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## Peers, near-peers, and outreach staff to build solidarity in global HIV research with adolescents

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### Keywords

Adolescent; HIV; Bioethics; Community Engagement; Peer Educator; Global Health; Kenya

In the global HIV epidemic, solidarity-building approaches to engage adolescents in HIV prevention research are not just advisable, but are imperative. In low resource settings, research-driven interventions have decreased HIV transmission among adults; adolescents, however, have not seen in the same declines (UNAIDS 2019). One reason is that research on adult HIV prevention interventions cannot be applied to adolescents - adolescents are undergoing puberty, have different romantic and sexual relationships, are dependent on families, have higher concerns about confidentiality and privacy, and have less access to care (Patton et al. 2016). Despite this need for research with adolescents, adolescents are often excluded from adult studies because of difficulties with consent – particularly for biomedical interventions such as voluntary medical circumcision and pre-exposure prophylaxis (PrEP), and for interventions targeting highly marginalized groups, such as lesbian, gay, bisexual, transgender, queer and questioning (LGBTQ+) youth and youth using substances. Investigators also face recruitment and enrollment challenges with adolescents in the most at-risk and stigmatized groups. Street youth, orphans, youth in antenatal care, LGBTQ+ youth, and adolescents living with HIV, are difficult to recruit and retain in research because of concerns about reinforcing stigma, confidentiality, and privacy. We believe that these difficulties with research consent, recruitment, and retention may have its roots in a lack of solidarity between research teams and these highly vulnerable and marginalized adolescent

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participants. We describe the employment of peer, near-peers, and outreach staff, and the use of research methods that engage youth as co-investigators, to build solidarity between Western Kenya research teams and these adolescents most at risk for HIV.

Solidarity is considered a transformative value in global health research, challenging and changing the relationship between researcher and participant. Solidarity in research involves researcher and participant explicitly acknowledging interconnectedness, equal vulnerability, and interdependence (Tosam et al. 2018, Pratt and al. 2020). The practice of solidarity requires empathy and the moral imagination to view one's own actions, rights, well-being, and dignity as interconnected with those of others (Jennings and Dawson 2015). In adolescent global health, researchers and participants are as distant as possible from each other geographically and in economic, political, and social power, and the practice of solidarity requires building relationships between the two. Why is solidarity important? Solidaristic approaches have the potential to advance social justice, redressing inequities and past wrongs, and co-create knowledge (Pratt and al. 2020).

Solidarity is critical to advancing global adolescent health research, particularly in low-resource settings. Adolescents are a vulnerable and under-represented group in research. They have no political or economic power, and frequently do not have legal ability to consent. Adolescents most at risk for HIV are frequently the most marginalized and vulnerable – street youth, pregnant and parenting teens, LGBTQ+ adolescents and those with substance use experience even higher levels of stigma and poorer outcomes than their adult counterparts.

The employment of peers, near-peers, and young adult outreach staff has been one of our most successful approaches to recruitment and enrollment of vulnerable and marginalized youth in Western Kenya. We hypothesize that this approach is effective because it increases solidarity among research teams and adolescent participants. Peers educators are the same age as adolescent participants (e.g. both groups 14–17 years old); near-peers are just slightly older than participants (e.g., 19–24 years old), and outreach staff are adults, many of whom had similar adolescent experiences. Recent work has employed human design methods, as a way to engage adolescents as co-investigators. We have employed these methods over the past decade to build effective research relationships with marginalized adolescents in Western Kenya.

- The Orphans and Separated Children's Assessments Related to the Health & Wellbeing (OSCAR) study recruited HIV orphans in different care environments and followed them longitudinally to examine the influence of care environment on health. The social worker on the project was street-connected as an adolescent. Outreach staff include near-peers for street youth, several of whom have lived on the street, and, for orphans in family care or children's homes, community health workers who live in the same communities (Embleton et al. 2014).
- A Peer Navigator intervention hired two near-peers (18–24 years old) with experience on the street, and successfully recruited, linked and maintained street-connected youth to HIV testing and anti-retroviral treatment (Shah et al. 2019).

