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LESSONS AND EXPERIENCES

From community as data providers to data users: developing a community-led research platform using routine program data in Kenya

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ABSTRACT

Community-based organizations (CBOs) are critical in providing trusted and tailored HIV/STI services to gay, bisexual, and other men who have sex with men (GBMSM). Despite significant strides in CBO involvement in HIV/STI research in Kenya, there remain gaps in meaningful engagement and capacity-building, especially quantitative research. We share our experience and lessons learned in developing HEKA (Health Research Intervention Kuthamini Afya Yetu), a community-led research platform where community members are leveraging their routinely collected program data to design research aimed at strengthening HIV/STI programs. HEKA focuses on building capacity and quantitative scientific literacy within CBOs.

Guided by the program science framework, an iterative, bi-directional framework linking research and program implementation, our seven CBOs identified areas for quantitative skills development and together with academic partners, established interactive learning activities through a workshop and set a common research agenda for future steps. The collaborative process centered around applying the skills learned to appraise program coverage and its drivers, so as to improve HIV/STI outcomes for the communities we serve.

The workshop included introductory sessions on quantitative research methods, data structures, and R programming (an open-access software environment for data management and analysis). We also maintained engagement through a new online group where we have met monthly. Through our experience, we learned that using a co-leadership framework where research direction evolves through shared/delegated leadership between staff from the different organizations and peer-to-peer mentorship was instrumental to our success. However, we encountered some challenges in the process, including sustainability of funding to maintain engagement. Other challenges have included balancing varied learning paces due to diverse staff roles, navigating a volatile socio-political climate with regard to GBMSM issues, and long commutes for in-person meetings. Competing demands from program funders, such as stringent monthly reporting requirements amongst these, have also contributed to delays in participation.
Despite these challenges, HEKA demonstrates the potential for community-based and led research in the HIV/STI field. Our experience can serve as a model for other CBOs aiming to lead collaborative or independent research and build capacity.

Keywords: Community-based participatory research, HIV, STI, program, data, science.

Abstract in Español at the end of the article

INTRODUCTION

Since the early days of the HIV epidemic, communities have demanded to play an active role in HIV research. HIV activists have challenged the portrayal of people living with HIV as *"victims"*, shifting the narrative to self-empowerment and community-led HIV research [1]. There has been some progress in collaborations within clinical research and the social sciences, such as the recently completed polling booth survey where community members acted as data collectors [2]. However, there remain gaps in meaningful community engagement in many quantitative fields (e.g., mathematical modeling) for determinants of HIV/STI disparities, with concerns surrounding community involvement as a checkbox (minimal community engagement to fulfill the appearance of community participatory research) [3].

A recent review of peer- and community-led HIV responses revealed gaps in meaningful community and academic collaboration [3]. This is particularly so around alignment between academics' research goals and the priorities of community programs (*"democratic deficit"*) [3]. Many reports on community engagement provide a narrative of experiences and lessons learned (usually a researcher-curated viewpoint), with fewer reports appraising their effectiveness in adding value to the delivery of community programs and health outcomes (the community viewpoint) [3].

More often, a paternalistic approach to research persists, where communities identify local issues, and academic researchers lead the research/response—often positioning themselves as the holders of quantitative expertise. The problem with this approach is that the community organizations fall behind in research capacity to conduct assessments using program data, adapt program delivery, and independently secure competitive funding. There have been attempts at developing community-led research networks in Kenya focused on quantitative research, such as the G10 through the International AIDS Vaccine Initiative (IAVI). However, G10's capacity has mostly been as an advisory board for quantitative research [4].

Against this backdrop, our seven community-based organizations (CBOs) serving gay, bisexual, and other men who have sex with men (GBMSM) in Kenya came together to form a community-led research initiative (HEKA: Health Research Intervention Kuthamini Afya Yetu) to lead quantitative research through community-led program science. Program science is a framework that systematically encourages a bi-directional approach where program implementers inform research, and research, in turn, informs program implementation and policy in an iterative process [5]. This framework has the potential to unify community-academic researcher collaborations to inform the three pillars of program decisions: strategic planning, program implementation, and program evaluation.

