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Power to participants

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Full Title: Power to participants: Methodological and ethical reflections from a decade of adolescent advisory groups in South Africa.

Authors: Lucie Cluver^{1,2} & Jenny Doubt¹, the Teen Advisory Groups South Africa, Inge Wessels^{1,3}, Carine Asnong⁴, Samantha Malunga⁵, Kerry Mauchline⁶, Beth Vale⁷, Sally Medley¹, Elona Toska^{1,8,9}, Kate Orkin¹⁰, Yasmin Dunkley¹¹, Franziska Meinck^{12,13}, Noxolo Myeketsi¹⁴, Samkelo Lasa¹⁴, Caroline Rupert⁷, Mark Boyes¹⁵, Marija Pantelic^{1,16}, Lorraine Sherr^{1,7}, Lesley Gittings^{1,8}, Rebecca Hodes⁵, Angelique N Chetty^{1,8}, Mildred Thabeng^{1,9}

Affiliations:

1. Department of Social Policy and Intervention, University of Oxford, Oxford, United Kingdom
2. Department of Psychiatry and Mental Health, University of Cape Town, Cape Town, South Africa
3. Department of Psychology, University of Cape Town, Cape Town, South Africa
4. Centre for Tropical Medicine and Global Health, Nuffield Department of Medicine, University of Oxford
5. AIDS and Society Research Unit, University of Cape Town, Cape Town, South Africa
6. Ministry of Education, Western Cape Government, Cape Town, South Africa
7. Independent.
8. Centre for Social Science Research, University of Cape Town, Cape Town, South Africa
9. Department of Sociology, University of Cape Town, Cape Town, South Africa
10. Blavatnik School of Government and Centre for the Study of African Economies, University of Oxford, United Kingdom
11. Positive East, London, United Kingdom
12. Optentia Faculty of Health Sciences, North-West University, South Africa
13. School of Social and Political Science, University of Edinburgh, United Kingdom
14. Teen Advisory Group, South Africa
15. School of Psychology, Faculty of Health Sciences, Curtin University, Perth, Australia
16. Brighton and Sussex Medical School, University of Sussex, United Kingdom
17. Health Psychology Unit, Institute of Global Health, University College London, United Kingdom

Abstract

Whilst the HIV response has made significant progress in increasing representation of adults affected by HIV, the meaningful inclusion of children and adolescents has lagged. But this may be a pivotal moment of change. We report on a decade of conducting adolescent advisory groups in South Africa, to reflect on youth advisory processes. Data was collected from 2008–2018 from adolescent advisors (n=60) and researchers (n=25), and included feedback sessions, social media, anonymous ‘post-boxes’ and interviews. Findings include the value of adolescent involvement in multiple stages of research co-creation and engagement in policy processes, the need for a safe environment; and supporting adolescents living in extreme vulnerability. We also discuss the reconfiguring of power and personal relationships, and logistical and financial needs of adolescent advisory groups. Findings suggest that adolescent co-creation of research is feasible, even with very vulnerable adolescents, although ethical considerations need to be carefully addressed. Benefits include increased methodological rigour, enhanced adolescent acceptability of research, and the recalibration of research dynamics for the empowerment of their target beneficiaries. Future studies could benefit from meaningfully involving adolescents through youth advisory groups.

Keywords: Adolescent participation, youth, children, methodology

Introduction

Advisory groups in HIV research: Since the 1990s, there has been progress in the inclusion of HIV/AIDS-affected adult populations in research. Largely in response to demands of AIDS activists, Community Advisory Boards are now required for many clinical trials (Mwinga & Moodley, 2015) and in the ethical review process. Recent guidelines include those by GNP+ (2017), U.S. NIH/NIDA (2014), and UNAIDS (2011). These focus on ethics and meaningful engagement, including using community networks to increase recruitment into clinical trials (Strauss et al., 2001; UNAIDS, 2006).

