

STRENGTHENING COMMUNITY PARTNERSHIPS IN THE PROMOTION OF HEALTH LITERACY IN UGANDA

End of Project Report [September, 2012]

BY



COMMUNITY HEALTH AND INFORMATION NETWORK
[CHAIN]

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GLOSSARY

CHAIN-Community Health And Information Network

NDA-National Drug Authority

VHTs-Village Health Teams

CMDs-Community Medicine Distributors

TCMPs-Traditional and Complementary Medicine Practitioners

CBOs-Community Based organisations

IEC-Information Education and Communication Materials

AGHA-Action Group for Health, Human rights and HIV/AIDS

CONSENT - Consumer Education Trust

ESAU-Epilepsy Support Association Uganda

JFSCU-Joyce Fertility Support Centre Uganda

SAU-Sickle Cell Association Uganda

TASO-The AIDS Support Organization

UWOCASO-Uganda Women's Cancer Support Organization

WHO-World Health Organization

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1.PROJECT BACKGROUND

1.1 Overview of the Project

Community Health And Information Network (CHAIN) with support from Merck Co. Inc., implemented a one (1) year project on '*Strengthening Community Partnerships in the Promotion of Health Literacy In Uganda*'. CHAIN is registered as a charity and company limited by guarantee in Uganda. It promotes the empowerment of people living with HIV/AIDS; lobbies for increased access to Antiretroviral drugs, promotes treatment literacy, good policies on HIV treatment and care and provides capacity building support to community based organizations.

1.2 Description of Program Activities

The project goal was to strengthen community partnerships in the promotion of health literacy in Uganda. The major aim was improving the health and welfare of the nation through increased health literacy levels. Uganda currently faces low levels of health literacy and this has resulted into consumption of substandard medications, self medications and seeking alternative health care from traditional private practitioners.

1.2.1 *Specific Project Objectives*

The specific Objectives included:

- a). Working with patient organizations to design and implement health literacy campaigns tailored to different types of health needs of clients (Cancer, Heart disease, Epilepsy, Diabetes, Uganda Association of Physiotherapy, Mental Health Uganda, etc).*
- b). Organizing dialogues with line government ministries and departments on implementing health literacy (NDA, Ministries) programs.*
- c). Engaging 20 community owned resources (VHTs, CMDs, CBOs, Media) in health literacy campaigns targeting the grass root communities*
- d). Supporting 6 consumer associations implement a number of campaigns aimed at raising health literacy levels of the general public on consumable health goods.*

The implementation strategy involved engaging and working in partnership with line government Ministries and departments including Ministry of Health, National Drug Authority; World Health Organization (WHO), media, traditional practitioners as well as greater involvement of patient and consumer organizations at national levels.

2. PROJECT ACHIEVEMENTS AND OUTCOMES

2.1 Working with Patients' Organizations to Design and Implement Health Literacy campaigns

Patient organisations were mobilised, engaged to design and implement health literacy campaigns that are tailored to different patient needs identified through participatory and interactive sessions, dialogues with patients themselves and the community.

It also targeted massive health literacy campaigns at the community on early detection and early diagnosis of different diseases.

2.1.1 Launch of Health Literacy Campaigns in Uganda

CHAIN in partnership with Uganda Cancer Society (UCS); Uganda Child Cancer Foundation (UCCF), Uganda Cancer Institute (UCI), Save a Woman Initiative (SAWI) and Makerere University Students' Association, organized a Patient Solidarity Day on December 20th, 2011 and launched the Health Literacy campaign.

Over four hundred (400) participants including patients and patient organizations across all diseases (Cancer, Diabetes, Heart, Epilepsy, Sickle cell, HIV and AIDS), representatives from WHO, Ministry of Health, National Drug Authority, Health Care Professionals, Media and children suffering from cancer attended.

Key achievements of the event include:

- ➔ Ministry of Health and WHO made commitments to strengthen collaboration with patient organisations to promote health literacy.
- ➔ National Drug Authority pledged to work in collaboration with patient groups to raise awareness on substandard and counterfeit medicine.
- ➔ Patient organizations pledged to collaborate with government and use their networks to sensitize the grassroots people on early diagnosis and treatment.
- ➔ Health Care professionals promised to give services that are patient centred.



A group photo with children suffering from Cancer

2.1.2 Meeting with Leaders of Patient Organisations to Discuss Strategy for Engagement of their members in Health Literacy Campaigns.

