

## Involving lay community researchers in epidemiological research: experiences from a seroprevalence study among sub-Saharan African migrants

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### ABSTRACT

Community-based participatory research (CBPR) has received considerable attention during past decades as a method to increase community ownership in research and prevention. We discuss its application to epidemiological research using the case of second-generation surveillance conducted among sub-Saharan African (SSA) migrants in Antwerp city. To inform evidence-based prevention planning for this target group, this HIV-prevalence study used two-stage time-location sampling preceded by formative research. Extensive collaborative partnerships were built with community organizations, a Community Advisory Board provided input throughout the project, and community researchers were trained to participate in all phases of the seroprevalence study. Valid oral fluid samples for HIV testing were collected among 717 SSA migrants and linked to behavioural data assessed through an anonymous survey between December 2013 and August 2014. A qualitative content analysis of various data sources (extensive field notes, minutes of interview, and training protocols) collected at 77 data collection visits in 51 settings was carried out to describe experiences with challenges and opportunities inherent to the CBPR approach at three crucial stages of the research process: building collaborative partnerships; implementing the study; dissemination of findings including prevention planning. The results show that CBPR is feasible in conducting scientifically sound epidemiological research, but certain requirements need to be in place. These include among others sufficient resources to train, coordinate, and supervise community researchers; continuity in the implementation; transparency about decision-taking and administrative procedures, and willingness to share power and control over the full research process. CBPR contributed to empowering community researchers on a personal level, and to create greater HIV prevention demand in the SSA communities.

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### Introduction

Sub-Saharan African migrants (SAM) are the second largest group affected by HIV in Western Europe, thus constituting a key population in HIV prevention (European Centre for Disease Prevention and Control [ECDC], 2013). Yet, considerable data gaps have been hindering evidence-based prevention planning for this group. Among them are the lack of sound HIV-prevalence estimates and insights in factors increasing the risk for acquiring HIV in host countries.

Vulnerabilities related to migration (Alvarez-del Arco et al., 2010; ECDC, 2010) together with intersecting forms of stigma and discrimination (Marsicano, Lydié, & Bajos, 2013; Nöstlinger, Rojas Castro, Platteau, Dias, & Le Gall, 2014) contribute to low HIV prevention demand among SAM (Ibrahim, Anderson, Bukutu, & Elford, 2008). In addition, heterogeneity of the communities and unstable leadership (National AIDS Trust.

HIV and Black African Communities in the UK, 2014) make them a “hard-to-reach” group for sexual health interventions and research (Prost, Elford, Imrie, Petticrew, & Hart, 2008).

Ownership of prevention is crucial for its effectiveness, in particular for achieving sustainable outcomes (Campbell, Foulis, Maimane, & Sibiyi, 2005; Gupta, Parkhurst, Ogden, Aggleton, & Mahal, 2008). Community-based participatory research (CBPR) approaches have demonstrated to be a promising approach in creating such ownership among vulnerable populations (Leung, Yen, & Minkler, 2004). CBPR requires the systematic adoption of participatory methods throughout the full research process, from its preparation to interpretation of data to dissemination of findings (Minkler & Wallerstein, 2003). The TOGETHER Project (Loos & Nöstlinger, 2015) applied CBPR to explore HIV prevalence and transmission dynamics among SAM

in Antwerp (Belgium). Led by a scientific team, community lay researchers were engaged in the full research process of a second-generation HIV surveillance study to inform sustainable HIV prevention. In this article we describe the experiences and lessons learned of involving a team of lay community researchers in this epidemiological research.

### Research context and methods: the TOGETHER project

To establish collaborative partnerships with the affected communities, we first conducted a series of consultation rounds with stakeholders from SAM communities originating from 48 sub-Saharan African countries in the Antwerp region. This resulted in establishing a Community Advisory Board (CAB). In addition, we engaged and trained nine lay community researchers. Selection criteria for lay researchers reflected as much as possible the communities' diversity in terms of gender, age, origin, duration of residence, education level and employment status, and specific study-related criteria. In line with GIPA (Greater Involvement of People living with HIV/AIDS) principles (UNAIDS, 1999), we actively recruited people living with HIV.