Engagement of adolescents. But these important efforts remain largely adult-focused (Mwinga & Moodley, 2015). In Sub-Saharan Africa, adolescents are now at the centre of the HIV epidemic: AIDS is the leading cause of adolescent death (Global Burden of Disease SDG collaborators, 2016), 14,9 million children are orphaned by AIDS (UNICEF, 2018), and a further 70 million have a HIV+ caregiver (Short & Goldberg, 2015).

Consequently, adolescents have increasingly become a focus of HIV research (Sherr, Croome, Parra Castaneda, & Bradshaw, 2014). But this has not brought a matching influence of adolescents on the research agenda (Melles & Ricker, 2018). Youth have articulated the need for involvement in scientific research and decision-making (ATHENA, Global Youth Coalition on HIV/AIDS (GYCA), & LinkUp, 2013). Searches found minimal studies mentioning adolescent advisors, suggesting that adolescent co-creation of research is limited and/or challenging to implement (Skovdal, Ogutu, Aoro, & Campbell, 2009).

Outside research, several new HIV initiatives aim to boost adolescent engagement, for example the IAS Adolescent HIV Treatment Coalition, the Global Network of Young People Living with HIV's READY movement, the International HIV/AIDS Alliance and the Peers2Zero coalition, led by Paediatric Adolescent Treatment for Africa and Africa Youth Positives Network. There are also examples beyond HIV/AIDS of including adolescents in

research and policymaking, such as the Lancet Commission on Adolescent Health and Wellbeing (Kleinert & Horton, 2016). A key consideration is the inclusion of both older (15-19 years) and younger adolescents (10-14 years) in engagement, with some concerns that youth (18-25 years, who may be less complex in terms of consent as legally adults) are sometimes thought to speak ‘for’ adolescents despite differences in outlook and experiences.

Focus of this paper: Co-authored by researchers and adolescent advisors, this paper highlights challenges and approaches to meaningful involvement of adolescents. We explore the potential for active co-creation by and with adolescents of HIV/AIDS-related research, through ten years of engagement.

Methods

First, we examine the evolution of adolescent advisory groups, using 10 years of research notes from advisory group workshops and interim engagement, recorded by the research team. Second, we critically analyse experiences and lessons learned, through exploratory analyses of annual feedback from adolescent advisory group members and researchers in South Africa (2008–2018). This included 1) Written notes of focus group discussions, made by facilitators and adolescents during advisory groups (n=65 participants, over 11 years); 2) Individual interviews with adolescent advisory members and facilitators (n=19); 3) Anonymous ‘post-boxes’ to allow adolescents to express experiences without social desirability bias (n=20 participants); and 4) Messages on social media, established to encourage further feedback. A WhatsApp group comprised of 10 young people with access to cellphones was established from 2017–2019, with questions such as ‘How could we improve the teen advisory group?’ ‘What does teen advisory group mean to you?’ ‘What did you like and not like?’ and ‘What advice would you give for future groups?’.

Ethical approval was obtained from the University of Oxford (SSD/CUREC2/11-40; SSD/CUREC2/12-21) and the University of Cape Town (CSSR 389/2009; CSSR 2013/04).

Written informed consent was obtained from all participant and primary caregivers prior to advisory group weekends. Participants were assured of confidentiality, except in cases of serious risk of harm to themselves or others, in which case safeguarding processes were followed.

Primary data was analysed following Braun and Clarke's (2006) thematic analysis. Themes were refined and disagreements resolved during analysis through discussion between adolescent and adult authors. We used literature on youth engagement, particularly work by Skovdal and Cornish (2015) and Cornwall and Jewkes (1995) to guide participatory research as sequential reflection and action, conducted with and by local youth rather than on them.

Results

Processes of engagement and lessons learned

Evolution of adolescent advisory groups: The development of 'Teen Advisory Groups' (shortened to 'TAG Team' by adolescents), was organic and non-formulaic. The first workshop was held over a weekend in 2008 in order to elicit adolescent input to a planned national study of South African 10–18 year olds, focused on identifying needs and solutions for AIDS-affected families. The initial group was recruited from prior research participants, school and NGO partners, and word of mouth, and 10-17 years old. It was intended as a single consultation. However, adolescents gave two key feedbacks. First, they conveyed the emotional value of a weekend away with other adolescents experiencing similar life experiences. Second, they asked where next year's weekend would be (Advisory Group, 2008). Thus, it was through adolescent initiative that a relationship began between researchers and young people.

