

Promoting awareness, capacity, advocacy and accountability for NCDs in 7 sub-counties in Kamuli district, Uganda

1. Relevance of the intervention

The overall impact aimed at in this project, is **to improve health of citizens in Kamuli district, Uganda.**

The project's development objective is to **“Promote access to NCD health services in 7 sub counties in Kamuli district, by January 2019”.**¹

Three of UN's Sustainable Development Goals are supported by the project:

SDG 3: Good health and wellbeing: Ensure healthy lives and promote well-being for all at all ages.

SDG 16: Peace, justice and strong institutions: Promote peaceful and inclusive societies for sustainable development, provide access to justice for all and build effective, accountable and inclusive institutions at all levels.

SDG 17: Partnerships for the goals: Strengthen the means of implementation and revitalize the global partnership for sustainable development.

The project's specific objectives:

1. To increase the knowledge about NCDs and how to prevent and detect them, in 7 sub-counties in Kamuli district.
2. To strengthen the capacity of KANENGO and 21 Neighbourhood Assemblies (NAs) in advocacy and management.
3. To promote duty bearers'² accountability in implementing policy decisions taken about NCDs, and prioritizing treatment of NCDs in Kamuli District.

There is a great need to improve prevention, detection and treatment of Non-Communicable Diseases (NCDs) in Kamuli district.

The major causes for this situation were identified by the partners in a joint workshop, February 2017:

- An inadequate knowledge at community level about NCDs
- Inadequate knowledge and skills at community level to change to a more healthy livelihood behaviour
- NCDs are not yet a priority for the local government (non-funded priority)

¹ *Non-communicable diseases (NCDs) will be defined as only lifestyle diseases such as:*

- Chronic cardiovascular diseases: heart attack, hypertension, stroke
- Chronic lung diseases: asthma, chronic obstructive lung disease
- Cancer: all kinds of cancers
- Diabetes

NCD Risk factors are:

- Lack of exercise, drug abuse e.g. alcohol, smoking, poor/unbalanced diet.

² Local government officials at sub-county and district level. Health professionals at Health center 2-3-4 and district hospital.

- The communities have limited awareness about their rights to demand services from their leaders.
- Weak Neighborhood Assemblies (NAs). An NA is a peoples' democratically elected parliament operating at local community level.
- Village Health Workers from the NAs have not been officially introduced to the Health Centres. Their roles and responsibilities are not clear
- KANENGO's inadequate advocacy capacity
- Inadequate capacity of Local Government to understand policy processes: Drafting by-laws and ordinances, as well as passing the same.
- Decisions directly affecting the citizens are made at the health center/central government level, leading to a situation of inadequate medicine. The approved amount of medicine does not always arrive from the National Medical Stores.
- Referred patients do not go to the Health Centers, because they assume that treatment will not be available anyway.

The project is based on experiences collected from the project *CISU 15-1644-MP-apr: Strengthening the capacity at community level to prevent, detect and treat NCDs in 5 sub-counties in Kamuli district, Uganda*. This was the first project implemented by the partners Hope Denmark and KANENGO.

It revealed that the capacity to detect NCDs has improved in the small areas with voluntary Village Health Workers (VHW), trained as part of the project.

The deputy Chief Administrative Officer (CAO) admitted at the project evaluation meeting in February 2017, that until the project documented the high prevalence of diabetes and high blood pressure, the perception of the district's political leaders was, that *"We don't expect the poor man to have those diseases (NCDs ed.)"*

The project's context

The proposed project focuses on Kamuli district in Busoga region in Eastern Uganda.

In spite of reported improved economic growth, service delivery at community level is still poor. Several factors account for this situation, including inadequate financial funds, and leakages of resources, due to weak internal controls and corruption. There is also a weak capacity of local communities and citizens to monitor the implementation of service delivery in the community; and lack of forums for citizens and their leaders to engage each other on effective service delivery.

