' permission effectively limits their ability to join. The financial and time constraints of young people were anticipated and largely overcome through the provision of transport costs and flexibility around the timing of engagement activities.

While access to YP's engagement in research partnerships needs to be improved, adult researchers and practitioners also need to adapt their approach to be effective communicators to support genuine engagement with YP. This can be easier for some disciplines, for example social science which relies on developing nuanced understandings of social contexts and dynamics. In all case studies emphasis was placed on the necessity of adopting approaches which fostered equitable partnerships, for example, through the use of less scientific language and more fun and engaging participatory methods. However, there was no provision of formal or informal training on how best to adapt to using language and approaches that are accessible and acceptable to YP. The burden is often placed on YP to learn how to effectively communicate with various adults that they might encounter in their roles. More emphasis needs to be placed on the training needs of adults, in addition to those more explicitly recognised as needed for YP.

- Adequate budgeting to meet the resource need of youth engagement

For YP to be able to be influential partners in the design and implementation of research, the research itself cannot be fixed and needs to be malleable. To foster effective youth engagement which can genuinely change the direction of research to align with the collaborative decisions made by YP takes time and investment. There are two primary costs. The first relates to the time and flexibility required to ensure that the study accommodates the suggestions of YP as research partners. It is probable that increased consultation will involve a longer and costlier intervention development period due to the time for consultation and incorporation of suggested changes. However, this further reinforces the argument that it is more effective that YP are involved as partners in the research process earlier. It is important to note that some costs may be offset by producing research outputs, including interventions, which are more relevant, accessible, and potentially effective, indicative of the value of the investment. The second main cost of engaging YP as partners in the research process is covering the costs of the contributions YP are making in terms of their time. All case studies provided participating YP with incentives (e.g. airtime) and/or compensation for travel and their time (e.g. refreshments). The Youth Research Academy (CS 3) paid the participating YP and the CHIEDZA

champions and community mobilisers (CS2) were paid for their time monthly. Each study that is engaging with YP as research partners needs to have discussed and agreed with YP at a very early stage upon the important questions of what can reasonably be expected of YP and how this contribution should be fairly recompensed. In the case studies, payment was differentiated by the variation in role and remit of the YP as different types of research partners. For example, in the co-design workshops YP were recompensed at a commensurate level as research participants for interviews or FGDs. However, in the Youth Research Academy, as YP were contributing to the implementation of research at a similar level that might be expected of junior adult researchers and the role came with certain expectations and responsibilities (i.e. working a certain number of hours a week), they were recompensed at a similar level.

### ***Effect of participation on youth and others***

It is anticipated that participation has a positive effect on the young participants, other YP, other stakeholders, and the programmes developed and implemented. However, it is often very hard to measure these potential impacts. Across the case studies evaluation activities were conducted, but they tended not to be comprehensive, often focusing on only one of the engagement activities or at one point in time. In addition, where it was done it focused only on capturing the perspectives of the YP and not the other stakeholders involved in the partnership.

Youth participants reported having developed skills through participation including communication and research skills, and enhanced knowledge and awareness of other YP's perspectives of SRH services. However, YP also described how this advantage can also distance them from their peers which can be a cause of anxiety.

Sustaining the gains made through research partnerships with YP should be a priority and requires flexibility and longer-term vision. The case studies adopted different approaches, including shifting the roles of YP from advisors to mobilisers (CS2) or transitioning YP onto advising on other pertinent studies to further develop their skills and extend the mutual benefits of their involvement (CS1).

### ***Comparison to other research***

While several theoretical frameworks relating to youth participation exist,[8-10] there are relatively few detailed examples of youth engagement activities, and limited evidence on the effects of such engagement. Cluver et al report on their experiences with adolescent advisory groups over a 10 year period in South Africa, emphasising the feasibility and benefits of such groups despite some ethical and logistical challenges.[15] A scoping review of youth engagement in HIV prevention intervention research in SSA between 2000 and 2020 found that decision making was youth-led or shared with adults in only 9/74 (12%) interventions. [16] Similarly, a scoping review of children and YP's participation in developing interventions in health and well-being globally found sharing of power and responsibility in only 3/41 (7%) of included studies. [4] A conceptual framework for measuring outcomes of adolescent participation has been proposed around key features of meaningful participation: Space, Voice, Audience and Influence and empowerment.[17] Despite increasing levels of participation of YP in research, there is a recognised gap in empirical evidence on the benefits and costs of this increased participation. [18]

### ***Strengths and limitations***

Strengths of this research include the use of a youth engagement framework to describe the case studies, presentation of examples from multiple countries, and a focus on the practical lessons learnt. In addition, some voices of and reflections from YP as researchers were included.

The research was limited to three countries, to case studies among our network of existing collaborators, and most of the case-studies related to SRH interventions. There may be different opportunities/challenges for other health topics and in other settings.

