# Reflections on participatory HIV prevention research with fishing communities, Uganda

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## Introduction

In this article, we reflect on our experiences as a multidisciplinary team applying participatory learning and action methods to research HIV/AIDS prevention in fishing villages in Uganda. Our team included people born and raised in fishing communities with professional training in social and medical anthropology, behaviour change communication, health and social work. Because of our backgrounds, we were able to break down communication barriers and build trust with participants, facilitating discussions on issues that are socially sensitive and challenging deeply held beliefs and norms.

## Background

HIV prevalence in Uganda is estimated at 7.3% (MoH *et al*., 2012). But a recent study in the Lake Victoria basin fishing communities found a prevalence of 22% (Opio *et al*., 2011), while previous studies estimated it to reach up to 30% (MAAIF, 2005; Asiki *et al*., 2010). Yet these communities are not being reached effectively by existing health and AIDS services. Fishing and fish trading are mobile occupations and people may be absent from their homes when HIV counselling, testing, education and sensitisation services are available (Mojola, 2011; MoH and ORC Macro, 2006).

From July to September 2009, our multidisciplinary team conducted participatory research in six fishing communities in Lake Victoria at four landing sites and two islands in Wakiso and Mukono districts (see Box 1).[1] Our objective was to explore innovative, community-appropriate and gender-sensitive ways to reach those at risk of HIV infection and engage them in HIV prevention research.

[1] The research was done by the Uganda Virus Research Institute's International AIDS Vaccine Initiative HIV Vaccine Programme (UVRI-IAVI) in partnership with Africa Social Development and Health Initiatives (ASDHI), a local community-led organisation that is currently implementing HIV/AIDS and community development activities in the fishing communities of Ssi-Bukunja sub-county, Buikwe district in Uganda. The research was funded by The Wellcome Trust UK. See: UVRI-IAVI HIV Vaccine Programme: www.iavi.or.ug and Medical Research Council MRC/UVRI Research Unit on AIDS: www.mrcuganda.org

Photo: Peter Kayiira Byansi

**Ssenyi fish-landing site, Lake Victoria where the Africa Social Development and Health Initiatives offices are located.**

**Box 1: Our multidisciplinary research team**

Our team had two team co-leaders, Peter Byansi and Paul Bukuluki. Peter Byansi grew up in a fishing village and is trained in both social development and health. Paul Bukuluki is a medical anthropologist who grew up by the River Nile and now works in fishing communities. Six research assistants (three women, three men) have experience in HIV/AIDS and sexual and reproductive health (Rebecca Nabbosa, Ismail Ddumba Nyanzi, Jimmy Kalinda, Arthur Musasizi, Daphine Kasiwa Ntege and Easther Nassonko Kavuma). Four are from the Africa Social Development and Health Initiatives (ASDHI) and have a fishing background.

Our team worked in partnership with two researchers from the Medical Research Council/UVRI Research Unit on AIDS and staff from UVRI-IAVI (Janet Seeley, Pontiano Kaleebu, Leslie Nielsen, Kidega William, Simon Sigirenda and David Walugembe). Pontiano Kaleebu is a researcher from MRC/UVRI and trained in medicine and immunology while Janet Seeley is a social anthropologist. Leslie Nielsen (UVRI-IAVI) is trained in project management, and Simon Sigirenda in social science, while Kidega William and David Walugembe are trained in health services management and communication/public relations respectively. The UVRI Scientific and Ethics Committee and the Uganda National Council for Science and Technology granted ethical clearance for the research.

## Methods and processes

Two weeks before the research, we (team leaders Peter and Paul) visited two of the research sites and observed people going about their activities. Our aim was to assess which research methods would be appropriate for working with most-at-risk individuals or groups. We also identified key contact persons and groups to work with in identifying and selecting participants.