Adolescents continue to shape the concept and development of the advisory groups. All took place as weekend activity-based workshops, with group sizes of 20–35 varying by

year and adolescents in the original group becoming group leaders. The groups became multi-generational, including younger siblings, babies and children of advisory group members, and maintaining a range of younger and older adolescents. Activities evolved to focus on three objectives. First, adolescent co-creation of research. Second, supporting personal development of adolescents; and third, providing a fun environment (see Figure 1 for logistical and financial considerations).

Adolescent involvement in research co-creation (Table 1). The adolescent advisory groups co-developed a set of large-scale longitudinal cohorts with embedded qualitative studies, including a national survey of adolescents ($n=3500$) (Meinck, Cluver, & Boyes, 2015), cohorts of adolescents living with and without HIV ($n=1519$) (Toska et al., 2016), and of adolescent mothers and their children ($n= 1027$), as well as randomised controlled trials of parenting support programmes (i.e. $n=1400$) (Cluver, Meinck, et al., 2018), and new Africa-wide research to identify services that improve multiple adolescent SDG outcomes (Cluver et al., 2019).

Adolescent advisors contributed to the initiation and refinement of research questions, and selection of study settings. For example, when examining adolescent ART-adherence, advisors identified unreliable responses in clinical facilities, where they were on ‘best behaviour’ (Advisory group, 2013). Consequently, this five year cohort conducted interviews in participants’ homes and adolescent-chosen locations (Toska, Cluver, Hodes, & Kidia, 2015). Recently, adolescent advisors have contributed through remote and online engagement to understanding adolescent experiences and research design during the COVID-19 pandemic.

Advisory groups also co-designed adolescent-friendly quantitative and qualitative research tools. For examples, surveys as ‘teen magazines’ with celebrities, quizzes and fun sections on sports and music (Cluver et al., 2013); visual life history narrative tools using the

metaphor of a ‘road of life’, (Cluver & Orkin, 2009; Gittings, 2019), and a series of ‘dream’ exercises, for adolescents to identify their wishes for clinics (Cluver, Pantelic, et al., 2018), medications (Hodes, Vale, et al., 2018), communities, schools and social welfare services (Toska et al., 2019) and aspirations (Hodes, Doubt, et al., 2018). They initiated and refined research questions and assessed feasibility of research methods. Adolescent advisors also co-designed training for fieldwork staff, emphasising the importance of non-judgemental, reciprocal approaches, genuine warmth, and high sensitivity towards risks of stigmatisation and gossip.

Adolescents in training and policy engagement. Advisory groups have increasingly co-led knowledge exchange, policy development and wider processes of youth engagement. The South African government has been actively engaged: adolescent advisors took part in the development of the South African Adolescent and Youth Health Policy 2017–2022, with the National Department of Health and UNFPA (National Department of Health, UNFPA, Hodes, & Cluver, 2017), Senior National Department of Health officials have joined adolescent advisory group weekends, and adolescent advisory group members have led consultation sessions by the South African National AIDS Council, informed UNAIDS global meetings, and been included in UNAIDS documents (UNAIDS, 2018). This has also built confidence amongst participants - one adolescent noted the importance to her that she could ‘*give advices to the department of health on how it can improve its services based on our situation and also the current services we were receiving from the health clinics.*’ (Individual interview, 2017)

In 2009, adolescents asked to make a film about their experiences and their advice to policymakers. They worked with a local filmmaker to make short videos, which were used by Save the Children, UNICEF and USAID with substantial policy impact. This raised ethical questions: adolescents wanted their experiences and challenges to be understood by a wider

community, but names were changed in case of future concerns about confidentiality. Over time, as social media use has become more widespread, adolescent advisors have shifted to using video for developing training for healthcare workers and policymakers, for example, in 2015–16 a series of ‘good clinic/bad clinic’ videos depicted the experiences that adolescents wished for in clinical settings, and those that deterred them. These were used by Paediatric Adolescent Treatment for Africa, to train healthcare staff in 24 countries regionally (Mark et al., 2017).