The perspective presented here is that of the authors and the views of YP is limited to the few YP who are co-authors and an informal discussion with one of the learners who participated in CS4. YP not represented here may have different views on the types of skills and experiences that they gained, and on the level of participation that was achieved.

### **Conclusions**

We have presented four case studies as examples of existing youth engagement in health research and summarised lessons learnt. It is still relatively new to have young people recognised as key partners within the conduct of research, but despite this progress there is still a considerable way to go to ensure that young people from diverse backgrounds, particularly those with disabilities and alternative sexualities are provided with equitable opportunities to participate. There is a need for more open and honest discussion, reflection and sharing of examples of challenges and best practices. In this relatively novel area, learning should be celebrated as a contribution to progress, rather than just glossing over the challenges.

The desire to engage with YP throughout the research process can be in tension with the pace at which research and intervention design is expected to be delivered to meet real and urgent targets. This tension demands that we engage in critical discussion about what it takes for meaningful participation to occur with genuine impact. It needs to be sufficiently resourced and thoughtfully planned by being built into budgets and timelines and this in turn needs understanding on the part of those that fund research. The funders were supportive of the youth engagement activities described in the case studies, however, research funding structures including fixed-term contracts make engagement more difficult to sustain. In Zimbabwe, a second Youth Research Academy has been funded by another donor as part of a broader youth engagement initiative demonstrating interest in and commitment towards youth engagement.

The opening up of the research process to the scrutiny and input of YP involves humility on the part of adult researchers and a reconfiguration of what constitutes 'expertise'. It is unlikely to be realistic to expect to achieve full youth-led decision-making at the first attempt. A stepped approach could be taken where researchers and YP gradually build their skills, experience and trust to move from a model of youth consultation towards joint or youth-led decision making.

It is not unusual that reflections on the process of the research are not prioritised publication outputs, and this

reflects the priority of funders and applied research. Moving forward, we should create opportunities to engage in collaborative dialogue as is the attempt of this paper, to avoid decelerating the broader learning. Our recommendations for the engagement of YP as partners in research are presented in Box 1.

**Box 1:** Recommendations for the engagement of Young People as partners in research

- **Early involvement of YP in the research process** e.g. through mechanisms built within research organisations as opposed to within individual projects, so that they can contribute to setting the research agenda, the design of planned studies and thus increase the scope of their engagement from the beginning.
- **Structures and skills:** Researchers take responsibility and lead efforts to develop the structures through which YP can genuinely influence the design and delivery of the research throughout the lifetime of the study. YP and adults should be trained on how to effectively communicate and collaborate with each other. Academic courses should be developed for researchers to help them to develop skills as regards the involvement of YP in research projects. The burden should not fall on YP to make this a productive relationship.
- **Early agreement on expectations** Discussion and agreement ahead of time about how YPs contributions and suggestions will be considered and taken on board, so that expectations are clearly and fairly set out from the onset of the work. Need to strike a balance on how both researchers and YP can benefit from the collaboration.
- **Adequately resourced and planned activities:** To avoid youth engagement being a tokenistic tick-box exercise, activities need to have adequate time and financial resources, and all those involved need to be aware of what is expected of them. Plan activities in a way that would allow a range of YP to be able to participate- i.e. those who are in school, in employment, with family caring responsibilities.
- **Increase diversity of YP who are involved.** This can begin to be accomplished by encouraging a more transparent, inclusive and rigorous recruitment process to select YP for participation (similar to what was accomplished for the Youth Research Academy) and can be fostered by continuing to work with groups of YP on an ongoing basis. Cultural and contextual factors may limit the benefits of participation for the most marginalised youth but raising their voices would be an important step towards advocating with young people for their needs and demonstrating the benefit of their participation.
- **Increased community engagement** may be required to encourage parents and guardians to allow YP to participate and have a voice.
- **Evaluation:** Youth engagement activities need to be evaluated from the perspective of all stakeholders including young people themselves with a focus on opportunities to engage, the level of engagement achieved, and impact of engagement. Future research could explore whether YP were able to participate in the way that they wanted/had expected, and whether they had any unexpected positive or negative experiences. Existing frameworks may be helpful when defining evaluation questions. From the beginning, researchers should provide space for learning, and involve young people in encouraging critical reflection of what does not yet work, as well as what does, to enable improvements.

