Solthis
Committed expertise in health

Support groups' pivotal role to empower recipients of care and improve HIV quality of care

Successes and lessons learned from Solthis and NETHIPS experience

Why does Solthis and NETHIPS propose this lessons learning leaflet?

The HIV epidemic in Sierra Leone is considered mixed, generalized and heterogeneous but concentrated in key population groups (KP). The HIV epidemic affects different population subgroups and all sectors through multiple and diverse transmission dynamics. The national adult prevalence rate stood at 1.7% (with women 2.2% and men 1.1%)[1].

The Global AIDS Strategy aims to reduce inequalities that drive the AIDS epidemic and prioritize people who are not yet accessing life-saving HIV services. One of its strategic priorities aims to break down barriers to achieving HIV outcomes with fully recognized, empowered, resourced and integrated community-led HIV responses for a transformative and sustainable response ensuring that people living with HIV, key populations and people at risk of HIV enjoy human rights, equality and dignity, free of stigma and discrimination.

During the past 8 years, **Solthis and NETHIPS co-implemented Empower project** that aimed to contribute to the reinforcement of civil society in exercising the right to health in Sierra Leone and specifically **to empower users for quality, patient-oriented HIV care in 3 districts** (Western Area Urban, Western Area Rural and Port Loko) in Sierra Leone.

The project provided health care workers capacity building at district and health facilities level and supported NETHIPS capacities and twenty of their support groups (SGs) to allow them to empower and support people living with HIV/AIDS for quality health care.

The proposed leaflet is presenting some of the results from Solthis SHARE project ("**Sharing HIV Actions, Results and Experiences for decisions**").

SHARE project, supported by the Agence Française de Développement (AFD) Group and implemented in partnership with NETHIPS, aims at influencing positively HIV response in Sierra Leone. **The project is focusing on knowledge generation and dissemination exploring Solthis and NETHIPS past experiences and practices on two specific components: (1) service delivery capacity building and (2) community engagement.**

STIGMA MITIGATION

PSYCHOSOCIAL AND WELL-BEING SUPPORT

SUPPORT GROUPS ACTIVITIES

PATIENTS EMPOWERMENT

COMPREHENSIVE HIV QUALITY OF CARE

1 - National AIDS Secretariat Sierra Leone (2020) The Sierra Leone National HIV & AIDS Strategic Plan 2021-2025

2 - https://www.unaids.org/sites/default/files/media_asset/global-AIDS-strategy-2021-2026-summary_en.pdf

SHARE lessons learning methodology in brief

Experiences considered for knowledge generation include implementation during Empower phase 1 & 2 project implementation (2016-2022).

The knowledge generated aims to look at how support groups activities impacted adherence to treatment, retention to care and more broadly quality of care and well-being for recipients of care (RoCs) and how support group members and RoCs perceive this support. The knowledge generated is expected to influence stakeholders and decision makers in Sierra Leone on the importance and benefits of support groups activities.

| Quantitative data collected and analysed	Qualitative Data collected and analysed in 3 districts
► Treatment adherence scores (12 HFs, Empower 1) ► Retention in care scores (12 HFs, Empower 1)	► 5 focus group discussions with about 32 SG leaders ► 5 focus group discussions with about 30 RoCs ► 1 focus group discussions with 5 health care workers ► 6 key informant interviews with national stakeholders ► 3 key informant interviews with HIV district supervisors

Key results from quantitative analysis

Solthis and NETHIPS capacity building investments and efforts to strengthen HIV support groups (SGs) contributed to positive impact on recipients of care's adherence to treatment and retention. Complementary to health care workers capacity building, adherence to treatment and retention in care were also supported by numerous activities conducted with the support group such as strengthening the capacity of SGs, conducting health talks to increase treatment literacy and acceptance of the status, supporting expert client/CHW to conduct defaulter tracing activities, promoting linkage to support groups, empowering RoCs to claim their rights for care and treatment and strengthening the relationship between the health care workers and the RoCs.