Informal conversations with fisherfolk, local leaders and women and men living and working at these sites revealed that there are individuals, structures and networks that act as gatekeepers who could positively or negatively influence the research. First we needed to identify and engage with these gatekeepers, including community leaders, boat and net owners, landlords, peer networks and informal local leadership structures in different ethnic groups.

Most gatekeepers help to mobilise participants to link with a research team.

However, some wield power and influence which may impact upon people's agency. For example, some gatekeepers monitor and enforce government fisheries policies and guidelines. Some provide employment. Others own or control landing sites or camps on islands. When gatekeepers endorse a research intervention, individuals may feel obliged to participate for fear of compromising their security, tenancy or livelihoods. Gatekeepers might also try to control the process, for example by influencing our research team to work with certain groups and not others. These visits also revealed that daytime-only research would miss crucial information from individuals and groups such as fisherfolk, sex workers, fish driers, barmaids and restaurant workers. In addition, most fisherfolk are busy and may prefer not to talk to a researcher in their free time.

At this point, we made two key decisions. The first was to make full use of our team members with a fishing background, interacting with the communities by helping to sort nets or mend boats. Secondly, we decided that our research team would spend four days at one of the research islands, to experience life there first-hand. This was a key strategy for encouraging participation and learning more about the context and relevant issues. It enabled us to build rapport with gatekeepers and community members and helped to allay suspicions. Gatekeepers could express feelings, opinions and information without feeling threatened or undermined. Both gatekeepers and community members also felt comfortable discussing who speaks for whom. For example, we learnt that men and husbands often speak for communities and wives respectively. We sought to identify and understand such power dynamics by deliberately reaching out to those that would be silenced.

We divided into three sub-teams, each with a member with a fishing background. Our assistants were trained in the use of PLA methods. Research tools and checklists were pre-tested at Ggaba, a large landing site near Kampala, and throughout the preliminary analysis. To improve the quality and relevance, the checklists were refined to build on learning from the communities. Supervised by the team leaders, the research assistants helped in the participatory data collection processes and so were well informed about community issues.

Community participation in our research took the form of 'cooperation' and 'co-learning' (Kanji and Greenwood, 2001). Cooperation is 'where local people work with outsiders to determine priorities; the responsibility to direct the process lies with outsiders'. Co-learning is 'where local people and outsiders share knowledge, create new understanding and work together to form action plans'. We chose this approach so that participants could reflect and share their own ideas on how to effectively reach them, use terms that related to their realities and experiences, and identify community resources for communicating HIV prevention messages and HIV prevention research.

PLA methods were important in enriching our understanding of fisherfolk's experiences, behaviour, sub-cultures, power structures, cultural and socio-economic dynamics. It helped us to understand how these relate to HIV prevention research, HIV risk, and vulnerability in most-at-risk individuals and groups. Approximately 220 people participated in the research, including commercial sex workers, fisherfolk, boat and net owners, young people, business men and women, motorcycle (*boda boda*) transporters, lumberjacks, wood-loaders, restaurant, lodge and bar owners and workers, religious and local leaders, and staff from civil society organisations working in the research areas. The participants were aged between 15 and 49 years old.

Using PLA methods helped to create knowledge, construct new meanings and

mobilise community capacities to cope with and transform their situations (Cornwall and Jewkes, 1995). We used a variety of methods, including Venn diagrams, seasonal calendars, causal linkage diagrams, pair-wise ranking and scoring, brainstorming, social mapping and key informant and focus group discussions. Informal conversations, in-depth interviews and participant observation were mainly used during interactions with people sorting nets, women drying fish, and in restaurants, bars and venues such as video halls (known locally as *bibanda*) and trading centres, markets, landing sites and sports fields. Informal conversations and interviews took place spontaneously while we were observing or joining in activities. In-depth interviews were used with commercial sex workers and their selected clients.