CHAIN conducted meeting with leaders of patient's organisations to discuss strategies of implementing health literacy activities to reach the wider community.

They also discussed how to engage their members in pushing the health literacy agenda. Thirty (30) participants attended the meeting including, Sickle Cell Association of Uganda, TASO, Joyce Fertility Centre, Consumer Education Trust (CONSENT), Epilepsy, Youth Caravan (Young Positives), Mental Health-Uganda, Uganda Child Cancer Foundation, AGHA. Interaction with leaders of patient organisation revealed that they did not have a clear understanding of the concept of health literacy, had no clear strategy and therefore limited activities on health literacy. The meeting was used to sensitise patient leaders on healthy literacy and their role. Outcomes of the meetings included: drawing up of an engagement plan by patient leaders with their members and networks, strategies and approaches for community engagement.

2.1.3 Meeting with National Care Centre (NACARE)

CHAIN in collaboration with National Care Center (NACARE) organised a meeting in Makindye division to identify health literacy gaps with particular focus on mental health, alcohol and drug abuse; and also suggest ways for addressing these gaps. Forty (40) participants attended including; NACARE members and partners, local leaders and representatives from patient organisations.

The gaps identified included myths and misconceptions about mental health; limited public awareness and knowledge of the dangers of alcohol and drug abuse; inadequate government intervention; limited services and few mental health support organisations. The meeting came up with strategies to include; increase public awareness and education on the dangers of alcohol and drug abuse by patient organisations and other key stakeholders, lobbying government to come up with friendly policies and laws, increase access to mental health services. Partnership working was emphasized.



2.1.4 Engaging Persons Living with HIV&AIDS in Promoting Health Literacy

A workshop for people living with HIV [PLWHIV] was held at Mulago Hospital to identify health literacy gaps; assess the role of PLWHIV in promoting health literacy, share challenges, lessons and best practices of HIV prevention and treatment.

Sixty six (66) attended the workshop representatives of patient organisations also attended. Key outcomes of the meetings include:

- Increased knowledge on pharmacovigilance in sessions conducted by NDA officials
- Increased knowledge on substandard and counterfeit medicines, adverse drug reactions (ADRs) and to buy medicines only from registered drug outlets
- Increased knowledge on HIV and AIDS issues e.g discordance and adherence
- Acquired knowledge on various diseases including sickle cell, epilepsy and cancer and the need for early diagnosis and early treatment
- Strengthened partnerships between PLWHIV and other patient groups (cancer, sickle cell).





Group discussions on strategies to promote health literacy among people living with HIV



A member of the young positives club making a presentation.



A member of the young positives club making a presentation.

2.1 .5 Meeting with Joyce Fertility Support Center Uganda (JFSCU) members

To identify health literacy gaps and raise awareness on infertility. Thirty six (36) participants attended the meeting. Representatives of patient organisations also attended to raise awareness on other diseases such as cancer, epilepsy , HIV and AIDS.

The workshop revealed that a lot of myth and misconceptions around infertility, stigma and discrimination .which led many women to resort to traditional practitioners that have not only cheated them but have exposed them to harmful herbal concoctions.

Key results include;

Acquiring knowledge on how to deal with infertility and available options.

Increased networking and partnerships with patient organisations of various diseases

➔ to promote health literacy.

➔

2.2 Supporting Consumer Associations to Raise Public Awareness on Health literacy

2.2.1 Public Dialogue on Health Literacy with all Patient Groups and Consumer Associations to Increase Health Literacy among the Public/Wider Community

CHAIN in partnership with a network of Patient organizations including; Epilepsy Support Association Uganda (ESAU), Sickle Cell Association Uganda (SAU), Uganda Women's Cancer Support Organization (UWOCASO), Action Group for Health, Human Rights and HIV/ AIDS (AGHA), Joyce Fertility Support Centre Uganda (JFSCU), TASO, Consent, Uganda Child Cancer Foundation and NACARE conducted a public dialogue on health literacy at Gayaza Catholic playground. The dialogue which attracted over 600 people was officiated by Dr. Kaggwa Muggaga from WHO and in attendance was Ministry of Health



Dr. Kaggwa Mugagga representative from WHO giving remarks at the public dialogue.



Guest of Honour touring the exhibition



Participants during a group work session



CSOs, academia, CBOs, media, health professionals, Village Health Teams (VHTs), students, religious, local and cultural leaders.