- A study of voluntary medical circumcision for street youth coupled with a cultural rite of passage and health education program similarly employed near-peers with street experience for recruitment and retention (Galarraga et al. 2018).
- A qualitative interview and focus group study of street-connected youth reproductive and sexual health needs employed a street outreach worker for to assist with sensitization and trust building in the street community prior to the research (Wachira et al. 2016)
- The Rafiki Center of Excellence in Adolescent Health is the first adolescent clinic in Kenya (Bwisa and Kipsang 2016). Rafiki employs peer mentors who work with adolescent patients. Peer mentors are near-peers, many living with HIV, integrated into the clinic team. In addition to engaging adolescents for clinical activities (health education, social support, navigating the health system), peer mentors contribute as team members to quality improvement and implementation research. A study of barriers and facilitators to the uptake of HIV pre-exposure prophylaxis was able to recruit Kenyan LGBTQ+ adolescents, a group facing not just social stigma, but legal persecution, because of trusted relationships with peer mentors.
- A project uses a human centered design methodology to engage adolescents in the design of an adolescent friendly antenatal care program. The project hired and trained pregnant or parenting adolescents as part of a youth design group, who participated in all aspects of the research process (Thorne et al. 2019). Use of a design approach not just brought marginalized adolescents to the table, but tasked them to participate in the solution.

The employment of peers, near-peers, outreach staff, and team members (hereafter referred to collectively as “peers”) enacts solidarity in research settings. Solidarity requires seeing oneself in others. When adolescents see peers on the project staff, they can imagine themselves on the research team. When professional research staff interact with peers on their own teams, they are more likely to see the possibilities inherent in each adolescent, and to see adolescents as people, rather than participants. The employment of peers helps researchers become more empathetic, to better understand adolescent perspectives and contexts, to see power inequities, and to respect adolescents’ strengths. Peers on research teams helps youth and researchers alike recognize their interdependence.

The employment of peers meets the social justice goals of inclusion of vulnerable communities in meaningful ways in research pertaining to them. Peers on research teams not only represent marginalized voices and experiences, but facilitate the broader inclusion of all participants’ voices and experiences to be represented in the research process. On a pragmatic level, the employment of peers builds the trust and rapport necessary for work with vulnerable adolescents, providing the social “scaffolding” necessary for meaningful adolescent participation.

Solidarity closely aligns with core principles of adolescent development (Patton et al. 2016). Adolescents with strong, bidirectional connections to supportive adults have lower risk behaviors (Resnick et al. 1997). The employment of peers connects adolescents to research

staff through outreach, and connects research staff to adolescents through empathy and understanding. Mentoring is a core principle of adolescent development. Peers on research teams can act as mentors for adolescent participants. Part of adolescent identity formation is finding a vocation. Employment implies the moral recognition of an individual's strengths and value to the research team. The employment of peers signals to adolescent participants that the research team values the perspectives and experiences of the marginalized group. Positive youth development necessitates a strengths-based approach. Solidarity between vulnerable adolescent populations and researchers is necessary for researchers to see the possibilities in each adolescent, and for adolescents to see these possibilities in themselves.

In global health contexts, the gap between adolescents and researchers in education, power, and access to resources is wide. Transformative approaches that simultaneously build solidarity and positive youth development, such as the employment of peers, are necessary to bridge that gap. Peers, near-peers, outreach staff and human-centered design methods enhance solidarity and facilitate the co-creating knowledge, making research more relevant and impactful for adolescents themselves.

## Brief Bio

Dr. Ott, Professor of Pediatrics and Adjunct Professor of Philosophy and Bioethics, is an adolescent medicine physician and pediatric bioethicist at the Indiana University School of Medicine. Her research focuses on community-based approaches to adolescent pregnancy and HIV prevention, and ethical issues related to adolescent capacity, consent and confidentiality. She has collaborated with AMPATH and University of Toronto research teams in Eldoret, Kenya for the past 5 years.