At community level there are generally low levels of awareness about basic health issues, such as personal health and hygiene, preventive measures for life style disease conditions, and generally low accessibility to modern medical services. The communities are not well sensitized and mobilized on how they can access better medical services.

These activities are expected to be the responsibility of the local authorities, but in most districts, they are not functioning. Alternative structures like Neighbourhood Assemblies are instead seen as more active and relevant in complementing the responsibilities of local government.

Nationally, non-Communicable Diseases (NCDs) have been recognized as a "silent killer", currently responsible for more than 35% of all deaths in low and middle-income countries.

A high prevalence of NCD risk factors has been documented in Uganda. An association between obesity, hypertension, and risk of type 2 diabetes was found in a study among women, of whom nearly 80% were overweight. The STEPS survey in Kasese (a semi urban area) has demonstrated

that chronic non-communicable diseases and their risk factors constitute a public health problem in Kasese district, The majority of people with raised blood pressure did not know that they had such medical problem. Only 3.7% of people found with high blood pressure were on treatment.

The non-scientific analysis executed as part of the partners' NCD project in Kamuli, supports these findings:

- 1000 citizens, 20 years old or more, were measured for diabetes and blood pressure by VHWs in the 5 sub counties, who also filled out questionnaires. 13% had diabetes and 22% high blood pressure.
- 89 % of the people measured to have diabetes, were not treated for their illness, and 59 % of the people measured to have high pressure, did not receive treatment.

The health units at community level are lacking critical staff, medical equipment, medical supplies and facilitation that can ably respond to the huge disease burden.

Uganda's Ministry of Health has only recently started to prioritize NCDs. The Uganda NCD Alliance has been at the centre of lobbying government's commitment to NCDs. The alliance has opened up 10 branches, and the 11th branch has recently been launched in Kamuli and is affiliated to KANENGO. The project intends to use the capabilities of UNCDAs, both its NCD resources and its NCD advocacy expertise. The outcomes of the project and data collected by KANENGO will be shared with UNCDAs, and used for national lobbying and advocacy about NCD.

Neighbourhood Assemblies

The core instrument in this project is the Neighbourhood Assemblies in Kamuli district. A Neighborhood Assembly (NA) is non-governmental, a peoples' democratically elected parliament operating at local community level. Fundamentally, an NA is based on voluntariness, and the purpose is active citizenship, i.e. finding ways to make citizens take active responsibility for their own lives. A neighborhood assembly is organized like the real Parliament of Uganda, which is the main legislative assembly of the country. The NA is made-up of ministers of sectors (education, Agriculture, Health etc), just like those of key sectors at national level. The NA is governed under the leadership of a speaker, elected from the ministers. Below the ministers, there are sector working committees, which are made up of members representing zones. The members are elected by the people from 5-7 villages, usually forming a parish.

According to DENIVA (a national network of NGOs and CBOs in Uganda, with over 700 members), NAs help to build peoples' knowledge and capacities, which any community, region or country needs in order to challenge or question what their leaders do and how they represent the community interests and concerns.

There are NAs in several parts of the country and Moses Kyewalyanga, coordinator in KANENGO, has been appointed national NA facilitator by Deniva. The NAs in Kamuli district are young and most of them are still learning to dare take a stand opposing the duty bearers. KANENGO supervise, monitor and guide the NAs on their activities. It is in fact the major task for the KANENGO staff.

The external evaluation of the NCD project implemented by the partners, concludes that

- *From a situation on ground where 2.4% were able to mention three NCDs correctly and only 0.7% able to mention three risk factors leading to NCDs in the five sub-counties, it can be concluded that the awareness level of NCDs in the five sub-counties has increased as a direct result of the project.*