As in many countries in Southern and Eastern Africa, there is a high prevalence of HIV/STI in Kenya [6]. In this context, operationalizing community-based HIV/STI program science has largely drawn from qualitative and social science practices, with a few examples using quantitative practices [7]. These include but are not limited to, building capacity in qualitative data collection such as project ethnography. When quantitative methods are used in program science, such as cross-sectional surveys or analyses of programmatic co-

hort data, community partners have previously been engaged through consultation to develop routine data collection tools and/or to design interventions [8]. Often, input on the quantitative analyses takes the form of community advisory boards (CABs)or expert advisory groups that provide some research oversight ensuring that analytic interpretations are contextually relevant (validating that findings *"make sense"*). CAB members primarily contribute their lived experience.

Experience of developing HEKA and lessons learned

In this article, we detail the experience of our seven CBOs in developing HEKA. We also share a collective reflection on the lessons learned in the process from the community perspective. Particularly, we share reflections on building community-community and community-academic trust and shared leadership; logistics and practical considerations; and based on facilitators or barriers that emerged, we share pathways for community-led quantitative HIV/STIs research. The HEKA initiative also highlights the innovative way in which we are conceptualizing the use of the data that are routinely collected by our programs. This aligns with the WHO's Consolidated guidelines on person-centered HIV strategic information, which emphasized the potential impact of using programmatic data as a reliable way of tracking HIV indicators (prevention, testing, and treatment) in order to enhance timely decision-making and linkage to STI and other services [9].

Site setting

GBMSM in Kenya experience disproportionately high rates of HIV and STI [6]. The existence of regressive laws and resurgence in public discourse that reinforce discrimination against same-sex sexual practices in Sub-Saharan Africa, and in Kenya particularly, amplifies disparities in health and wellbeing [10]. Qualitative studies show that GBMSM in Kenya feel more comfortable utilizing community-based services, and CBOs have been associated with effective/targeted approaches to addressing the HIV/STI epidemic [11]. The seven CBOs currently serve six counties: ISHTAR (Nairobi County), HOYMAS (Nairobi), HAPA KENYA (Mombasa), AMKENI-Malindi (Kilifi), KYDESA (Nakuru), Q INITIATIVE (Uasin Gishu and Trans-Nzoia), and MAAYGO (Kisumu), representing a mix of moderate to high-priority counties.

Guiding principles and authors' roles and positionality

The HEKA research initiative was founded in 2018 under the principles of GIPA/MIPA-Greater/Meaningful Involvement of People Living with HIV/AIDS [12,13] and Community-based Program Science – program coverage framework for HIV/STI research [5]. GIPA/MIPA highlights the importance of the meaningful involvement of people living with or affected by HIV/AIDS in the HIV epidemic response. Complementary to that, community-based program science in HIV/STI coverage emphasizes community collaboration in the iterative use of routine program data to monitor and tailor program delivery.

The organizations were identified through the GBMSM HIV prevention network of organizations implementing HIV programming in Kenya. Twenty-one community program managers and monitoring and evaluation staff from across the organizations constituted the team. The program managers and monitoring and evaluation staff were included because they are directly involved in coordination and data management in their organizations. Through our shared experiences as program staff - some living with HIV, some identified as sexual/gender minorities, or closely connected to these communities - we brought critical lived experience and professional knowledge to this collaboration. These positionalities shaped our commitment to peer learning and mutual support. We have progressively mobilized for program-to-program support. In 2019, the HEKA collective reached out to the Mishra Lab through SM for technical support as an academic collaborator with formal training in epidemiology and mathematical modeling.

SM is a clinician scientist working in the field of mathematical modeling of infectious disease transmission, specifically focusing on HIV and other sexually transmitted diseases. LL, PB, and RL are social scientists working on community-based research in the HIV/STI field, including in Kenya and with some of the HEKA organizational partners. NT is an epidemiologist who has supported HIV/STI programming in a public health department and is serving as the rapporteur for this paper. NT, KCYY, HM, RL, PB, LL, and SM as academic partners, have provided ongoing mentorship and support through research and facilitating capacity-building for our community researchers.

HEKA Research Initiative collaborative process

Figure 1 details the systematic process we are undertaking since establishing the research initiative.

At a national level, all sexual and reproductive health CBOs would meet quarterly (for peer assessment meetings) to foster peer-to-peer support across programs and enhance program delivery, through sharing best practices and local advocacy.

