

EDUCATING AND COMMUNICATING ABOUT BREAST AND CERVICAL CANCER IN THE COMMUNITY AND STRENGTHENING THE ROLE OF RURAL COMMUNITY AMBASSADOR IN CREATING CANCER AWARENESS AND ACCESS TO CANCER SERVICES

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### Introduction

### Who can use this Book?

This workbook is designed to train health workers, Civil society organizations, advocates and community health workers to communicate and educate about women's cancer. However, the workbook may also be used to train non-specialist nurses who have begun working in women's cancer and may also be used by governmental and non-governmental organizations, if they intend to set up outreach and/or psycho-social support services. If the learning objectives laid out below fit with your organization's needs, then this is the workbook for you!

The book is divided up into a section of theory and concept based learning and a section of practical exercises. These can be tailored to individual and organization's needs.

### **Learning Objectives**

This guide will enable you to:

- Engage and communicate effectively with the community about women"s cancer
- > Describe women's cancer, how it is caused and ways to prevent the disease
- Instruct on the correct course of action for people with symptoms
- Teach self-screening methods
- Care for people with cancer in the community
- Connect women with relevant treatment facilities

### The Role of the Community Ambassadors

The role of the health workers and community health-workers (RURAL COMMUNITY AMABSSADOR) is to provide correct information about cancer and motivate new protective behaviours including self-screening. RURAL COMMUNITY AMABSSADORs are also there to offer psychosocial support and guidance for women who are undergoing treatment for the disease. It is important for the RURAL COMMUNITY AMABSSADOR to:

- Develop an on-going dialogue among community members about cancer.
- Bring people together to decide on the actions they need to take in their community.
- Promote cancer prevention, control, and supportive behaviours.
- Work with people to harness new skills for prevention.
- Connect community members to cancer screening and treatment services.
- Be supportive of patients and their families.
- Facilitate discussion and decision-making on how to help others in the community.

RURAL COMMUNITY AMABSSADORs are key to educating and mobilizing the community to fight cancer together. This is because RURAL COMMUNITY AMABSSADORs are trusted in the community and have extensive experience with communicating with the population.

RURAL COMMUNITY AMABSSADORs should focus on prevention and early detection. We have included all information about how cancer is treated in this workbook, but it is a complicated disease and needs the attention of a specialised doctor. The role of the health workers and RURAL COMMUNITY AMABSSADORs, then, is to make sure that people in the community are educated and engaged and to connect them to screening and treatment facilities.

Educating the population about cancer will mean engaging the community through larger, smaller and group education sessions as well as individual visits. This means building relationships, sharing information, and problem solving with the

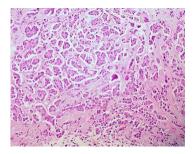
community to build a supportive environment in which screening for cancer is a practice that is accepted and encouraged.

The last session of this workbook consists of a series of activities that will use your skills as a communicator to motivate and educate the community. We also provide you with a set of tools that you can use to support your efforts to educate the community. Find out what works and what doesn"t and develop your own communication strategies.

### Module 1: What you need to know about women's cancer

### What is Cancer?

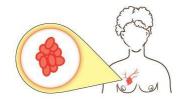
Our whole bodies are made up of small units called cells. Cells allow our body to function and are constantly replenishes when they become old or when they are destroyed. For example, when you get a cut on your finger your skin grows back and closes the cut. These are cells regenerating (being born again) and growing back.



**Cancer** is a disease that happens when cells keep on multiplying and do not stop. This is why the most common sign of cancer is a tumour, which is a growth, in or outside the body. Cancer kills people primarily because the replicating cells and/or tumor use up all of the energy a body needs to survive however it can also cause death for other reasons.

Cancer is a treatable! Cancers grow with time so if the person with cancer doesn't go to the doctor to get treatment or to have the tumour removed, it will get bigger and bigger until it spreads throughout the whole body. You are much more likely to survive cancer if you <ind it early and seek treatment before the cancer is "out of control". Many treatments can "kill" or treat the cancer if detected early but don't work if the cancer has progressed or grown too much. This is why it is very important for

people to recognize the signs/symptoms of cancer and is not afraid to see a doctor to start treatment early. Cancer that has spread all over the body is called metastatic cancer. If the cancer has spread or is too big the person may die.