- *The majority of VHW are able to measure blood pressure and measure blood sugar. The VHW can refer patients with high blood pressure and blood sugar to a health center and by February 2017, 350 people had been given a written referral letter by a VHW to a health center. The Health Centers confirms receiving patients referred by the VHW. Families from the primary target group have made changes in their diet as a result of the advice from VHWs.*
- *NAs are able to advocate for change at Sub-county level. Half of the old NAs have shown very good results and visibly improved NCD service delivery in their local Sub-county. The other half has taken the initiative to advocate and the result is yet to be seen. New NAs are demanding for space to engage with local leaders. Sub-county officials are aware of the NCD project and NCDs have been on the agenda.*
- *Since the second half of 2016 Kanengo has been an official member of the District Planning Committee and the Technical Planning Committee. District officials are aware of the NCD project and have taken steps to improve service delivery as a result of Kanengo's engagement at Sub-county and District level.*
- *At national level Kanengo and individual NAs have successfully engaged the Speaker of Parliament and secured equipment to a Health Center 3 and Kamuli District Hospital.*

The first NCD project focused on NAs' and their Village Health Workers' capacity to create awareness and to detect NCDs. Secondly, to encourage the NAs to advocate for policy change and improved service delivery in regards to NCDs.

This project will focus on strengthening both NAs' and KANENGO's capacity in advocacy and self-governance, in order to keep advocating duty bearers to prioritize NCDs and hold them accountable for their plans and promises. It will strengthen the links to Health Centers and local government stakeholders at Sub-county and District level. At the same time, the project will keep promoting awareness and prevention of NCDs in all parts of Kamuli with NAs.

2. Partnership and partners

Hope and KANENGO have experienced that we share the same general vision and values. In December 2014 the two organizations signed a partnership agreement. During the first mutual project there have been challenges (financial management, activity planning and the role of expat volunteers), but they have been discussed openly, and the problems have been solved.

KANENGO have proved to be able to carry out two projects at the same time. It has a strong network in Kamuli District, good relationships with local leaders, and its coordinator has excellent lobbying skills. KANENGO still need to improve its administration capacity, including data collection and documentation of results.

In the project KANENGO will be responsible for the implementation of project activities, as well as monitoring and evaluation of the project activities carried out by Neighbourhood Assemblies (NAs), and their Village Health Workers (VHWs). KANENGO will work with Ugandan NCD Alliance (UNCDA), using their expertise and experience in training and advocacy related to Non-communicable Diseases (NCDs)

Hope has the overall project responsibility of ensuring that the project is implemented within the guidelines of CISU. Hope will contribute its expertise in working with donors in Denmark and will use its extensive networking experience and contacts in providing knowledge, as well as contributing to the project with experts in nursing and health on a voluntary basis.

The division of roles in project implementation will be governed by a Memorandum of Understanding (MOU) between HOPE Denmark and KANENGO. The project will be implemented in partnership and coordination meetings to review progress will be held. The project, through monitoring and evaluation, will assess how the partnership has been functioning and any gaps and constraints will be identified and appropriate amendments taken.

The ongoing project, which will finish in July 2017, identified each partner's strengths and weaknesses, and how the two partners can benefit each other: Hope's expertise in health, organisational development and financial control, and KANENGO's long experience in civil society development "on ground". Hope's local representation in Jinja, Uganda, and the possibility of frequent face-to-face meetings and volunteer activities will particularly strengthen the partnership.

The evaluation report for the first project concludes that "*KANENGO is capable of implementing activities and reaching the project targets.*"

Kanengo needs to improve on the quality of data collection, to ensure that it can be used for evidence based advocacy, a necessary capacity as stated in the newly published report by CISU, the Report on Thematic Review on Results from Advocacy Work in CISU supported projects in Uganda.

Therefore, Kanengo and NA will be trained in advocacy and data collection. The project will use social accountability tracking to follow up on promises given by local government in regards to NCD budget allocation, e.g. testing machines for Health Centers" and to follow up if the correct amount of medicine arrives in Kamuli from the National Medical Stores.

3. Description of the intervention

As mentioned in section 1, KANENGO and Hope Denmark held a joint planning workshop in February 2017 to plan this project. Both board members from Hope DK and KANENGO, KANENGO staff and volunteers participated. The workshop used the Logical Framework Approach as guideline, and the results are described below and the findings incorporated in this project proposal.