The major objective was to identify health literacy gaps and raise community awareness on health literacy. *Activities included: HIV counseling and testing (305 tested for HIV, 20 HIV+); Cancer screening (67 females, 15 males for breast cancer); blood donation, testimonies by patients of different diseases. Music, dance and forum theatre was also used to pass on messages while entertaining the public. Patient organizations showcased their work, provided information, and responded to questions raised from the public. Outcomes included access to health services and increased networking and partnerships.*

2.3 Engaging Community owned Resources in Health Literacy Campaigns

2.3.1 Engaging Village Health Teams (VHTs) in Promoting Health Literacy

CHAIN conducted 3 trainings on health Literacy in Kampala District for 133 Village Health Teams (VHTs). Village Health Teams (VHTs) are community resource persons trained by Ministry of Health to link and educate the community about health issues and existing health services. The major aim of the meeting was to increase their knowledge on various diseases to effectively promote health literacy in their communities.

The outcome was that VHTs were able to acquire knowledge on safe use of medicines, HIV and AIDS, epilepsy, cancer, sickle cell, management. They came up with work plans for implementation at the community level to promote health literacy.

2.3.2. Dialogue with health workers

A meeting for health workers was organised to discuss their role in promoting health literacy; share experiences, best practices and challenges; and suggest possible ways of promoting health literacy. Fifty(50) health workers attended the dialogue, representatives from patient organisations also attended to exchange ideas with the health workers and raise awareness of diseases including cancer, sickle cell that have been greatly mismanaged by health workers. Issues of attitude, inadequate training and limited involvement of health workers in health promotion campaigns e.g. Immunization days, Child days, Hygiene and sanitation improvement campaigns, health Education sessions at clinics were also discussed.

Key results included increased knowledge on different health issues such as cancer, sickle cell and its management, substandard and counterfeit medicines and how to be vigilant in fighting counterfeit medicines, improved health worker patient relationship.



Dr Christine Nabiryo - Executive Director TASO addressing health workers during a dialogue to health literacy



Ben Mwesige MPS - Head Pharmacy Uganda Cancer Institute presenting on substandard and counterfeit medicines

2.3.3 Engaging Traditional and Complementary Medicine Practitioners (TCMPs) to Discuss Health Literacy Activities

CHAIN held meetings with thirty three (33) Traditional and Complementary Medicine Practitioners [Herbalists, Traditional Birth Attendants and Borne Setters] in (5) divisions of Kampala district. The main objective of engagement was to increase their role, Knowledge and involvement in Health Literacy Campaigns in Uganda. The outcomes of the meetings showed that most TCMPs still handled a number of clients yet their level of knowledge of various diseases remained low with poor hygiene and misinformation to the public.

They were sensitized on improving sanitation and hygiene, need for referral of cases to health centres and need to update their knowledge on various diseases areas. TCMPs showed the need for training and sensitization concerning various diseases as well as logistical support in terms of medical supplies e.g. gloves, cotton wool etc.



Teo Namisango a recognised Traditional Birth Attendant (TBA) helps mothers deliver about 10 babies from either her sitting room or bedroom depending on the hours of the day. "During day, mothers deliver from my bed while at night this sitting room turns into a labour ward" she narrates

2.4 Dialogues with Line Government Ministries and Departments on Implementing Health Literacy Programs

2.4.1 Public awareness on substandard and counterfeit medicines

CHAIN in partnership with National Drug Authority (NDA) organised the above event in Kampala. Over 700 people including; representatives of patient organizations, government agencies, local council leaders, security and the public attended. The events major focus was to raise awareness on substandard and counterfeit medicines. The meeting which started with a march through the city with patient

organizations displaying placards with messages on substandard and counterfeit medicines, early diagnosis and treatment generated a lot of interest.

Major achievements include: Three hundred and fifty (350) people received free HIV Counseling and Testing services, 80 registered for Safe Male Circumcision (SMC), 78 screened for TB, 137 men and women screened for breast Cancer, 30 women screened for cervical cancer; 50 people donated blood. Information communication materials were also distributed by patient organizations through exhibitions and interaction with the public. The public interacted with National Drug Authority and learned more about their work. NDA was also able to interact and hear patient views on quality and safety of medicines, and their recommendations on how NDA should improve its services to meet the needs of the community.



Dr. Gordon Ssematiko - Executive Secretary National Drug Authority Addressing the public at the Health Literacy event on his right is Hellen Ndagijje - Head Pharmacovigilance Department - National Drug Authority.