During one such meeting in October 2018, the seven CBOs initiated conversations between our respective representatives. This took place in the context of long-standing academic collaborations where we felt excluded from some of the analytical-focused research components and the population mathematical modeling working groups. We (CBOs) set up monthly meetings thereafter, where we gathered information on the programmatic priorities of our organizations and assessed the baseline research expertise in our respective programs. We recognized the need for sustainable and rigorous capacity building within our research initiative, and as such, approached an academic colleague (SM) to co-design a skill development plan. We decided to organize an in-person meeting with all team members

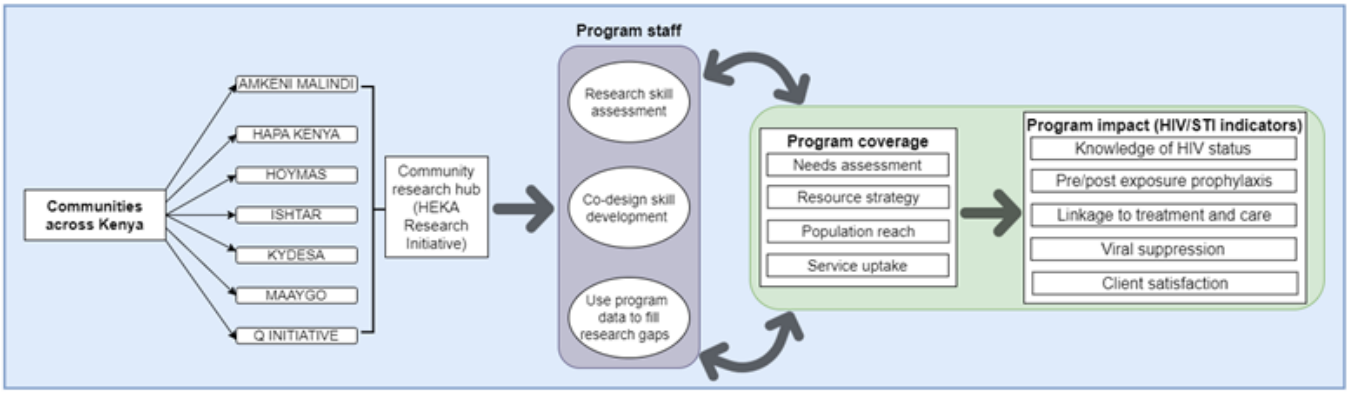

Figure 1. Systematic illustration of the HEKA Research Initiative collaborative process.

from the respective CBOs to initiate skill development and set up a regular meeting agenda.

Organizing in-person meetings with representatives from across the country required financial resources, so we prioritized applying for funding. The COVID-19 pandemic brought our efforts to a pause, though it provided us with time to reassess our in-house tools in program delivery. We had generated routine or day-to-day person-level data through all the years of client contact. As such, we pursued funding to align our goal of holding regular in-person and virtual program staff research skill development, with the use of routine programmatic data to guide our response along the HIV/STI prevention and treatment cascade. In 2023, we submitted the proposal, *"Characterizing the HIV epidemic, prevention gaps, and opportunities among men who have sex with men in selected counties in Kenya using routinely collected program data before, during, and after the COVID-19 pandemic: a community-based research initiative"* to Amref Health Africa and NACOSTI (National Commission for Science, Technology, and Innovation). The proposal was successful, and we obtained pilot funding to support our regular meetings and initiate the implementation of the proposed project.

At the center of the HEKA research initiative is ensuring that we deliver optimum services and improve the health outcomes for the communities we serve. Through quantitative skill development, we aim to use routine programmatic data to assess the needs of our communities (e.g., quantifying the client population longitudinally); to map program initiatives and resources to population size (resource strategy); and use analytic tools to assess disease drivers and contextual factors influencing population reach. The HEKA research initiative systematic process is intended to be iterative.

Collaborative meeting and outcomes

With the pilot funding, we organized the first official in-person meeting in November 2023. Beyond using this to set up our overall goal as a research group, we designed this as a three-day intensive workshop. This included interactive teaching and hands-on exercises on research concepts and methodology of quantitative analysis. The choice of three days and a mixture of didactic information sessions, hands-on learning, and small group projects was based on prior collaborative work and the Coordinating with Communities guidelines for improving community involvement in HIV prevention [14]. For the workshop, we co-designed a skill development plan with our academic partners (NT, HM, and SM); this included an introductory session on the use of R programming language (an open-access software environment for data management and analysis) [15].