Target groups

The project will focus on the 7 sub-counties in Kamuli district with Neighbourhood Assemblies. The first NCD project had selected citizens in 5 of the 7 sub-counties as target group.

The primary target groups are defined to be:

- 21 Neighbourhood Assemblies in the 7 sub-counties. The 21 NA have 1050 members (50*21).
- Duty bearers at sub-county level: Sub-county chiefs, person in charge of Health Center, chairperson of Local Council 3.
- Duty bearers at district level: District health officers, chief administrative officer, District Community Development Officer, District planner, speakers, Chairperson of Local Council 5, Secretary of Health.
- KANENGO staff and volunteers (16 persons)

Secondary target group that will be reached by the NAs is 25000 adult men and women in 7 sub-counties in Kamuli District.³

Particularly adult men and women with NCDs will benefit: Both patients detected and in treatment, as well as new cases detected by VHWs.

The project's strategy and goals

The project aims at increasing the knowledge and skills to promote a more healthy lifestyle to as many people as possible in Kamuli district, but will limit the activities to the sub counties, where there are NAs and VHWs. The VHWs will receive training in NCDs, and the VHWs who have not yet received training in using measurement equipment will receive that. The equipment purchased in the first NCD project will be utilized during health days in all the 21 NAs, to enable all VHWs to measure blood sugar and blood pressure. They will be able to refer those who have too high values, to the health centers or hospitals. Funding of strips for blood sugar measurement is out of scope for the project.

The activities listed above are expected to substantially increase the demand for NCD services. These services are not available at the health units, so the project will have as its focus to advocate as strongly as possible for the provision of these services. The citizens are often reluctant to go to the health units, as they (often rightfully) lack confidence that the units can help them. The VHWs must encourage their fellow citizens to go, while the NAs and KANENGO will advocate for the duty bearers to provide the services.

Most NAs are weak in advocacy and administration. Therefore, the project will focus on improving the capacity of both NAs and KANENGO in these areas. When the NAs are strengthened, they will be in a much better position to engage with duty bearers. The increased capacity in advocacy is planned to be both through training and frequent follow-up activities with the individual NAs. Generally, experiences and findings will be monitored, documented and shared between KANENGO and NAs, as well as among NAs.

In order to promote self-governance and provide the possibility to practice guidelines from training in a sustainable way, the project's budget includes seed capital for the recently created VSLA. One probable activity for the VSLA is to provide loans for VHWs to buy bicycles.

The project will strengthen the skills of Kanengo to collect, analyze and package information for advocacy. KANENGO will use the documentation from NAs and VHWs, and present the findings to the NAs, so they will be able to advocate for improved services at local level.

The advocacy activities will be based on the "Advocacy strategy", which KANENGO and NAs are already using. The strategy is used by NAs at sub-county level and KANENGO at district level. By using the strategy to promote duty bearers' accountability related to decisions about NCDs, NAs and KANENGO will be encouraged to use the same strategy for advocacy in other areas.

³ Each NA represents a parish, about 7-8000 citizens. This means that the potential number with 21 NAs, is 150.000 citizens. But as each VHW has the responsibility for 30 households (2-3 adults and 5-6 children) a more realistic number is $21 \times 5 \times 30 \times 8 = 25.000$

- First, a positioning paper is developed, listing necessary improvement and actions to be taken, using the information collected and analyzed. For NAs, the positioning paper is presented, discussed and approved at an NA meeting.
- Next, the positioning paper is sent to the relevant duty bearers at sub-county or district level
- Then an interface meeting is held between NA/KANENGO and the respective duty bearers. The interface meeting is a forerunner for a Dialogue meeting.
- Finally, a dialogue meeting is held at sub-county level or district level. At sub-county level the leadership from the NAs meets with the government executives + sub-county chief and/or sub-county administrative officer. At district level KANENGO and involved NAs meet with the district executives, district councilors, sub-county chiefs, and village chairpersons. Once a year the NAs arrange Manifesto days at sub-county level, with drama, demonstration, band in the streets, drinks, banners, etc. The purpose is to provide space for dialogue between the general community and Local Government. The day before the Manifesto day, Kanengo host a radio show.