*Blood donation during
the Health Literacy event*



*HIV counselling
and testing during
the health
literacy event.*





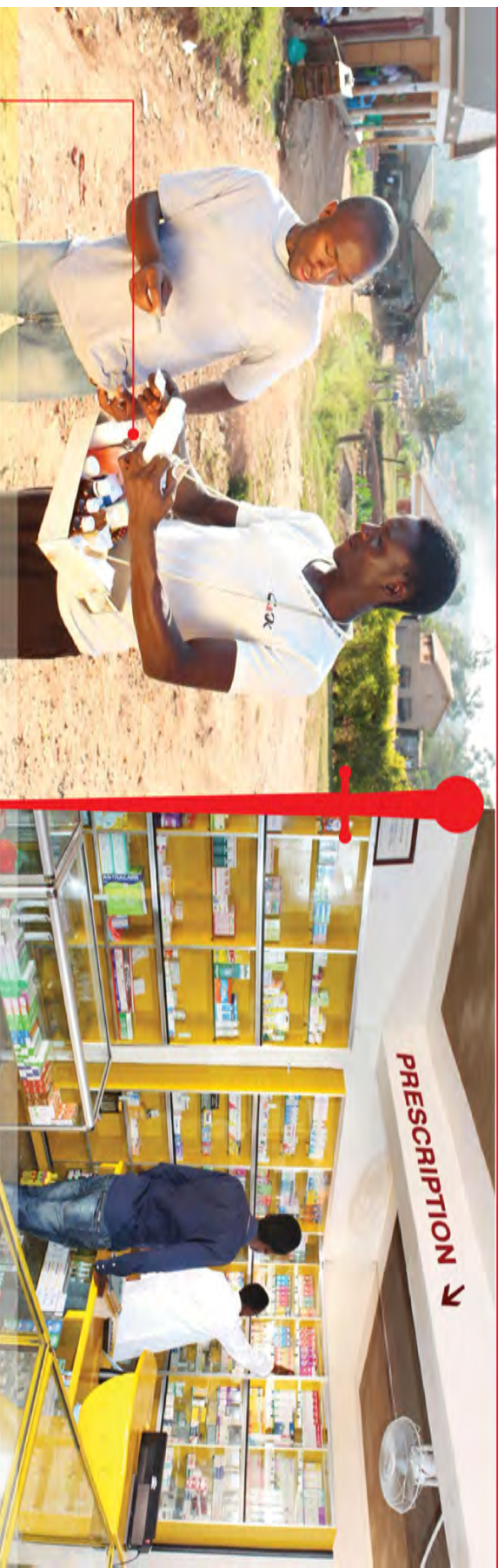
A breast cancer survivor telling people about breast cancer.





Developed and disseminated IEC materials on quality and safety of medicines

BEWARE OF MEDICINE FROM HAWKERS



• These medicines are Cheap & Easily accessible, BUT are substandard or Counterfeit, **Therefore NOT SAFE**

Buy medicines from only National Drug Authority licenced pharmacies or drug shops.

ONLY SAFE DRUGS SAVE LIVES.

For more information,
Call: 0776 110008 or 0712 001199



SELF MEDICATION IS HARMFUL TO YOUR HEALTH



**Ensure getting medical advice from
a qualified health professional.**

ONLY SAFE DRUGS IN RIGHT DOSAGE SAVE LIVES.

For more information,
Call: **0776 110008** or **0712 001199**



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LESSONS LEARNT AND RECOMENDATIONS

Health literacy should be an ongoing program due to knowledge gaps identified in the community.

The Civil Society need to further engage Ministry of Health to develop a comprehensive strategy on health literacy. Experience with this project was that engaging the government is a process involving orientation, ongoing consultations and engagement that would require more time than one year.

There is need for further engagement of Traditional Medical Complimentary Practitioners [TMCPs] to sensitize them on improving their health complimentary practices. One of the key lessons has been that engaging TMCPs requires long term engagement in terms of understanding their needs and designing tailor made interventions.

Bringing together various patient organizations to sensitize the public on various diseases yields good results as compared to single organizations conducting sensitization sessions. However, this requires a lot of resources, time and wider mobilization. The strategy of integrating awareness with service delivery was a best practice that required scaling up.

A key lesson has been that health literacy has not been integral to government health and patient groups/civil society programs. Few education sessions exist for clients of various diseases but there is limited interaction after treatment. There is therefore need for widening information channels between doctors and clients before and after treatment.