The didactic component included sessions on study designs, formulating a *"good"* research question, types of variables, and principles for generating research study data from routine program data. The hands-on component involved preparing data from Microsoft Excel files as wide and long data formats and learning to use R to import data, using a dummy dataset. The team was split into three small working groups where we formulated three research questions, and each small team presented their work to the whole group, before questions were refined and specific objectives included.

At the end of our three-day workshop, we had drafted the overarching research goals for HEKA (Table 1), identified three pertinent research questions (Table 2), and set up a regular online meeting schedule for once a month with continuous communication via a new WhatsApp group.

Since the initiation of our collective research initiative, we have informally engaged in reflective conversation to gather thoughts on what lessons we have learned so far in the process and based on challenges that have emerged, what our recommendations would be. After our first in-person meeting, we formalized the various thoughts we had in writing; the draft was reviewed by team members before final inclusion in this paper. Quotes from HEKA members (co-authors) are also included as lessons learned. These quotes are included anonymously, to protect confidentiality. We have ethics approval for HEKA's work through AMREF Health Africa (ESRC P1490/2023) and the University of Toronto (RIS Human Protocol Number: 46631).

Reflections on lessons learned

1. Co-leadership framework

As community researchers, we often are token members of research teams, and so, would lead activities within the confines of the research plan of our academic colleagues. Contrary to the usual approach, the HEKA research initiative has been uniquely successful because we adopted a co-leadership framework, where the direction of our work evolved through shared and delegated leadership across all seven CBOs. Our co-leadership approach ensured that decisions were consensus-driven and adaptive, hence staff took more ownership of the research. We all feel equally engaged as HEKA created a space for open conversation, where staff were active contributors to the decision process and actions in achieving our research goals. As one of our staff shared, *"We are moving from data generators to also being data users." "Let's have a personal stake in this; I will renew my commitment – when we are doing our virtual engagement, this is "our baby" as a team."* The benefit of equitable participation was apparent as it allowed staff to take initiatives and be accountable.

Table 1. Overarching research goals.

1. Advance our scientific literacy in epidemiological research
2. Generate research questions and develop study designs
3. Learn the basics of an open-access software, R, to advance our data analysis & data visualization capacity
4. Develop a harmonized longitudinal study database using programmatic data
5. Develop a community of epidemiological research practice
6. Begin building expertise in community-based data science and community-based participatory mathematical modeling
7. Develop a research team entirely made up of and led by GBMSM living in Kenya
Notes. GBMSM: Gay, bisexual, and other men who have sex with men

2. Accompaniment approach to learning about quantitative methods and R programming

A major part of our collaborative process was the integration of R programming to facilitate data management. After its introduction, it was apparent how much interest the staff had in learning skills that would facilitate their tasks. We were successful because we adopted an accompaniment approach, where the academic partners did not merely provide didactic sessions, but worked alongside staff, providing continuous support, guidance, and collaborative problem-solving. We learned about the fundamentals of quantitative methods in research, securing us with a link between our intuition and observations and the standard terminologies that researchers use. That is, recognize how our lived experiences and insights can be integrated with quantitative approaches. This provided staff with the tools to engage on a more level playing field when it came to co-designing not only the research questions but also the analytic plans. The accompaniment approach meant that we were jointly learning, processing, and negotiating skills at every step of the data analysis process. *"Learning R has been a journey. It has been both physical workshops backed up by constant weekly virtual meetings both as a whole team as well as one-on-one meetings. This has led the team to continue being united, and hence the constant meetings have led to the process feeling like on-the-job training."*

3. Program data and rethinking HIV/STI indicators

Through direct interrogation of the data generated, our ability to understand the data beyond our donor requirements for monthly reports grew. We learned to critically examine our data collection tools and the quality of the data, to identify gaps (e.g., missing important indicators), and news ways to leverage the data for research purposes. A key realization was that many of our current indicators were shaped by external funder requirements rather than by community priorities, prompting reflection on how to align metrics more closely with what matters to our communities and advocating for a uniform data collection process regardless of funder. Going forward, we plan to prepare a separate paper detailing the data cleaning and harmonization process, including recommendations about preventing duplication of clients and standardizing tools across programs with funder-required indicators as supplemental variables. As one of our staff reflected, *"Through this process, community-based organizations are not only producers of data to be consumed by researchers, but as we gain more skills, the researchers (coming from these KP organizations) can be able to analyze and interpret the data from program implementation and identify existing gaps in the program…This means we can analyze our own data much easier and know and see the gaps – not the other way around, where donors tell us what our gaps are and what to implement."*