In regards to lobbying for NCD policy change at national level, Kanengo will use its relationship to UNCDA to lobby and approach the national Parliament's Committee on NCDs. Kanengo will share collected data from Kamuli and share with UNCDA. Kanengo will also develop a best practice model for advocacy at sub-county and district level to be replicated in other districts with UNCDA branches.

Activities and output

| Objective | Output | Activities |
|---|--|---|
| 1. To increase the knowledge about NCDs and how to prevent and detect them, in 7 sub-counties in Kamuli district. | 1.1. Citizens will have heard the message about NCDs | 1.1.1 Conduct 7 NCD outreaches with VHWs, Health Center 3 and 4 during "Family days" 1.1.2 Establish a KANENGO drama group and use drama and video in awareness creation about NCD 1.1.3 Publicize a newsletter 2-4 times a year to stakeholders and others interested in the project. Distribution by Email. 1.1.4 Provide at least 15 NCD messages through social media, e.g. Facebook |
| | 1.2. Increased skills of VHWs in 21 NAs to create awareness about how to prevent NCDs, to detect and to refer people with NCDs | 1.2.1 Identification and training of 15 VHW in the 3 new NAs 1.2.2 Refreshment training for 90 VHW 1.2.3 Quarterly supervision of 105 VHWs by 7 nurses from Health Centers 1.2.4 Identification and mobilization of expert patients to work with VHW |
| 2. To strengthen the capacity of | 2.1 The capacity of KANENGO and NAs to carry out advocacy for | 2.1.1 Conduct 5 day training for a 9 member Trainer-of-Trainers team and 7 |

| Objective | Output | Activities |
|--|--|--|
| KANENGO and 21 NAs in advocacy and management | health service delivery strengthened | <p>Kanengo staff on advocacy, NAs management and documentation</p> <p>2.1.2 Conduct 3 days training for 105 NA leaders: NA concept, Advocacy, developing positioning papers, writing minutes, report writing, etc.</p> <p>2.1.3 Follow up of NAs on a monthly basis (writing position papers, writing minutes, conducting meetings, etc.)</p> |
| | 2.2 The capacity of KANENGO and NAs in management strengthened | <p>2.2.1 Improve NA management guidelines</p> <p>2.2.2 Provide seed capital for VSLA to practice self management</p> <p>2.2.3 Support the leadership of the 10 new NAs to have 2 exchange visits to other NAs</p> |
| 3. To promote duty bearers' accountability in implementing policy decisions taken about NCDs, and prioritizing treatment of NCDs in Kamuli District. | 3.1 Information about NCDs collected, analyzed and distributed to duty bearers at sub-county level and district level | <p>3.1.1 KANENGO staff will collect, analyze and package data on NCDs across the 7 sub-counties and on district level: budget, spending, medicine, staff, equipment</p> <p>3.1.2 Kanengo will share the collected information with the NAs</p> <p>3.1.3 In each of the 7 sub-counties, the NAs will conduct orientation workshops about NCDs for Local Council leaders (210 people)</p> |
| | 3.2 Duty bearers at sub-county level and district level have been challenged on their decisions and implementation of policies related to NCDs | <p>3.2.1 KANENGO will support NAs to develop one positioning paper each</p> <p>3.2.2 The NAs will hold one dialogue meeting in each of sub-counties (35-40 people)</p> <p>3.2.3 KANENGO will arrange manifesto day</p> <p>3.2.4 KANENGO will arrange preparatory meetings for interface and dialogue meetings at district level</p> <p>3.2.5 KANENGO will hold 2 interface meetings at district level</p> <p>3.2.6 KANENGO will conduct one dialogue meeting at district level</p> <p>3.2.7 Meeting between KANENGO and UNCGA to develop a strategy for areas of common advocacy on national level</p> |

Employed KANENGO staff:

75% Project coordinator/manager

30% administration /Accountant

100% field officer (Follow-up of 21 NAs, monitoring and monthly reporting)

50% Office assistant

15% Nssf

As mentioned above, NAs and KANENGO need to improve their capacity in advocacy and administration. Therefore, the budget includes purchase of office equipment.