Treatment adherence scores (Baseline May 2016, endline December 2018, 12 HFs /Empower 1 project)

To evaluate adherence to the treatment among the RoCs receiving HIV care in 12 supported health facilities, Solthis & NETHIPS developed a modified medication adherence questionnaire (MMAQ) to assess the level of adherence to treatment. The assessment is a combination of subjective and objective methods of self-reporting asking the patient 5 questions, checking the patient cards for compliance with their appointment and refill dates combined with a test to identify the pills they are taking on daily basis.
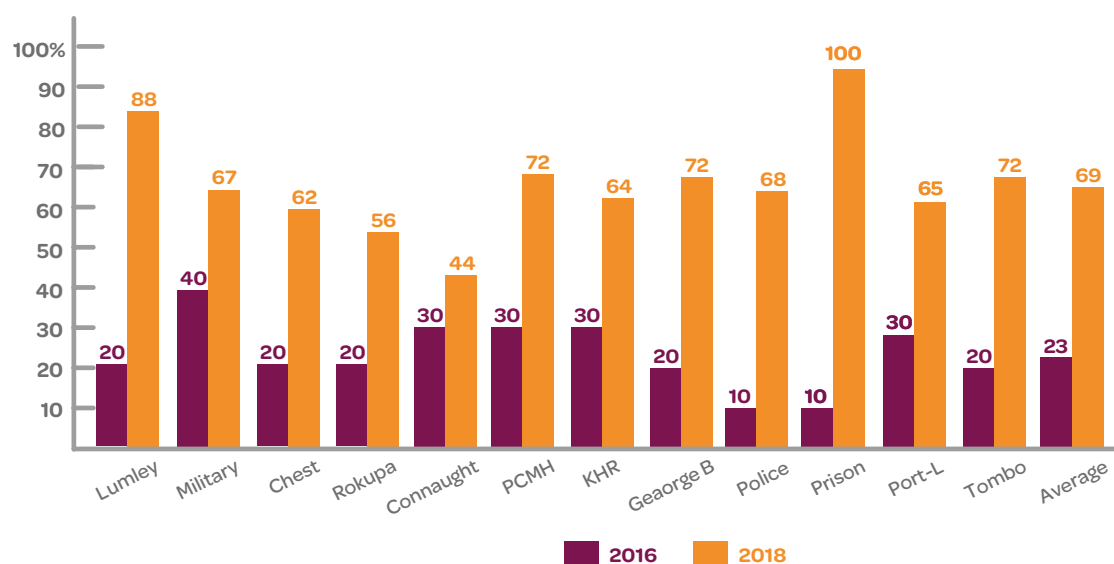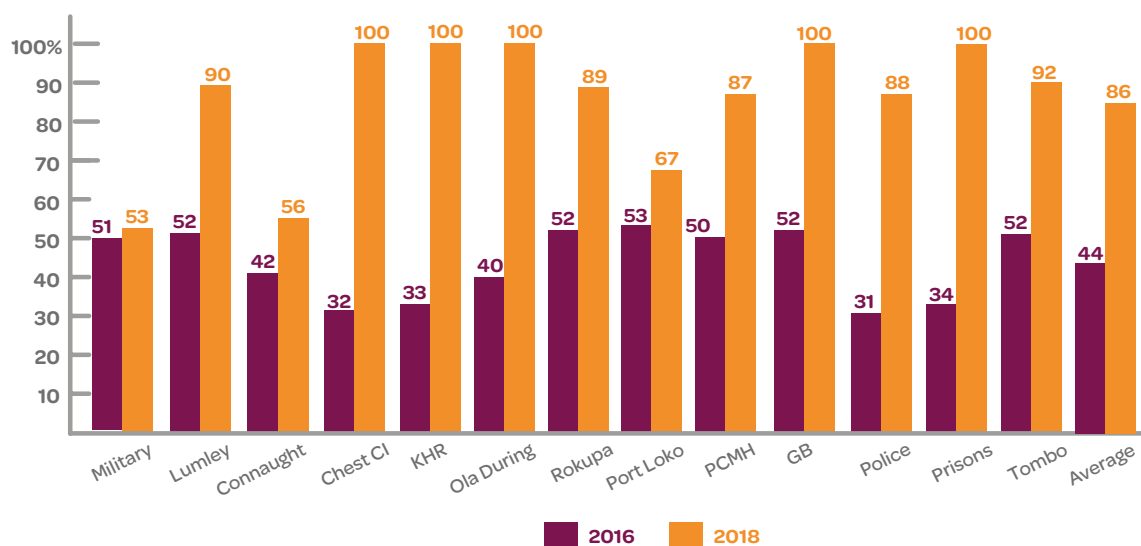
The baseline adherence scores were generally low, reaching only the maximum of 40% score. At endline, all facilities reached a higher adherence score (from 44% to 100%) compared to the baseline.

Overall, among the 12 health facilities, average treatment adherence score increased from 23% to 69% (+ 46%).

Retention to care scores (Baseline May 2016, endline December 2018, 12 HFs /Empower 1 project)

To evaluate retention rates among the RoCs receiving care in the 12 supported health facilities, Solthis and NETHIPS developed a scoring system for quality-of-care assessment, with the last indicator being retention in care score. The retention score measured the percentage of new patients in care six months after initiation on ART.