4. Peer-to-peer mentorship and trust-building

By nature, HEKA became a peer learning network. The research initiative was structured around small working groups, where staff of different CBOs were grouped around common pertinent research questions. It was built-in so that staff supported each other by sharing insights into learning a skill like R and checking in with each other, so that we were on track to meet our deliverables and advance our collective goal. By encouraging staff interaction between group meetings, we not only strengthened technical capacity but also built trust, solidarity, and long-term professional relationships across CBOs. This approach also allowed staff to mentor each other, thus facilitating a self-sustaining learning and collaborative ecosystem. One of our staff shared, *"I feel like everything is an opportunity for learning within HEKA. This is also helping my organization improve, and I have been learning from other organizations and putting into practice what other organizations are doing."*

In our experience of developing HEKA, we have also identified challenges, mainly external, that have had or could have an impact on the success of our community-led research initiative.

Table 2. Preliminary HEKA research focus.

Program priority topic	Program-relevant research question	Counties
Sexually transmitted infections (STIs) and condom supply	How did condom stockouts impact rates of sexually transmitted infections (STIs) among GBMSM who receive services at the CBOs?	Nairobi
oral HIV pre-exposure prophylaxis (PrEP)	What are the factors affecting the initiation, re-initiation, and retention of HIV oral PrEP among GBMSM between 18-24 years old and 35+ years old within the coastal region?	Kilifi, Mombasa, Trans Nzoia, and Uasin Gishu
Mental health among MSM living with HIV	What are the effects of mental health on viral suppression amongst GBMSM living with HIV in Kisumu and Nakuru, Kenya?	Kisumu and Nakuru

Challenges and recommendations for facilitating integrated community-led HIV/STI research

1. Sustained engagement through funding

Community researchers have a responsibility to run community-based programs and as such, go beyond their work schedules to lead research such as with the HEKA initiative. HEKA has been a success because we prioritized the compensation of staff to cover the extra time spent on important research, including covering logistical costs for in-person meetings. The initial meetings and workshop were possible through a small competitive grant. To ensure long-term sustainability, HEKA's resource mobilization plan focuses on securing funding, particularly multi-year options for both virtual and in-person meetings, recognizing that limited financial resources and strict timeframes pose barriers to engagement. We advocate for more long-term funding commitments to support community-led research initiatives.

2. Difference in learning pace and community researcher engagement

Staff come from diverse roles and backgrounds, with some, such as data clerks and monitoring and evaluation staff having more direct experience with data than others. This influenced the balance in learning pace across the group, given that workshops are limited to a few days. To bridge this gap, we should explore extending workshop durations, leverage on-demand courses, and encourage more peer mentorship opportunities where resources allow.

3. Beware of the socio-political climate

Due to the rising, state-sanctioned anti-LGBTQI+ movements, some of the in-person meetings were sometimes disrupted or postponed to ensure the safety of our teams. While we leveraged virtual spaces such as WhatsApp communications and Zoom sessions, security concerns sometimes limited participation particularly for the organizations in regions most affected by anti-LGBTQI+ protests. Often, these tensions delay data collection and service delivery by the different programs.

4. Lengthy travel hours and accessibility

Long hours of travel for in-person meetings have contributed to some of the limited productivity at workshops due to fatigue. With adequate funding, we would recommend arranging flights for long-distance travel when feasible and exploring smaller regional meeting hubs to minimize travel time and exhaustion. Funding would also allow for longer duration workshops using time more effectively.

5. Data abstraction processes

Differences in data entry processes, variations in formatting, and limitations with the use of Excel workbooks as the main form of data storage and management, led to slower data abstraction, cleaning, and harmonization to initiate HEKA's research plan. The lack of standardized data collection tools created inconsistencies, increasing the burden on teams working on data harmonization. Due to limited exposure to the analytical tools, time was spent learning the tools and additional virtual meetings were required to troubleshoot and complete data abstraction and anonymization. To streamline this process, we recommend standardizing data collection tools and reporting templates across organizations, and building in more workshop and mentorship hours to facilitate R programming training for CBO-level data management.

Conclusion

We have presented a novel example of community-led research using programmatic data, with insights into steps taken, reflections, and practical perspectives on sustainable and successful community-led collaborative research. We hope to inspire other community-based organizations in the HIV/STI research field to see that it is possible for funding organizations to facilitate the autonomy of community organizations to independently seek competitive grants towards the ownership and utilization of their programmatic data to inform service delivery.