Experiences of adolescents

Understanding vulnerability and creating safety. Adolescents highlighted the need for engagement to take into account the severity of impacts that poverty and HIV/AIDS had on their lives and mental health:

“One advice that I would give to the researchers planning to set up TAG team is that they should be able to understand and be persistent and patient with the children that they will be working with. It is not easy to come from a rough background and sometimes it affects the way we think and the decisions we make but that can be possible to change if patience and support exists from who are trying to help.” (Individual interview, 2016)

Adolescents valued the supportive and open environment of workshops, and acknowledgement of all their perspectives. Older adolescents expressed that they took group leadership roles to ensure peer-group rules of kindness and welcoming of participants with different languages, from different locations, and those with disabilities (Focus Group, 2016). These adolescent-led dynamics were likely pivotal in enabling vulnerable participants to engage fully in advisory group activities.

Co-design and connection to the research: Adolescents also emphasised the importance to them of co-designing their own advisory groups, including the next year’s location, logistics, and programme of activities (Focus Group, 2017). They felt that it was

essential that they understand the aims of advisory workshops and intended benefits of different activities in order to ‘feel connected to the research’ (Individual interview, 2018). Both adolescents and researchers reported the value of workshops that lasted a full weekend, and took place in a safe location away from their own, high-crime communities. Adolescents expressed that whilst they wanted research in their local communities (Focus Group, 2018), in their home environments they had to be more guarded and less trusting, and that it initially took some time to feel safe during advisory workshops (Focus Group, 2011).

Personal connections. Adolescents reported that the development of personal relationships with researchers and peers was meaningful and maintained their involvement – and was facilitated by meeting annually. However, some also described an unequal weighting in knowledge of personal lives: ‘You know our stories; we don’t know your stories’ (Focus Group 2018). In response, staff adapted how they introduced themselves and engaged with adolescents, but challenges remain in thinking about how to come closer to real equity of knowledge.

Personal development. Adolescents asked for, and activities were designed to support their careers and goals (Table 1).

‘Coming from the kind of background anything could have happened or I could have made bad decision just to live a better life but TAG also has also served as an advising team.’ (Individual interview 2017).

But this also broke down conventional research study boundaries (Researcher interview, 2014). Increasingly, researchers linked adolescents to NGOs that could provide financial and educational support, and gave advice and support when requested on topics like contraception, school or professional development. In some cases, adolescents contacted researchers in emergency situations, and they were able to intervene to provide referrals and support (Researcher interview, 2016).

*‘What TAG means to me: Change, **advise, guidance, improvement, protection**’* (Individual interview 2017).

But these personal relationships also led to tensions between continuity and new recruitment. After ten years, none of our original group were still adolescents, and so a series of graduation workshops and ongoing support programmes were established, with some advisors joining the staff team. But recruiting ‘new’ adolescent advisors was challenging for both researchers and adolescents, with a sense of breaking a community established over years.

A stigma-free space. A common theme was the importance of the adolescent advisory group in creating friends who had also experienced HIV/AIDS in their families or lives, and providing a secure space in which they could discuss a highly-stigmatised disease:

‘Joining TAG made, [me] realise that I was not alone...we got the opportunity not just to share our stories amongst each other but also to advise each other’ (Individual interview, 2017).

The high value that they put on this informal peer support has also been demonstrated in the use of the TAG Whatsapp group, which members rely on for informal communication, posting messages to encourage their friends through difficult times, and checking on each other’s welfare.