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**Table 1.** Case studies of young people as partners in health research

Case-study	Objective	Activities
<p><b>Case study 1</b> PopART for Youth (PARTY)- a community-level combination HIV prevention package study, Zambia</p>	<p>Promote youth participation and representation through the platform of an Adolescent community advisory board (ACAB)</p>	<p><b>1)</b> In consultation with YP, adult community advisory boards (CABs), and organisations working with YP, guidelines and criteria to develop ACABs and select members were developed. ACABs were created in each of the 12 study communities comprising 10 members each (120 in total).</p> <p><b>2)</b> Before the study commenced, ACAB members were consulted about the possible approaches for recruiting and retaining YP in the study. They were also asked to suggest approaches for delivering the YP interventions during the Study Advisory Group (SAG) meeting where formative research findings were presented to a broad audience. They also reviewed study material.</p> <p><b>3)</b> During study implementation, ACABs participated in regular consultative meetings to discuss and adapt study interventions. They also helped organize study mobilisation events e.g. making school announcements, community fairs, sports events, community meetings. Monthly ACAB meetings were held to provide feedback and hear study progress updates from researchers. Some ACAB members were later employed as survey enumerators but they had to relinquish their membership.</p> <p><b>4)</b> ACAB representatives attended high level study oversight meetings such as the steering committee meetings. They encouraged the investigators to obtain a waiver of parental consent during the cross-sectional survey and suggested the actual modalities for implementing the survey.</p>
<p><b>Case study 2</b> CHIEDZA- trial of community-based sexual and reproductive health intervention for 16-24-year olds, Zimbabwe (Harare, Bulawayo and Mashonaland East Provinces)</p>	<p>Meaningfully engage and involve YP in the design, development, and implementation of the CHIEZA intervention</p>	<p><b>1) Participatory co-design workshops</b> - In total, 45 YP aged 16-24 years took part in co-design workshops. During the two one-day workshops, conducted with HIV negative youth (11 males and 13 females) on Day 1 and HIV positive youth (10 males, 11 females) on Day 2, feedback was obtained on the preliminary outline intervention. YP's comments and suggestions were used to further refine intervention elements.</p> <p><b>2) Youth Advisory Group (YAG)</b> - Select participants from the participatory workshops were invited to join the YAG to provide input on intervention design and development on an ongoing basis. During the first 6 months, the YAG met three times following the workshops: (1) to provide input into designs from the marketing team, (2) to attend the interviews to hire the intervention teams, and (3) to discuss the use of the Ithaka platform for HIV self-testing.</p> <p><b>3) CHIEDZA champions and mobilisers-</b> During intervention implementation YP at the intervention sites helped with community engagement and mobilisation.</p>



<p><b>Case study 3</b> Youth Research Academy , Zimbabwe (Harare, Bulawayo Provinces)</p>	<p>To train youth researchers to conduct research including research question formulation, data collection and analysis, and dissemination of findings.</p>	<p>1) <b>One-week residential orientation program</b> aimed at training YP on research concepts, methodology and implementation. The residential focused on skill building incorporating several activities such as; group work, role plays and games to promote learning through action. Time was allocated to discuss issues of concern to participants including value clarification, personal beliefs, judgments and definition of concepts. Training topics also included how to engage stakeholders, the use of research to strengthen advocacy, and opportunities to develop other transferable skills such presentation skills.</p> <p>2) <b>Youth researchers (YRs) planned and conducted research.</b> YRs were allocated to one of five research topics and worked with a mentor to design a relevant research question and methodology. Research plans were presented at a Stakeholder Ceremony. Supervised by their mentors the YRs spent 2-3 days/week over 2-3 months (180 hours) implementing their projects.</p> <p>3) <b>Project results were disseminated to stakeholders</b> upon completion, and some YRs presented their findings at a conference in Uganda.</p>
<p><b>Case study 4</b> HAYA - a package of research projects on the health and well-being of young people, South Africa (Rural Kwa-Zulu Natal)</p>	<p>Youth-led dissemination of the results from a package of research projects on the health and well-being of young people</p>	<p><b>School-going YP:</b></p> <ol style="list-style-type: none"> <li>1) The research findings were presented to the Traditional Authority members and the Community Advisory Board (CAB) members who were informed about the next phase of dissemination involving youth engagement.</li> <li>2) Letters were written to the principals of five schools requesting them to identify learners to be part of co-creation of dissemination products i.e. 3 boys and 3 girls per school, which made a total of 30 YP. This was followed up by physical visits to schools to discuss details of the entire process.</li> <li>3) Learners, accompanied by their educators, attended two workshops, which were held on two consecutive Saturdays that lasted the whole day, to learn about research findings, and to co-create and professionally record Hip-Hop songs.</li> <li>4) On a third Saturday, learners performed their songs live in front of their peers, teachers, parents and members of the CAB.</li> <li>5) On each of these Saturdays, learners were collected from their respective places by an Africa Health Research Institute vehicle and had to bring consent forms signed by their parents on the first day of the workshop.</li> </ol> <p><b>Out of school YP:</b></p> <ol style="list-style-type: none"> <li>1) Six peer navigators were randomly selected in consultation with the Study Co-ordinator of the programme</li> <li>2) They were briefed about their participation in films portraying health messages.</li> <li>3) They got involved in a series of workshops, including honing their acting skills; and factsheets were shared with them</li> <li>4) They were then divided into 3 groups of two. Each group assisted with developing a story board that will form the basis of three films about the main themes that have emerged from the HAYA studies. Each group worked with the film crew as actors in the short film.</li> </ol>