We held separate PLA sessions for different groups of female and male adults and youth (aged 15 to 30). Community members and researchers carried out on-the-spot preliminary analyses of emerging themes and issues. This helped to triangulate and validate the results and ensure community ownership and understanding. Representatives from these groups then presented the results to other community members at the different data collection sites. Copies of social maps were left in the community with the session leaders. The research team also facilitated discussions and provided feedback from informal conversations, in-depth interviews and participant observation. These meetings helped community members to enhance their knowledge of the drivers of HIV, discuss community-appropriate communication approaches and identify HIV service gaps. Crucially, they were also able to ask questions about the little-understood concept of HIV prevention research.

## Lessons learnt, critical reflections and analysis

We used a range of methods to build trust and unravel realities, meaning and perspectives. We gained insights into people's day-to-day lives and behaviour, and made comparisons between different groups.

### Using appropriate communication channels

Some methods, such as informal discussions, allowed people to open up about culturally sensitive or potentially stigmatising issues, which they may have been reluctant to share in group settings. For example, in focus group discussions (FGDs), people said they preferred to receive information on HIV and HIV prevention from local, cultural/ethnic and religious leaders. These channels are targeted by health and AIDS information seminars and other service providers. However, informal conversations revealed that information is not always effectively passed on to others via some of these channels.

Religious leaders were perceived as moralistic and stigmatising in their communication approach about HIV and AIDS. Other local leaders were said to be seeking monetary gains and the prestige associated with NGO training and research, rather than to learn and share information. Instead, participants suggested alternative interpersonal communication channels. These included community events like funerals and weddings and individuals such as traditional healers, peers, friends, *sengas* and *kojjas*.[2]

These communication issues had not been mentioned in the earlier group discussions. Further discussions revealed the social and culturally constructed relationships that at times impede open discussion of deeper issues. We were able

[2] *Sengas* and *kojjas* (paternal aunts and maternal uncles) hold a special place in Baganda culture as sources of information, particularly about sex and marriage (Sengendo *et al*., 2001; Muyinda *et al*., 2003).

to explore these relationships and discuss the perceived use, effectiveness and reliability of using such communication channels to reach most-at-risk individuals and groups.

These informal conversations and interviews revealed some significant issues that shed more light on HIV risk and vulnerability. Women shoulder the biggest burden of HIV in Uganda. During group discussions and key informant interviews, people said that HIV risk was primarily driven by casual, commercial and multiple sexual relationships with people of unknown HIV sero-status, and that women's involvement in casual and multiple sexual relationships was motivated by the need to make money. However, informal conversations revealed other underlying reasons, such as the need for sexual satisfaction, companionship, support, security and love. Some women, for example, said that sex was a means of getting someone to talk to, share their problems with and/or protect them from other men. Unfortunately, they said, such men were rare, which is why the women changed sexual partners. Other women said they were driven into multiple sexual relationships to seek revenge and/or find solace from abuse they face at home.

Our research communities said that intimate partner violence was common, often sparked by jealousy over infidelity. These are sensitive family matters that participants felt unable to share during FGDs or other group PLA activities for fear of being ridiculed or shunned. Most Ugandan cultures forbid discussing such matters in public. The methods we used provided a safe space and enough time for people to share their thoughts, concerns and realities.

### Working with a multidisciplinary research team

Having a multidisciplinary team with knowledge of HIV and communication and facilitation skills was instrumental in asking participants the right questions. Our team members with a fishing background were able to brief the rest of us about the life and culture of fisherfolk. We went into the field with the right attitude, ready to listen and respect local people and their knowledge. Camping at one of the research islands, helping with community activities, playing football or just sitting talking with people helped with genuine communication. Participants were particularly open with those of us with a fishing backgound, who they felt understood their way of life, culture and realities. These approaches allowed participants more time to talk and for us to listen.