The TOGETHER Project's consisted of formative research and a core study, that is, a cross-sectional HIV-prevalence study among SAM in Antwerp city, conceptualized in collaborative efforts with the lay

community researchers. Using venue-based two-stage time-location sampling 753 SAM socializing in community settings were recruited between December 2013 and August 2014. In total, 77 study visits to 51 bars, churches, events, information meetings, shops, hairdressing salons, public parks, and squares spread over Antwerp city were undertaken. Bio-behavioural data to assess HIV-prevalence and transmission risk factors were collected at these venues. Oral fluid samples were tested for HIV using a validated testing algorithm (i.e., two ELIZA tests) and linked to an anonymous electronic behavioural questionnaire. The detailed methodology of the project has been presented elsewhere (Loos, Vuylsteke, Manirankunda, Deblonde, Kint, Namanya et al., in press).

The documentation of the CBPR approach, experiences, and lessons learned of involving lay community researchers in the HIV-prevalence study were documented in minutes of preparatory and -interview meetings, trainings, and extensive field notes produced during data collection. After every study visit, the principal investigator (PI) and two study assistants systematically described their own and the community researchers' experiences in extensive field notes revealing the reflexive process of an iterative approach. A qualitative content analysis was applied manually by both authors to all data sources to explore challenges, solutions, and opportunities of CBPR in three crucial stages of the research process: building collaborative partnerships to prepare

**Table 1.** Challenges and opportunities.

Emerging challenges	Opportunities and solutions
<i>Study preparation: building collaborative partnerships</i> Ensuring broad community support	Consultation round with stakeholders resulting in different study support mechanisms (community advisory board, lay research team); Specific selection criteria for recruiting lay researchers
Socio-cultural diversity of the lay research team	Reflected the heterogeneity of the sub-Saharan African community at large; Increased community support of the study
Lay researchers' different educational background	Research rationale and methods were translated adequately to facilitate informed decision-making among the lay research team
Lay researchers culturally grounded knowledge and beliefs	Knowledge and beliefs at times inconsistent with scientific evidence (e.g., HIV "risk"); Lay researchers gained insights in the complexity of HIV prevention; contribution to theory building
Equal contribution of all lay researchers to emerging issues	Leadership skills; Fostering a coherent team to facilitate equal contribution of all team members
Inflexible administrative rules in an academic context	Transparency about reimbursement ("volunteers"); Reimbursements within the boundaries of the project and the administrative rules (e.g., lay researchers' legal status)
<i>Study implementation: mobilization of community venues and data collection</i> Ensuring scientific rigour and data quality	Training and monitoring of the lay research team by the study PI (supervision, monitoring, trouble shooting); Improved research and data collection skills (e.g., interviewing) leading to enhanced data quality
Mobilization of community venues for study participation	Personal networks of lay research team useful in preparing study sites and recruitment of study participants
Support of community-leaders during data collection (i.e., HIV testing)	Using personal networks to gain community-leaders' support to improve study acceptability; Community-leaders acted as role models
<i>Study results: disseminating findings and prevention planning</i> Stigmatizing potential of study results	Instalment of a prevention task force to discuss dissemination of findings; Series of community-based workshops with wide community representation to decide on how to communicate the study findings
Translation of study results into concrete prevention activities	Prevention started during data collection due to visibility of the research teams at study sites; Organization of several feedback moments during the study to jointly interpret findings

the research; implementing the study; interpreting and disseminating results including prevention planning (see Table 1 for an overview of the emerging challenges and opportunities).

## Lessons learned

### *Building collaborative partnerships*

The diversity of the community researchers aiming at assuring broad acceptability of the study made it challenging to establish a collaborating team. Discussions during preparatory meetings were often vivid, particularly at the start of the study. Culturally grounded perceptions on what constitutes “risk” and “cultural sensitivity” were as diverse as the team. Yet, these discussions enabled the community researchers to gain insights in the complexity of HIV prevention and prepared them for data collection. For example, at the start some community researchers were convinced that HIV could only be acquired in promiscuous relationships and therefore only this behaviour should be addressed. Through intensive team discussions perceptions changed towards accepting multifactorial risks, which was useful for the field work:

“A guy was being difficult. He had filled in on his questionnaire that he was married, yet he received questions [in the survey] about his last sexual partner. According to him these were redundant: he was married, so he was safe of HIV”. I explained that this could be through for him, but this doesn’t apply to everyone. (field notes, Burundese bar)

Some community researchers questioned established scientific methodologies. They found it hard to understand that study participants diagnosed HIV positive could not be traced because of study participants’ anonymity. Research rationale and methods had to be explained according to community researchers’ different educational levels, ranging from university degree to not having concluded primary school, to support informed decision-making by the whole team. During this process, team-leadership was crucial to foster a coherent team in which all could contribute equally.