The baseline adherence score was generally low, reaching from only 31% to 53% score. At endline, all facilities improved their scores as compared to baseline with scores range from 53% to 100%.

Overall, among the 12 health facilities, average retention in care score increased from 44% to 86% (+ 42%).

Role and overall perception of support groups

Support group provide **psychosocial support to RoCs, support adherence to treatment and retention in care. It serves as a platform for peer groups to meet, share information about HIV and their experiences. It also helps through individual counseling to find tailored solutions for RoCs difficulties such as self-denial, status disclosure, stigma, stress management.**

Findings from qualitative and quantitative cross analysis are proposed later in this document in the following sections: key factors for success, challenges, lessons learned and recommendations. **The perceptions of support groups from the large majority of recipients of care interviewed were very good confirming their benefits and pivotal role for optimal treatment adherence, psychosocial support, self-empowerment, stigma mitigation and retention in care.** Following RoCs testimonies illustrate this perception:

The support group helps me to allay my fears as I don't want people to know about my status and help me to take my medication regularly.

Since I became a member of this support group, I have benefitted greatly. Initially, I never wanted to disclose my status for fear of being pointed fingers at. Since I joined, the support has been immense. They often assist me in collecting my medication or mobilizing someone to deliver it to my doorstep, especially when I am facing self-stigma and don't want people to know my status.

...Due to the knowledge gained with support groups, I changed my mind about my university entrance as I thought that people living with HIV have no right to mingle and attend universities or any public places. Now, I can boast that I will soon graduate and have empowered myself. If I am taking the drugs regularly, I can be whatever I am aiming at.

Support groups' pivotal role to empower recipients of care and improve HIV quality of care

Key aspects leading to success

Overall findings from quantitative and qualitative data collection demonstrate that **support groups contributed to increased treatment adherence, retention to care and are perceived very beneficial by RoCs.** Key success factors have been identified by participants interviewed on how support groups have provided such positive impact.

Comprehensive patient centered support beyond treatment adherence and retention in care objectives

Ensuring that support groups do not only provide support for adherence treatment and retention in care has been considered very important. Recipients of care recognize **the significant impact of support groups helping them accepting their situation, supporting them not to remain isolated, finding solutions to their personal and daily difficulties.** Adherence and retention are objectives for quality of care while individual and patient centered support provided by support group members creates an enabling environment toward these objectives.

> *Had it not been for the SG in my community, I don't know what would have happened to me by now. When I contracted the virus, I almost committed suicide until I came in contact with one SG member. She was friendly and opened up to me because I thought I was alone. Since her counseling and encouragement, I became a member of the SG, and now I look at myself as if I am without the disease; I am living like any other person. Counseling and encouragement from people and the community is critical in the fight against the disease.* **RoC**

Sensitization and involvement of the families and communities to reduce stigma and facilitate RoCs support

To mitigate existing stigma and create supportive environment, community (including leaders and families) has been identified by participants as a key element to support RoCs. Even though stigma remains a challenge, **HIV sensitization and involvement of the community facilitated by support group members is impacting positively RoC sustainable quality of care and well being.**

> *I recall when the community accepted my situation, at times when I didn't have the finances to pay my transport fare for my supplies from the health facility; often, I am supported by family and friends to help me pick up my medication.* **RoC**

Coordination and alliance with health care workers toward RoCs' well being and quality of care

The collaboration with health facilities was considered very important to ensure that efforts and support provided by support groups members and health care workers to RoCs are consistent and complementary.

> *The HCWs, together with support group members, provide joint counseling services in health facilities and provide educational services on adherence to treatment. All these are possible due to the level of coordination between both parties.* **Support group leader**
>
> *I am grateful to the nurses. It would have been a different story with me if it had not been for their timely interventions. Whenever I go to the health facility, they provide me with guidance, counseling, and support.* **RoC**

Positive impact of differentiated service delivery in providing adapted and close support to RoCs

Recent implementation of **decentralized differentiated service delivery (allowing multi months drugs delivery** and strategies for treatment access closer to RoCs home) **have played a positive role toward treatment adherence and access to care.**

> *The introduction of differentiated service delivery (DSD) has been helpful by allowing peer groups to assist RoCs with their treatment by collecting their medications through yellow cards. …The DSD has enabled people with HIV living in remote areas from health facilities to get their services.* **Recipient of Care**

Differentiated support groups to ease access and RoCs motivation to join

NETHIPS implemented **differentiated approach creating specific elderly, pregnant women or youth support groups. This approach was considered relevant** as it allowed RoCs **to be more comfortable to share their experiences and feelings with their peers.** This initiative would need to be extended to other groups of population (i.e. Key populations).

