Documenting communty learning as part of the Breakthrough Partnership pilot project: KIDAID Cameroon

Background

This concise report presents the lessons learned by community partners during the four-month pilot phase of the Paediatric Breakthrough partnership in Cameroon. A separate report is available for Tanzania. The aim is to develop a care package for the two-year proposal and the overall Breakthrough plan with partners in these two countries. Specifically, Aidsfonds want to document learning about the interventions for communities in addressing paediatric HIV and what this means for the coming two years.

Methodology

The team used the Appreciative Inquiry approach to design the interviews. We conducted a literature review of published and grey literature, project reports and interviews with community health workers. We interviewed health facility staff, a district official and held a team discussion with KidAid staff, taking into account feedback from Aidsfonds.

Lessons learned

1. General

KIDAID began fully implementing project activities in June 2024. The main activities of this phase focused on identifying target groups, including HIV-positive pregnant and breastfeeding women, exposed babies, and children and adolescents living with HIV/AIDS in each district. Due to a delay in signing the contract, activities such as testing, ensuring linkage to care, and promoting retention in treatment began only in mid-July. KIDAID concentrated the initial phase of the pilot on securing project buy-in, developing, and disseminating key elements and launching their first testing campaign.

For the pilot phase, the KIDAID team had originally only had two staff members working on the project, together with focal points in the communities. However, they pooled resources from other projects which enabled five staff members to work on the pilot.

KIDAID observes that the international consortium-based project setup has fostered genuine engagement. At national level, working with PATA/CBCHS and EGPAF has enabled a comprehensive strengthening of the health system at district level, including the involvement and contribution of community health actors such as the 'Agents de Santé de Proximité' (APS) and the Agents de Santé Communautaire Polyvalents (ASCP). KIDAID notes that collaborating with community health workers already registered with the district provides a sustainable model.

For KIDAID, a key takeaway from the pilot is the importance of flexible collaboration with administrative authorities, local elected officials, traditional chiefs, community-based organizations, community health workers, and people living with HIV in health training. Continuing this model is expected to achieve optimal results in Phase 2.

2. Barriers to Paediatric HIV services

KIDAID had to address a severe lack of information about Mother-to-Child transmission of HIV, along with associated fear and rejection of the topic of HIV in general. This is also well documented in the community research baseline. On this basis, KIDAID knew they had to work very closely with members of the community including teachers, farmers, churches, and mosques to understand how to communicate the messages of the project.

KIDAID learned that they had to address very practical and essential aspects of people's lives. This included providing transport to and from the clinic, budgeting for phone credits, and also making home visits.

During the pilot phase, KIDAID used a flexible emergency fund to cover transportation costs for individuals unable to travel to the hospital. Approval of the use of this fund was based on feedback from home visits conducted by the APS. If the home visit report indicates that the person has no financial resources for critical visits to the hospital such as renewing medications and attending HIV PCR tests, KIDAID can allocate the necessary funds. While KIDAID could use a predefined framework for these decisions, they find that relying on home visit feedback is more practical. KIDAID wants to ensure to only offer support they can realistically provide.

KIDAID has included a flexible emergency fund in their two-year program to address urgent transportation needs. Since transportation is a broader issue beyond this program, it is recommended that partners in the program (KIDAID, EGPAF, UNICEF) collaborate with the district and learn from other urban districts in Cameroon to develop more sustainable solutions.

3. Existing community structures that can contribute to paediatric HIV treatment and care

The first thing KIDAID learned was how to launch the project effectively. This was against a backdrop of a lack of information and a refusal to talk about paediatric HIV. To overcome this, and gain community acceptance of the project, KIDAID organized information meetings in the three target regions to raise community awareness, ensure active involvement, and prevent resistance to the activities.

These meetings were attended by representatives of APS and ASCP of the districts. KIDAID also visited local chieftaincies (chaufferie) to invite influential community leaders, as well as religious leaders from both Catholic and Muslim communities, associations and cooperatives of farmers and well-established local HIV organisations. Representatives from the hospital and administration also came to the information meetings. These meetings marked a turning point in the program, as KIDAID gained insights into the dynamics between health centres and patients and learned how to effectively and diplomatically communicate objectives of the project and keep everyone engaged in the project.