We acknowledge the challenges involved in developing a community-led research platform with coordination across multiple geographically dispersed community organizations. The challenges we presented are not unique to our research initiative. Nonetheless, community-led collaborative research is a promising approach to mobilizing and addressing HIV/STI issues that are pertinent to our communities. HEKA boasts of multiple contributions to community-based research in Kenya:

1. It is the first time our CBOs have come together to interrogate quantitative data collected by our organizations.
2. It is the first time our CBOs have hands-on training in quantitative data analytic concepts and methods.

As our collaborative work continues, next steps include publishing the process we have undertaken to develop a harmonized database. HEKA demonstrates the potential for community-based/led research in the HIV/STI field. Future steps involve analyses to address the research questions identified and the implementation of community participatory mathematical modeling.

DECLARATIONS

Publication Consent
Not applicable.

Competing interests
The authors report no conflicts of interest.

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Author contributions
AN, NO, CK, EO, FL, GA, JedW, JAN, JM, KM, KOl, KOu, LN, PM, ST, and JW conceptualized the project. NT, KCYY, RL, PB, HM, LL, and SM supported the design of the project. NT wrote the first draft with JW, and input from SM. All the authors participated in funding acquisition and the draft and revision of the manuscript, and approved its final version. SN and JW are Co-senior authors.

Data availability
Not applicable.

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Ethics and consent
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De la comunidad como proveedora de datos a usuaria de datos: desarrollando una investigación liderada por la comunidad utilizando datos rutinarios de programas en Kenia

RESUMEN

Las organizaciones comunitarias de base (OCB) son fundamentales para ofrecer servicios de VIH/ITS confiables y adaptados a hombres gais, bisexuales y hombres que tienen sexo con hombres (GBHSH). A pesar de los avances en la participación de las OCB en la investigación sobre VIH/ITS en Kenia, persisten brechas significativas en su participación y en el fortalecimiento de sus capacidades, especialmente en investigación cuantitativa. Compartimos nuestra experiencia y las lecciones aprendidas en el desarrollo de HEKA (Health Research Intervention Kuthamini Afya Yetu), una plataforma de investigación liderada por la comunidad en la que sus miembros aprovechan los datos rutinarios de sus programas para diseñar investigaciones destinadas a fortalecer los programas de VIH/ITS. HEKA se centra en fortalecer capacidades y promover la alfabetización científica dentro de las OCB.

Guiados por el marco de "ciencia programática" —un enfoque iterativo y bidireccional que vincula la investigación con la implementación de programas— nuestras siete OCB identificaron áreas prioritarias para el desarrollo de habilidades cuantitativas y, junto con socios académicos, establecieron actividades de aprendizaje mediante un taller y definieron una agenda común de investigación para el futuro.

El taller incluyó sesiones introductorias sobre métodos de investigación cuantitativa, estructuras de datos y programación en R (un entorno de software de acceso abierto para la gestión y el análisis de datos). También mantenemos el compromiso a través de un nuevo grupo en línea donde nos reunimos mensualmente. A partir de nuestra experiencia, aprendimos que la utilización de un marco de co-liderazgo —donde la dirección de la investigación evoluciona mediante liderazgo compartido o delegado entre el personal de las diferentes organizaciones y el acompañamiento entre pares— fue clave para nuestro éxito. Sin embargo, enfrentamos algunos desafíos durante el proceso, entre ellos, la sostenibilidad del financiamiento para mantener la participación activa. Otros desafíos incluyeron equilibrar los distintos ritmos de aprendizaje debido a la diversidad de roles del personal, enfrentar un entorno sociopolítico inestable en torno a temas GBHSH, y las largas distancias para asistir a reuniones presenciales. Las exigencias de los financiadores del programa, como los estrictos requisitos de informes mensuales, también contribuyeron a retrasos en la participación.

A pesar de estos desafíos, HEKA demuestra el potencial de la investigación comunitaria basada y liderada desde las OCB en el ámbito del VIH/ITS. Nuestra experiencia puede servir como modelo para otras OCB que buscan liderar investigaciones colaborativas o independientes y fortalecer sus capacidades.

Palabras clave: Investigación participativa basada en la comunidad, VIH, ITS, programa, datos, ciencia.

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