Support groups' pivotal role to empower recipients of care and improve HIV quality of care

Key challenges

From quantitative and qualitative analysis, key challenges appear to limit positive impact of support groups support provided to RoCs.

Lack of resources allocated to SG activities toward comprehensive support.

Due to lack of resources, support groups face challenges to provide comprehensive support to RoCs. Participants expressed SGs difficulties to ensure RoCs participation to SG activities, to support essential needs such as nutritional/food intake or to be able to provide individual support at RoCs' home. More globally, it was mentioned that support groups national coverage is still far from the needs with 26,000 support group members among 76,000 Rocs.

NETHIPS has a mandate, as the parent body dealing with PLHIV, to bring everyone on board. There are over 75,000 PLHIV, and they are on treatments, but when you look at the membership of the support groups, less than half this number are members of a support group. **Implementing partner**

Barriers to access support groups activities and health care

Access to health facilities or support group activities remain a challenge for many RoCs. Economic vulnerability of many patients and distance from home to services are negatively impacting support groups membership and participation in activities. Moreover, it appears from respondents that support groups have difficulties to get membership from RoCs that are economically comfortable and/or educated while it could be positive to have mixed members profiles.

Most of us are poor, and getting money to eat well and pay transport for SG meetings is a severe challenge. If we can be supported financially or livelihood project, that will assist us greatly. **RoC**

The issue is that some RoCs are not vulnerable because they are well-to-do and financially strong. They see the support group as a place for the poor and vulnerable RoCs. …. I even went further and asked one educated and affluent person I know who has the virus about the existence of our support group. The answer was, I don't need it, and besides, what can you offer me? **Support group leader**

Persistent community stigma and misconceptions limiting positive impact of support group activities

While investing in community sensitization and participation has been considered as a key aspect to support RoCs, respondents declared that there is still a lot of work to be achieved. Support groups efforts are still facing community stigma affecting negatively their efforts toward RoC's well-being and access to quality care.

It depends on the community. Some are good, while others are hostile to us. In my community, if they know your status, people will react to you as if you had committed the worst crime. I recall one day, when my community knew I had contracted the virus, even my best friends isolated me and called me names until people started coming to the community to sensitize them before their attitude changed. **RoC**

We are being discriminated against by people in our community, including our family members. I remember during one fateful day, I drank water from a cup, and a community member saw me and lashed at me seriously and damaged the cup, stating we are not supposed to drink from the same cup so I will not spread the virus to her. **RoC**

Lack of coordination with health facilities along with some health care workers persistent discrimination

Participants highlighted that despite observed improvements (thanks capacity building provided to health care workers), lack of coordination between health facilities and support groups and persistent discrimination from some health care workers are still representing a challenge to ensure quality and complementary support to RoCs.

The healthcare worker whom I used to collect my medication lacks respect for me, she talks to me harshly. I had to change my center, not knowing I had gone to the worst center. So, now, I prefer to stay at home because of these nurses. **RoC**

Healthcare workers need to accept HIV patients. They are one of the primary sources of stigmatization. Some nurses mistreat us, making us not go to them again. How can we coordinate when they look at us as if we are not human beings? With this type of behaviour, it is difficult to have any good relationship with them. **SG leader**

Support groups' pivotal role to empower recipients of care and improve HIV quality of care

Lessons learned and recommendations

Based on the results and findings from quantitative data analysis, FGD and KII, key lessons learned and recommendations are proposed below.