In this high-stigma context, HIV status disclosure remains low. No group setting can ensure confidentiality, and so initially none of the advisory groups asked adolescents about their personal experiences around HIV. However, adolescent advisors developed their own code of conduct, including confidentiality of anything shared between them (Focus Group, 2009). Each weekend started by adolescents establishing a set of ‘ground rules’, written down and signed by each member. This process also contributed to the design of research-

developed interventions such as parenting programmes, which all include group-developed ground rules (Doubt et al., 2018).

Adolescent acceptability: Finally, adolescents reminded us of the importance of fun (Table 1). These young people living in extreme hardship expressed the value of opportunities to be playful in a safe environment. They appreciated activities that reduced adult-adolescent power discrepancies, including recreational activities such as painting t-shirts, board-games, campfires, movie nights, graffiti sessions and talent shows. This importance and value of fun has filtered into many aspects of research and programme design (Doubt et al., 2018), and into adolescent co-designed studies that demonstrated high retention (>90%) despite mobile and highly vulnerable adolescent populations (Cluver, Orkin, Yakubovich, & Sherr, 2016).

Discussion

There is growing demand for better data to address the needs of adolescents, including replacing categorisation of age bands from 0-14 and 15-49 years with disaggregation that recognises the key risk period of adolescence. Within this, are also increasing recognition of the importance of engaging children, adolescents and young people in the research that affects their lives (Nininahazwe et al., 2017). Our findings suggest the value of adolescent advisory groups. They also support calls to make adolescent engagement an expectation for HIV research (Oliveras, Cluver, Bernays, & Armstrong, 2018). Advisory groups take time, money and enthusiasm in order to benefit both research and adolescents themselves. These resource needs must be included in funding proposals and research timelines, suggesting a valuable role of funding bodies in holding researchers to account for genuine engagement with adolescents.

This paper explores some of the complexities, challenges and opportunities of engaging adolescents over a decade of research. There are important limitations – first that all advisory groups were in South Africa, and future research should examine other contexts and regions. Second, that much of the adolescent feedback used in this paper was not collected as rigorous research data, but rather as a part of improving our engagement and their experiences. Third, that the more critical feedback from adolescents came primarily from informal conversations, suggesting that adolescents may have hesitated to give negative feedback in group-based and even ‘anonymous box’ approaches.

Despite these limitations, findings provide insights that may be valuable for establishing or continuing adolescent advisory groups. In sum, they suggest three lessons. First, that adolescent engagement is *feasible*, with willingness to invest time, resources and reduce power differentials. Second, while many adolescents affected by HIV and AIDS are vulnerable, advisory group processes can be *safe*, non-stigmatising and beneficial, and result in frank and real engagement. And third, that engagement is *fundamental* to research: from research questions, to methods, to policy impact. Amongst these adolescent advisory groups, meaningful engagement has included being recognised for their expertise and authority, and opportunities to translate their experiences into supporting other young people. For researchers, this has been a sometimes challenging process through which power is re-signified – where adolescents co-direct the terms, questions and methods of research. And through this, new forms of understanding for both the ‘researchers’ and the ‘researched’ have been created.

We note that these processes also brought substantive ethical questions. Adolescents were co-researchers, with an emphasis on empowerment and co-creation. At the same time, adolescents were clearly exceptionally vulnerable. These dichotomies blurred traditional roles: many researchers reported difficulties in determining what level of engagement with

adolescents beyond advisory group weekends was appropriate. ‘Advisory group manuals’ provided some guidance, nonetheless, the relationships between adolescent advisors and researchers remain complex, requiring individual decisions that aimed to uphold ethical precepts of maintaining adolescent safety, while avoiding expectations that could not be fulfilled.

These findings also suggest the potential of adolescent advisory processes. After ten years, none of our original group were still adolescents, and so a series of graduation workshops and ongoing support programmes were established. But the process has changed everyone involved: adolescents expressed the fundamental importance in their lives of adults who believed in their capacity to succeed, feeling respected, and being part of something with wider impact: *“the respect and unity here are my best things”* (Individual interview, 2018). For researchers, the advisory group fundamentally changed our approaches – moving from a focus on technical, scientific and logistical concerns towards more nuanced understandings of participants’ lives, a greater empathy for their experiences, and – ultimately - higher quality research.