Patient organizations need to develop a long term scale up plan with health literacy integrated into their daily activities.

Ministry of health should establish community based-health information centres at every sub-county managed by qualified health educators and take into consideration of the different population needs to enhance health literacy.

Health literacy on different diseases should be part of the broader health policy and strategy, and sessions should be more regular, better targeted and with proper follow up mechanisms.

The government and other key stakeholders in health should emphasize recruitment of professional health practitioners in health centers, preferably with exposure to some of these common diseases like epilepsy, sickle cell, cancer, mental health and diabetes.

Health workers need regular sessions with patients/clients to hear from them and get their feedback to improve on service delivery. This should further be strengthened with short sessions at health centres to educate patients of different diseases.

Widening information channels to the public by National Drug Authority at community levels to give regular updates on quality and safety of medicines.

Work plan for 2012 /13 with Milestones

Objectives	Key Planned activities	Indicators	Time Frame
Objective 1: <i>To engage line government Ministries (Ministry of Health and Gender, Labour and social Development) to develop strategies for implementing health literacy.</i>	<ul style="list-style-type: none"> Meeting with Department of Health Promotion and Education Ministry of Health to discuss strategies for raising awareness for health literacy 	4 meetings conducted in a year (1 per quarter)	Quarter 1, 2, 3 & 4
	<ul style="list-style-type: none"> Meeting with department of NCD Ministry of Health to discuss strategies for raising awareness for health literacy 	4 meetings conducted in a year (1 per quarter)	Quarter 1, 2, 3 & 4
	<ul style="list-style-type: none"> Meeting with Ministry Gender, Labour and social Development to discuss strategies for raising awareness for health literacy 	4 meetings conducted in a year (1 per quarter)	Quarter 1, 2, 3 & 4
	<ul style="list-style-type: none"> Design an 'Issues Paper' on health literacy gaps to inform policy 	A comprehensive Issues Paper that captures national health literacy gaps developed and submitted to Health Minister for action	Quarter 1 of Project Implementation Timeline
Objective 2: <i>To engage Traditional health practitioners in health literacy campaigns aimed at increasing their knowledge and skills</i>	<ul style="list-style-type: none"> Organize sensitization meetings with Traditional health practitioners on Health literacy 	4 sensitization meetings organized with traditional birth attendants in a year	Quarter 1, 2, 3 & 4
	<ul style="list-style-type: none"> Organize training of traditional birth attendants in partnership with health centres on maternal health 	2 Training sessions organized for traditional birth attendants	Quarter 1 & 2 of Project Implementation Timeline
	<ul style="list-style-type: none"> Design IEC specific materials targeting the role of traditional health practitioners in health literacy. 	Quantity/type of IEC materials designed and disseminated targeting the role of traditional health practitioners in health literacy	Quarter Four of Project Implementation Timeline
Objective 3: <i>To further engage patient organisations integrate health literacy into their programs</i>	<ul style="list-style-type: none"> Follow up meetings with patient organisation to facilitate integration of health literacy in their programs 	3 meetings organized with Patient organisations in a year	Quarter 1, 2& 3
	<ul style="list-style-type: none"> Follow up meetings with consumer organisations to facilitate integration of health literacy in their programs 	3 meetings organized with Consumer organisations in a year	Quarter 1, 2& 3
	<ul style="list-style-type: none"> Document best practices among the patient and consumer organisations on health literacy 	A comprehensive report best practices to be replicated by CSOs	Quarter 4

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World Health Organization (WHO)

Ministry of Health (MoH)

National Drug Authority (NDA)

Uganda Cancer Institute (UCI)

Uganda Child Cancer Foundation (UCCF)

Save A Woman Initiative (SAWI)

Uganda Cancer Society (UCS)

The AIDS Support Organisation (TASO)

Consumer Education Trust (CONSENT)

National Care Centre (NACARE)

Joyce Fertility Support Centre (JFSCU)

Sickle Cell Association of Uganda (SAU)

Uganda Women's Cancer Support Organization (UWOCASO)

Action Group for Health Human Rights and HIV & AIDS (AGHA)

Epilepsy Support Association Uganda (ESAU)

Youth Caravan

Health Aid

Village Health Teams

Community Based Organisations

Mental Health Uganda (MHU)

Religious / Local Leaders

Traditional Complementary Medicine Practitioners (TCMPs)



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