Increase support groups' resources to allow comprehensive and tailored patient centered support including following activities.
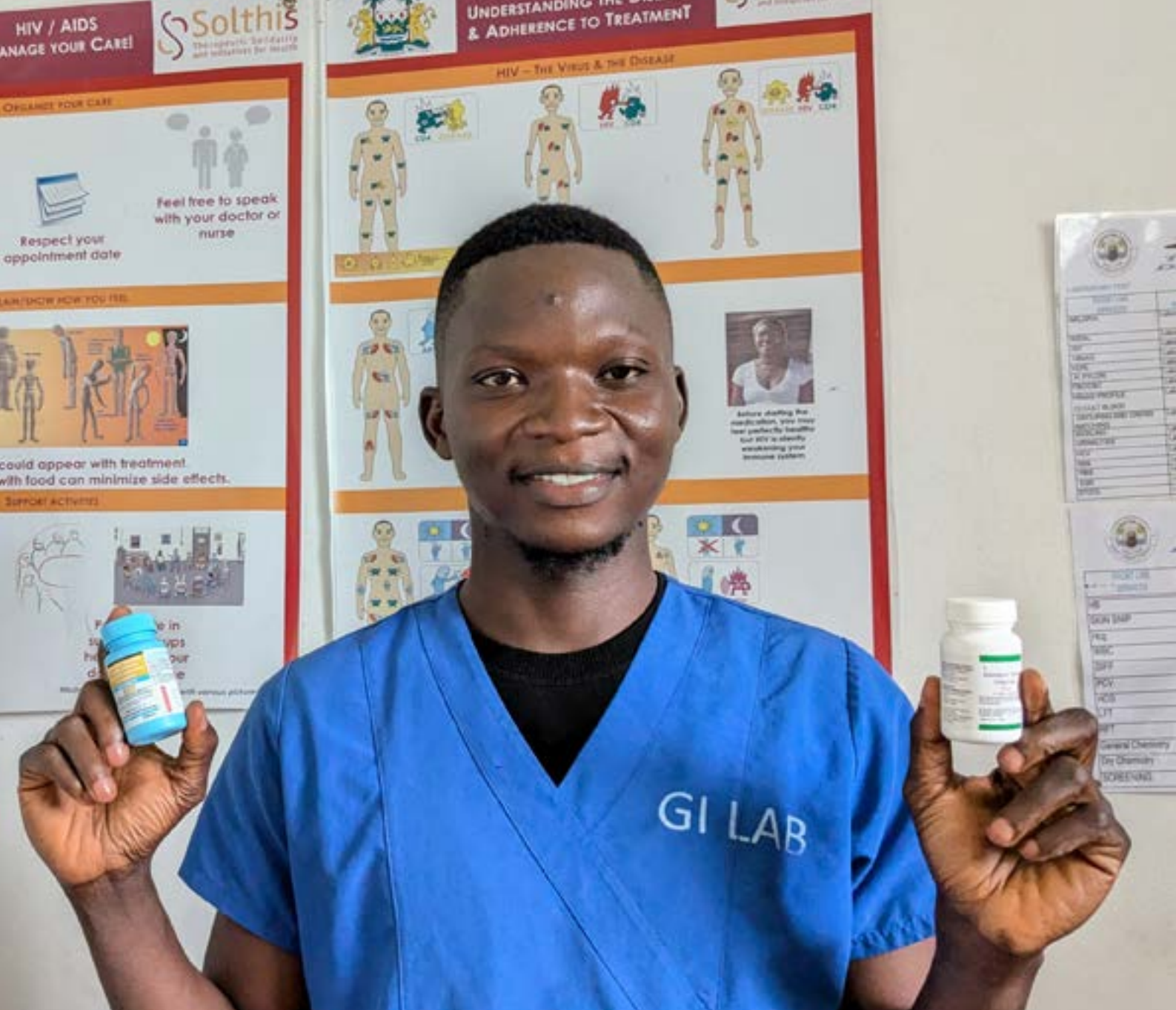
► Educational activities improving RoCs treatment literacy and supporting treatment adherence and care retention.

► Sharing experiences activities among RoCs mixing expert patients with new RoCs and promoting mixed socio-economic profiles participation.

► Psychosocial support along with families' involvement toward status disclosure and reduced stigma.

► Empowerment of RoCs capacity to defend their rights, increase their self-esteem and decision-making capacities.

► Community HIV sensitization and mobilization to reduce stigma and increase RoCs support and well being.

► Supporting activities to mitigate RoCs socioeconomic vulnerability and increase access to HIV services.

Mobilize resources and develop strategies to ensure SGs national coverage and coordination with health facilities.

► Mobilize resources to Increase and promote availability of support groups at national level to reduce HCWs burden and optimize access and quality of services.

► Strengthen coordination mechanism between health facilities and support groups to ensure full complementarity of services and comprehensive support to RoCs.

► Extend capacity building activities and strategies down to the community level to empower support groups to better complement services offered at health facility level and develop partnership with community leaders.

► Develop strategies and platforms to promote and work on patients/health care workers relationship.

Promote and strengthen differentiated service delivery strategies to enhance RoCs access to support groups.

► Reinforce supports groups involvement and strategies to provide decentralized and multi month treatment to RoCs.

► Maintain and strengthen strategies for differentiated support groups to enhance RoCs participation to activities and promote access to all RoCs (elderly, youths, pregnant women, key population support groups).

► Develop strategies to ensure that all RoCs profile (socioeconomic, group of population) have access and join SGs activities.