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Declaration of Interest Statement

No potential conflict of interest was reported by the authors.

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Table 1 Exemplar TAG activities

	AIM	ACTIVITIES	OUTCOMES
CONTRIBUTING TO RESEARCH	Identifying new topics that adolescents view as important for research	'TAG elections' where adolescents develop political manifestos of youth priorities for the next five years	Guided our research in incorporating adolescent parenthood and parent-child relationships as well as HIV/TB stigma in our research agendas
	Understanding youth priorities in health and community-level services in order to develop adolescent-relevant quantitative data collection tools	Adolescents plan new communities, 'dream clinics' and their own schools, identifying what they would include to support their goals	Adolescents have identified key sources of challenges not anticipated – for example regular sexual harassment of girls by security guards at healthcare clinics
	Youth input to emerging international development agenda	Sustainable Development Goal (SDG) games, including mapping tools of SDG priorities and how they are interlinked for young people	Strong adolescent emphasis on the importance of interlinked SDG goals across water, infrastructure, social protection, health, education and employment.
	Improving sensitivity training for research staff	Adolescents develop training sessions for researchers in how to recruit, interview and support them best.	Adolescents prioritise humour, warmth and absolute importance of being non-judgemental
	Conveying experiences of adolescents growing up in Africa	At adolescent group request, they made two short films of their experiences	Films used in training healthcare professionals, by NGOs such as Save the Children and the Coalition for Children Affected by AIDS
ADOLESCENT PRIORITIES IN GROUP PERSONAL DEVELOPMENT	Building skills in job-seeking	Developing CVs, learning about where and how to look for job opportunities, dressing for a job interview, planning how to respond to interview questions	
	Coping with family challenges	Informal and planned discussions of helpful coping mechanisms for challenges common to many advisory group members, such as living in a family affected by HIV, being HIV-positive, coping with violence.	
	Trying new experiences	Advisory group members are supported to try new activities that are not available to them in their home settings, for example slides, a walk up part of a mountain slope, climbing on rocks.	
	Spending time in nature	This was identified by adolescents as particularly important: exploring safely in a natural environment – for example, dipping into streams, seeing animals and birds.	
FUN	Art and creativity, confidence-building	Designing and making Teen Advisory Group t-shirts, newspaper-outfit fashion shows	
	Drama and singing	Talent shows, campfire adolescent-led singing sessions	
	Teambuilding	Building team towers	
	Group meals	Cooking together, picnics, barbeques and marshmallow-melting	

Fig 1: Logistical and financial considerations for running an advisory group workshop

	ITEM	CONSIDERATION
COST	Budget source	Will research funding approve a budget line for a workshop? Initial funding for teen advisory workshops was supported by funds from the principal investigator and researchers who volunteered their time.
	Sustainability	Sources of funding may limit or curtail the frequency and duration of adolescent advisory group meetings, despite adolescents expressing strong interest in enhanced and continued engagement.
	Unexpected participants	Children of participants or siblings unexpectedly accompanying participants need to be supported with childcare, food and sleeping arrangements need to be adapted.
SUPPORTING ADVISORY GROUP MEMBERS	Arranging transport to workshop	Reaching homes in multiple informal settlements; explaining indemnity forms associated with this, ensuring these are signed by participants.
	Medication	Ensuring this is not forgotten; Overseeing administration of medication and refrigeration if needed for medication.
	Consent to attend workshop	Contacting caregivers and teens without phones living in remote areas in order to secure consent to attend.
	Material support	Purchasing toiletries (toothpaste, sanitary pads etc) for participants who do not have access to these items.
WORKSHOP PLANNING	Facilitation	Engaging male and female facilitators, and those with local languages to optimise comfort for participants.
	Planning	Food, catering and research activities need to be planned in advance so materials and food can be prepared.