Being engaged in the research empowered the community researchers: having meaningful work increased self-confidence for those unemployed, and they became known HIV-resource persons in their communities. HIV-positive community researchers changed their stance towards their HIV status, some started to disclose HIV privately, others to give testimonies in public:

At one table the men were critical ... and quite discriminative towards HIV-positives. After 15 minutes, one of the community researchers living with HIV became irritated and intervened. She said: “I am HIV-positive and I am taking medication and am living a good life. Just

before you were looking at me interested. Now that you know I have it [hiv] will you still want to have sex with me?” The guy said yes and it was the start of endless questions. She answered them all. (field notes, Nigerian bar)

Community researchers received the maximum allowance for volunteer work according to Belgian law. While this was important given their economically vulnerable position, it required a transparent system with clear rules. Engaging volunteers in an academic context is a complex and time-consuming administrative procedure. Due to inflexible regulations people of undocumented status could not be hired as community researchers even though they may represent a significant proportion of SAM communities.

### *Study implementation and data collection*

After refining the standard operating procedures together, the community researchers received intensive training (total of 30 hours). They learned approaching study participants through interactive teaching, role-plays, and homework. Being part of the development process enhanced the community researchers’ interviewing skills and improved data quality. While they knew the rationale behind the procedures and instruments quite well, the PI constantly monitored the data collection process. This included being present at almost all data collection events, and using a standardized system for quality control of incoming data. These were complemented by individual follow-up of community researchers and two-monthly group interviews to discuss field experiences and find solutions for merging problems. Continuity in the community researchers’ team facilitated achieving the required data quality. Clearly, community researchers’ capacities and skills increased throughout the study. Apart from mistakes in data collection, also decline rates declined as the study evolved.

Community researchers’ personal networks played an important role in mobilizing and preparing the data collection sites (e.g., community-based organizations, churches, bars, shops, cultural events, hair salons and public places). Personal connections and credibility were essential for the acceptance of the study among the people attending the study sites. If leaders or venue-owners proactively showed their support, decline rates were lower.

### *Disseminating findings and prevention planning*

Prevention already started during data collection. The community researcher teams’ presence in community settings visualized the HIV epidemic and contributed to stigma reduction and increased awareness of HIV. Study participants often asked (intimate) questions

about HIV and sexual health to the community researchers and they referred to them to existing services:

A man came to me, he told me he had pain while peeing and it was itchy around his penis. I told him this might be an STI and he should get tested. I explained him about the low threshold testing centre. (field notes; Congolese event)

Preliminary study results were presented to the CAB and the community researcher for feedback and joint data interpretation at several moments. To deal with anticipated high prevalence rates, which can potentially be stigmatizing, the community researchers suggested the instalment of a “prevention task force”. Its role was to discuss within the larger SAM communities (i.e., going beyond the CAB and community researchers reach) how to disseminate the study findings and to plan for concrete prevention action. This was achieved through a series of community-based workshops in which the community researchers played an active role. Final results based on a sample of 717 valid oral fluid samples revealed a prevalence of 6.1% among SSA women and 3% among SSA men in Antwerp city (Loos et al., in press). It was consensually decided to not broadly communicate these figures using print-media, instead to raise awareness on condom-use, HIV testing, and acceptance of people living with HIV.

## Discussion and conclusion

Adding lay researchers’ insider perspectives within complex cultural contexts, as well as using different data sources for this secondary data analysis increased the study’s external validity (Wallerstein & Duran, 2010). Potential study limitations were community researchers’ subjectivity in terms of what they observed and documented in their field notes, leading to a potential bias inherent to qualitative research.

The documented experiences show that involving lay community researchers in epidemiological research is feasible when certain requirements are in place. These include sufficient resources to facilitate, coordinate, and supervise the research process to come up with tailored solutions to emerging problems during the research process. Willingness to share decision-making and to be transparent about the research process requires change on the side of the academic partners. It implies to share power and control over the process, while at the same time safeguarding scientific rigour (Horowitz, Robinson, & Seifer, 2009). This co-learning process (Minkler, 2004) enabled us to achieve several beneficial outcomes, which we may not have achieved otherwise. Through informal discussions, additional insights were

gained in understanding the socio-cultural realities in which SAM live through integration of their insider perspective. Community researchers were provided with the opportunity to improve knowledge and skills in relation to HIV prevention. They gained self-esteem as HIV-resource persons in the community (Mosavel, Ahmed, Daniels, & Simon, 2011), and the acquired research skills may be personally beneficial for them in the future. Clearly, the study design increased awareness among the wider community about HIV/AIDS, and prepared the ground for future interventions.

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