Having a team with men and women was also an advantage, but it was not without risk. Some male participants were drawn to the women on our team, while some women participants focused on the men, perhaps hoping to find a new partner. However, both men and women appreciated having someone of their own gender to talk to about HIV, treatment and other health issues such as sexually transmitted diseases. This gave us opportunities to discuss their experiences, perceptions of HIV risk and vulnerability, and participation in HIV prevention research. Health matters requiring treatment, consultation and counselling were referred to UVRI-IAVI partners, The AIDS Support Organization (TASO), Entebbe Hospital, and clinics supported by Marie Stopes Uganda.

### Benefits of using participatory approaches

Using PLA methods enabled us to discover that issues around gender, ethnicity and social position inevitably create differing realities, conflicting perspectives, interests and needs. To effectively uncover and mediate such conflicts, researchers must be adequately briefed and trained in participatory research, competencies and attitudes. PLA methods also enabled different participant groups to express and share their knowledge and realities, such

as sexual abuse. With their permission, we shared their anonymous stories with others during later community dialogues. This raised awareness of the problem and showed how abuse contributes to the spread of HIV. Discussions on the social maps showing key community resources (e.g. the TASO and UVRI clinics located near the study sites) revealed that some people had not known of their existence but were keen to take advantage of such resources in future.

### Community mobilisation

Importantly, the PLA methods showed people that they can gather data, analyse and use it to plan and develop context-specific solutions. Using the results of the research, UVRI-IAVI engaged study communities to plan and implement innovative communications outreach activities. Through their respective leadership structures, communities were involved in mobilisation, providing venues for activities, identifying community outreach teams and providing feedback. Communities identified and selected community peer leaders who were then trained by UVRI-IAVI. Community peer leaders led the process of sensitising communities and engaging them in discussions about HIV and HIV prevention research. Activities included the use of music, dance and drama, community dialogue, sports and painting boats with HIV prevention messages.

Community members realised that the participatory research had influenced subsequent interventions. This helped to build their confidence in mobilising their own capacities and participating in decisions and activities that affect their lives. Sustaining activities is still a challenge, but the fact that communities have started to use their potential to influence and share in planning and implementing community interventions is a sign that the empowerment process is taking place.

### Developing HIV prevention strategies that communities can relate to

Our final lesson is related to people's understanding of HIV prevention research and the chronic lack of consistent HIV and health services in the study communities. At the time of our research, people understandably knew little of HIV prevention research. UVRI-IAVI and MRC, with the support of the European and Developing Countries Clinical Trials Partnership, were conducting a three-year fisherfolk study in some of the study areas.[3] To them, the concept of HIV prevention research seemed both complicated and the preserve of scientists. By using participatory research methods, we realised that community members were more concerned about the lack of health and HIV/AIDS services. They only understood HIV prevention research within the context of increasing their access to HIV prevention, treatment and care services. If they are to stimulate systemic social change, HIV prevention research strategies need to integrate other programme elements and service provision, and involve developing partnerships with informal networks of ethnic/traditional, religious and opinion leaders and also decision makers at different levels.

In response to the health and HIV service gaps identified by the study communities, UVRI continues to work with service providers such as TASO, Entebbe Hospital and Marie Stopes Uganda to address these gaps. These organisations offered services in some communities before the research, but now their services are more sensitive and responsive to community issues and concerns, and involve community structures in planning and implementing interventions.

[3] This is a two-country study mapping the prevalence of HIV and tracking its transmission among individuals in the lake-shore towns and island villages in Uganda and Malawi.

Photo: UVRI


**A boat painted with an HIV prevention message, Kigungu fish landing site, Entebbe, Lake Victoria.**

## Conclusion

Complementing group methods with informal conversations and participant observation helped bring to the fore latent issues that people were reluctant to discuss in public. Using trained researchers from fishing communities that participants identified with helped to break down communication barriers and build trust, and facilitated the sharing of issues that participants perceived to be both sensitive and challenging. A blend of PLA methods and ethnographic approaches such as participant observation proved invaluable in our research with fishing communities, and would be with other vulnerable or high risk populations.

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