**Breast Cancer** is a lump or malformation of the breast. In most cases, you can see it or feel it in the breast.

**Cervical cancer** is another type of cancer. The woman's cervix is inside the ladies vagina and so is not visible. Only a doctor or a nurse can see the cancer during a vaginal exam with the help of a magnifying glass called a Colposcope. For this reason, many women do not realise



they have a cancer in their cervix.

When the cancer has spread to other parts of the body, it is called **metastatic** cancer. The brain, lungs, lymph nodes, and bones are common areas of cancer spread or metastasis. Treatment for metastatic breast cancer is lifelong and focuses on control of the disease and quality of life. Metastatic cancer does not mean that the person will die immediately. Although most people will ultimately die of their disease, some will live for many years.





### General Information on Cancer in Uganda

Invite the District Health officer to offer basic statistics on cancer prevalence and data in the district.

### Causes of Women's Cancer

Cancer is what a non-communicable disease is. This means that Cancer is a natural disease that happens because the body malfunctions and it is not transmitted from human to human, like HIV or Tuberculosis. This is because it is a disease caused by external and environment factors or because of genetics.

**Breast Cancer:** Factors that increase someone's chance of getting breast cancer include;

1) Being overweight



2) Drinking too much alcohol



3) Smoking tobacco



4) Genetics/ if breast cancer runs in your family



### Ways to avoid these risk factors:

One way to avoid becoming overweight is to avoid foods like Maggi, soda and meat with a lot of salt and fat.

This is because too much fat in the body can cause inflammation can cause cancer.

Drinking a lot of alcohol- including rum, beer, or wine- can also cause irritation and inflammation of the body, which can ultimately increase your chances of cancer.

Smoking cigarettes can cause every type of cancer. Cigarette smoke put a sticky, brown substance called tar into the lungs and this causes cancer.

Some women have genes that cause breast cancer. If a woman has had a family member- like a sister, mother, or grandmother who had breast cancer, she may be more likely to develop breast cancer.

Cervical Cancer: Risk factors of cervical cancer include;

1) Obesity (being too heavy and overweight)



2) Drinking Alcohol and smoking tobacco



3) Having a virus called HPV (Human Papilloma Virus). This is a virus that is transmitted from one person to another person during sex. The virus is not itself cancer, but it can cause cervical cells to multiply and possibly turn into cancer.



### **How to Prevent Cancer**

Cancer is a disease that is linked to the way we live and what we eat. Mostly, there is no one single cause of cancer, but there are ways that we can do our best to

prevent it. You can reduce your risk of developing cancer by eating things that are good for you, doing exercise, and keeping your mind and body healthy.

Eating lots of fruits and vegetables will reduce your risk of getting cancer. Keeping your weight down and staying active will also do this.







**Breast Cancer:** Breastfeeding can decrease your chance of getting breast cancer. There is less benefit for women who breastfeed for less than a full year. The longer you breast feed, the more protection you get from breast cancer.

**Cervical Cancer:** Cervical Cancer is caused by the HPV virus, which is transmitted during sex. Wearing a condom during sex and having fewer sexual partners reduces the risk of getting HPV and thus decreases your risk of getting cervical cancer.

Girls aged between 12 to 13 years old can also have a HPV (human papilloma virus) vaccination. The vaccine protects against cervical cancer.

Men in the community must play also an active role in this process by making responsible choices and attempting to not spread HPV.

### **Knowing the Symptoms**

When cancer develops it turns into a growth (tumour) and this can happen in any part of the body. Recognising these symptoms and educating the population about what to look for is one of the most important things in the fight against cancer. If people know what to look for they can come to a RURAL COMMUNITY AMABSSADOR or a clinic to test for cancer and treat it. If they do this early then they will have a much better chance of getting better.

### **Breast Cancer:**

The main symptoms of breast cancer are changes in the way the breast looks and feels. Breast cancer means that there is a tumour developing inside the breast and this can make the breast look:

--- Changes in the shape of the breast



--- Skin looks like the outside of an orange



--- A mass that you can feel





-•- Skin erosion



--- Fluid coming out of the nipple that isn"t breast milk





### --- Nipple is pointing inwards

The breast tumour could also be invisible inside the breast and this is why it is important for women to check their breasts by touching them when they wash or when they are putting on their bra once a month.