To ensure effective coordination, KIDAID plans to hold biannual meetings with all stakeholders in each district. They will also continue to manage the WhatsApp groups created for APS and ASCP in each district. These groups proved to be an efficient way of sharing information and continuously monitoring the project during the pilot phase.

Additionally, KIDAID organised regular monitoring meetings to identify success and address shortcomings. For example, during the meeting on June 24 at the Mintom health centre, issues with community health workers (APS and ASPC) were noted regarding planning, pre- and post-test counselling, and follow-up. Recommendations included taking the necessary time for counselling, scheduling follow-up appointments for the index cases and their partners and ensuring confidentiality.

These regular monitoring meetings are instrumental in allowing KIDAID to adjust its activities based on the needs identified during discussions. This dynamic approach ensures that interventions remain relevant and effective. The information gathered from these meetings is shared with the EGPAF team, fostering collaboration and knowledge exchange. While EGPAF focuses on strengthening the capacities of healthcare workers in adhering to hospital protocols, KIDAID's efforts are directed towards enhancing the skills of community health workers.

KIDAID plans to maintain quarterly monitoring meetings with APS and ASPC to promptly identify and address challenges. They will continue sharing findings and insights with the EGPAF team to ensure aligned efforts. It is recommended to continue the complementary approach of KIDAID and EGPAF, as it can significantly improve patient experiences by making them feel more comfortable and supported within the healthcare system.

Partnership with district health centres on interventions to address loss to follow-up:
The KIDAID team has established a strong partnership with registered health centres to trace young patients who are missing their routine HIV appointments.

The APS or ASCP at the clinics already have strong links with the patients. They have their contact information and organise essential routine visits. One of the problems is that there are not enough health care professionals in the health centres, which results in a lack of patient follow-up.

The KIDAID team has learned that it is essential to anticipate and first collaborate with the authorities to obtain access to patient databases. Establishing effective collaboration with the data technicians is key to improving patient follow-up. Once the contacts have been shared, KIDAID collects information from health care professionals in the event of a missed appointment. The initial steps involve community health workers (the ASP) conducting follow-up via phone calls. This approach was not previously used due to a lack of dedicated staff and a budget for telephone credits. Allocating a budget for telephone credits and having staff dedicated to making these calls is essential for optimizing follow-up and reducing missed appointments.

The loss to follow-up strategy is where KIDAID has already achieved results. Initial results have enabled 40% of these patients to be found, through tracking and tracing activities. In another example, at the Mbandjock health centre, there was a mix-up in the identification of project beneficiaries. Instead of listing only pregnant and breastfeeding women (PHW) and children/adolescents living with HIV, other health centre patients outside the target groups had been included. In response, KIDAID updated the directory of beneficiaries required at health centre level, which enabled the team to correct this error and target interventions more effectively. Following this screening, KIDAID was able to identify 39 people who had been lost to follow-up, including 8 children and adolescents living with HIV[1].

KIDAID also decided to work with unregistered health centres using what they called a 'humanitarian approach'. This unplanned, ad-hoc engagement enabled them to access a greater number of people at the community level.

This experience has been a learning opportunity for KIDAID, demonstrating the importance of accurate beneficiary tracking and the flexibility required to adapt strategies as challenges arise. KIDAID's will extend into other regions, focusing on regions with the highest shortage of healthcare professionals. One of the key elements is to continue to work with districts to establish partnerships for data access and work in collaboration with EGPAF to strengthen the data management system.

[1] Minutes Mbandjok update

4. New identification strategies

One of the main activities planned by KIDAID in the pilot was the localised communication activities, the 'micro plan', with a highly targeted message dissemination system. To develop this micro plan, it was vital to consider all aspects of community messages. The messages were developed with the participation of Multipurpose Community Health Workers (ASCP), community workers, women living with HIV, health centre staff, the health district and community leaders. This collaboration helped to identify differentiated approaches, key messages, the players to be mobilised and the necessary communication media.

Disseminating information: KIDAID collaborated with religious leaders to disseminate information, such as 'catechists' and imams, trusted local figures, and "town criers" who use megaphones. They also used banners and radio broadcasts to encourage people to get tested and learn more about the services available.