## References:

- Bwisa G and Kipsang W (30 11 2016). Youth in Uasin Gishu to get services at new centre in Eldoret Daily Nation. Nairobi, Kenya, Nation Media Group.
- Embleton L, Ayuku D, Kamanda A, Atwoli L, Ayaya S, Vreeman R, Nyandiko W, Gisore P, Koech J and Braitstein P (2014). Models of care for orphaned and separated children and upholding children's rights: cross-sectional evidence from western Kenya. *BMC International Health and Human Rights* 14: 9. [PubMed: 24685118]
- Galarraga O, Shah P, Wilson-Barthes M, Ayuku D and Braitstein P (2018). Cost and cost-effectiveness of voluntary medical male circumcision in street-connected youth: findings from an education-based pilot intervention in Eldoret, Kenya. *AIDS Research and Therapy* 15: 24. [PubMed: 30497481]
- Jennings B and Dawson A (2015). Solidarity in the Moral Imagination of Bioethics. *Hastings Center Report* 45: 31–38. [PubMed: 26332108]
- Patton GC, Sawyer SM, Santelli JS, Ross DA, Afifi R, Allen NB, Arora M, Azzopardi P, Baldwin W, Bonell C, Kakuma R, Kennedy E, Mahon J, McGovern T, Mokdad AH, Patel V, Petroni S, Reavley N, Taiwo K, Waldfogel J, Wickremarathne D, Barroso C, Bhutta Z, Fatusi AO, Mattoo A, Diers J, Fang J, Ferguson J, Ssewamala F and Viner RM (2016). Our future: a Lancet commission on adolescent health and wellbeing. *Lancet* 387: 2423–2478. [PubMed: 27174304]
- Pratt B and e. al. (2020). Solidarity and Community Engagement in Global Health Research. *American Journal of Bioethics*.
- Resnick MD, Bearman PS, Blum RW, Bauman KE, Harris KM, Jones J, Tabor J, Beuhring T, Sieving RE, Shew M, Ireland M, Bearinger LH and Udry JR (1997). Protecting adolescents from harm. Findings from the National Longitudinal Study on Adolescent Health. *JAMA* 278: 823–832. [PubMed: 9293990]

- Shah P, Kibel M, Ayuku D, Lobun R, Ayieko J, Keter A, Kamanda A, Makori D, Khaemba C, Ngeresa A, Embleton L, MacDonald K, Apondi E and Braitstein P (2019). A Pilot Study of “Peer Navigators” to Promote Uptake of HIV Testing, Care and Treatment Among Street-Connected Children and Youth in Eldoret, Kenya. *AIDS and Behavior* 23: 908–919. [PubMed: 30269232]
- Thorne J, Millar H, Mogaka R, Ogalo E, Doyle R, Atkinson-Graham M, Bernard C, Spitzer R, Vandermorris A, Onkware P, Rop M, Kibet V and Christoffersen-Deb A (2019). Starting from the Roots—Using Human Centered Design to Innovate an Adolescent-Centred Pregnancy Program in Western Kenya. *Journal of Obstetrics and Gynaecology Canada* 41: 735.
- Tosam MJ, Chi PC, Munung NS, Oukem-Boyer OOM and Tangwa GB (2018). Global health inequalities and the need for solidarity: a view from the Global South. *Developing World Bioethics* 18: 241–249. [PubMed: 29266755]
- UNAIDS (2019). *Global AIDS Update 2019: Communities at the Centre - Defending Rights, Breaking Barriers, Reaching People with HIV Services*. Geneva, World Health Organization.
- Wachira J, Kamanda A, Embleton L, Naanyu V, Ayuku D and Braitstein P (2016). ‘Pregnancy Has Its Advantages’: The Voices of Street Connected Children and Youth in Eldoret, Kenya. *PLoS One* 11: e0150814. [PubMed: 26942724]