The training, support and supervision in advocacy, administration, monitoring and evaluation, will be done by AnjaC Consult, based in Jinja, Uganda. Anja Christiansen Sakaly has performed the external consultancy assistance, which was given as advice by CISU's assessment committee in relation to the first project. She has also made the evaluation report, referred to above, and she knows the partners, the area and the project's subject very well.

Most of the field officers' time, the advocacy consultant's time, and about half of the project manager's time will be used on the activities listed above.

Indicators and Means of verification

| Objective | Indicator | Means of verification |
|--|--|--|
| 1. To increase the knowledge about NCDs and how to prevent and detect them, in 7 sub-counties in Kamuli district by December 2018 | 30% increase of adults 20+ who can mention at least 3 risk factors. | Baseline survey report. End of project survey report. |
| | 80% of the VHWs can diagnose and refer at least 3 out of 5 patients with hypertension or diabetes. | Controlled by nurses at Family Days during the last ½ year of the project |
| 2. To strengthen the capacity of KANENGO and 21 NAs in advocacy and management by December 2018 | 50% of NAs have conducted at least one dialogue meeting | Reports, photographs, minutes, attendance lists |
| | 70% of NAs have conducted at least 1 interface meetings | Reports, minutes, attendance lists |
| | KANENGO attend in 80% of the DTPC/DMC meetings | Minutes of DTPC/DMC meetings, photographs and attendance lists |
| 3. To promote duty bearers' accountability in implementing policy decisions taken about NCDs, and prioritizing treatment of NCDs in Kamuli District. | 20% increase in amount of hypertension and diabetic drugs at health centres. | Stock cards and delivery notes. Baseline survey report. End of project survey report. |
| | 20% increase in functional equipments for NCDs at the health centres. | Equipment inventory and physical counting for Glucometer, DP machine, Scale and meter. Baseline survey report. End of project survey report. |
| | 20% increased funds released at the district and sub county levels. | Budget estimates at district and sub county levels. |

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| | | Accountability reports from the health departments and health centres. Baseline survey report. End of project survey report. |
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Risk factors and mitigation

| Risk | Mitigation |
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| The new Ugandan NGO act, resulting in political intervention and intimidation | KANENGO will continue sharing with national NGOs (FHRI, DENIVA, CEW-IT, Transparency International, UNCDA, Anti-Corruption Coalition) on NGO Regulations issues, like political and intimidation intervention. It is a joint CSO effort. |
| Social accountability tracking can be risky for Kanengo and NAs if duty bearers are found to have redirected funds, misused funds or in regards to NCDs stolen medicine and equipment. | Kanengo and NAs will have to be aware of the risk and trained to minimize risk. (Kanengo could consider to become a member of Anti-corruption Coalition Uganda and draw on their experiences with social accountability tracking) |

4. Planned intervention-related information work in Denmark

The information about the project will focus on how NAs and VHWs can help in creating awareness about NCDs, and how they manage to catch the attention of duty bearers. Hopefully, it will also be possible to report about the advocacy results by activities performed by both NAs and KANENGO.

Hope Denmark will contact organizations and institutions in Denmark, and even in other countries, which are considered to have an interest in the project's purpose. 3-6 articles about the project's activities, participants and results will be written and published, e.g. on Hope Denmark's website or in Oasemag (3700 copies), the magazine for Hope Denmark's support base.

The project's results and findings will be shared with the Danish NCD Alliance.

Hope Denmark will also frequently upload posts, pictures and videos on Facebook, which will give Hope Denmark's followers a possibility to connect to the project's participants, and perhaps even be involved in project activities.