Based on the collaboration on the micro plans, KIDAID launched a targeted community testing campaign for pregnant and breastfeeding women. The communication campaign began three days prior to the opening of the testing site. During these three days, letters, posters, and radio messages are disseminated in churches, markets, and village council meetings to encourage community members to come and get tested at a designated site. The site is equipped to offer:

- Pre-counselling
- Rapid finger-prick tests
- Counselling and information for scheduling the next appointment

The KIDAID team assessed the targeted HIV information and testing campaign as successful. One notable example of success in reaching communities in hard-to-reach areas of Cameroon is the indigenous populations, such as the Baka Pygmies. Following the campaign and the dissemination of messages to the leaders (such as hunters) within the community, families accepted testing for children, adolescents, and pregnant and breastfeeding women.
However, due to time and financial constraints, the messages in the pilot phase are still only in French. KIDAID is planning to expand the micro-plans strategy and translate messages into local languages.

Moving forward, KIDAID's focus will be on addressing these limitations while building on the campaign's successes. By translating materials into local languages, KIDAID will further improve the effectiveness of its outreach. The experience has provided valuable insights into how tailored communication and strategic resource allocation can significantly enhance community engagement and health outcomes.

Here are some examples of the messages developed:

1) Femmes enceintes et allaitantes, dépistons-nous afin de garantir le bien être de nos familles (Pregnant and breastfeeding women, let's get tested to ensure the well-being of our families.)

2) Hey ado, le VIH n'est pas une fatalité, on vit mieux sous traitement, viens te faire dépister. (Hey teenager, HIV is not a death sentence. Life is better with treatment, come get tested.)

3) Pour le bien-être des familles, Chers parents, faisons dépister gratuitement le VIH chez nos enfants et adolescents âgés de 0 à 19 ans. (For the well-being of families, dear parents, let's have our children and adolescents aged 0 to 19 tested for HIV for free.)

4) Le VIH est une réalité : j'accepte, je vis, je suis soutenue et nous évitons de le transmettre à nos enfants. (HIV is a reality: I accept it, I live with it, I am supported, and we prevent transmitting it to our children.)

5. Retention strategies

Working with young women who are pregnant or living with HIV
One of the lessons learned demonstrating the responsiveness and flexibility of the KIDAID team was the participation of young women in the information meetings. On the first day, although the young women had been invited, they did not turn up. Knowing the context, the KIDAID team shared information about the purpose of the workshop with their companions, which enabled the young women to be reassured and to participate on the second day of the workshop. This kind of activity takes time and flexibility.

One of the pilot activities involved setting up a mentor mother group who have successfully managed their HIV status. The pilot phase of KIDAID's mentor mother group initiative offered valuable insights into the challenges and successes of supporting women living with HIV. The aim of the support group is to overcome the strong stigma and discrimination, by enabling women living with HIV to talk to each other and exchange advice.

L'UPPEC (Unité de Prise En Charge du VIH) has provided a list of contacts, but the women remained concerned about confidentiality and prefer not to meet as a group at a specific time for fear of being recognised. For the time being, the KIDAID team has noticed that young mothers living with HIV do not feel comfortable meeting in groups and prefer home visits. Currently, home visits are proving to be a more effective and personalised way to reach and support these women. This approach takes more time and highlights the need for flexibility when working with the community. Following the interviews for this report, an initial support group was successfully established, with the active participation of 14 pregnant women, breastfeeding mothers, and mentor mothers in the city of Mbanjoc. It is a success that KIDAID needs to reflect on and learn about.

The experience highlights the necessity of adapting strategies to the specific needs and preferences of the target group. Ensuring privacy and addressing concerns about stigma were crucial in making the support more effective. KIDAID plans to continue the mentor mother group approach but will prioritize individualized support methods for now. This adaptability will be key in enhancing engagement and ensuring that the support provided is both effective and sensitive to the needs of the women involved.

Activities with adolescents have not yet begun, but KIDAID has observed that they prefer to avoid clinics due to concerns about confidentiality. The team is currently looking for safe and welcoming places for them to meet.