**Cervical Cancer:** The most common symptom of cervical cancer is bleeding from the vagina that is not normal, such as bleeding between menstrual periods, after sex, or after menopause. Some women also experience pain in the lower belly, during sex and vaginal discharge that isn't normal. Women should pay close attention to their bleeding patterns so that they notice anything that is abnormal. If they notice irregular bleeding they should go to their doctor immediately.

### Screening

Healthcare Screening means checking people for medical problems before the problem develops. This means going to the doctor at regular intervals to check for cancer even if you don't have any symptoms. There are different ways of doing this.

**Breast Cancer:** One of the most effective ways to screen for breast cancer is what is called the Breast Self Exam. This is when a woman checks her breasts for lumps, changes in shape and skin abnormalities. The best time to do this is when you are putting on your bra or are washing yourself and should be done once a month (if still having periods then 1 week after your period starts).

There are many different ways for women to check that their breasts do not contain lumps. This way of screening can be done by women at home and therefore does not cost anything!

You will need to be able to teach this method so read this through and practice until you have it memorized. Take care to learn each step off by heart, in the correct order.

**Step 1:** Looking at your breasts with your shoulders straight and your arms on your hips.

Here's what you should look for:

- Breasts that are their usual size, shape, and colour
- Breasts that are evenly shaped without visible changes or bumps

If you see any of the following changes, bring them to your doctor's attention:

- Dimpling, puckering, or bulging of the skin
- A nipple that has changed position or an inverted nipple (pushed inward instead of sticking out)
- Redness, soreness, rash, or swelling





**Step 2:** Now, raise your arms and check for the same changes, using your right hand to feel your left breast and then your left hand to feel your right breast.

Use a firm, smooth touch with the first few finger pads of your hand, keeping the fingers flat and together. Use a circular motion, about the size of a coin.



**Step 3:** Alternatively, you can check your breasts while lying down, using your right hand to feel your left breast and then your left hand to feel your right breast.

Use a firm, smooth touch with the first few finger pads of your hand, keeping the fingers flat and together. Use a circular motion, about the size of a coin.



Doctors and nurses can also use a machine called an ultrasound to look inside your breast to see if there is a tumour. This is the next step to check the symptom a woman has found through a Self-Breast Exam. This can be done at a number of facilities.

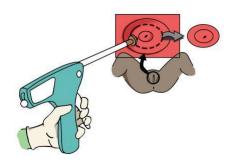
**Cervical Cancer:** Women should look out for symptoms of cervical cancer. But, there is no way for women to be able to check for cancerous cells or tumours on their own. For this reason women should go to the doctors and screen for cervical cancer at least once every 5 years. Women should start screening for cervical cancer from 21 years old.

There are different ways to test for cervical cancer.

<u>The "See and Treat" Methods:</u> The see and treat methods are not just to test for cervical cancer, they are also a way of treating early forms of cervical cancer. There are two different ways of doing this but both involve checking the cervix for cancer and removing any cancerous cells during the same gynaecological appointment.

1. Visual inspection with aesthetic acid and cryotherapy ('seeing and freezing")- commonly know as VIA/cryo. This is a procedure that can be done by a nurse. During the procedure the nurse applies vinegar to the cervix and the chemicals in the vinegar react with the surface of the cervix so that if any cancer cells are present they will turn white. The

nurse then freezes these cells with the cryo probe, killing all cancerous cells from the cervix. The cryo procedure is not painful and some women who get screening with a pelvic exam even need to get cryo therapy for cancerous or pre-cancerous cells. Pelvic examination screening every 5 years is very effective in preventing the development of cervical cancer. This is the most common procedure done in Uganda to screen for cervical cancer.



2. If there are many cancerous cells on the cervix, a doctor may then decide to do a slightly different procedure called colposcopy. Colposcopy is when a doctor uses a special magnifying device to look at the outside of your vagina, vagina, and cervix. If a problem is seen during colposcopy, a small sample of tissue (biopsy) may be taken from the cervix or if needed a LEEP procedure (loop electrosurgical excision procedure) to remove cancer cells may be performed. The procedure will effectively remove the cancer cells from the cervix.

3. **An HPV test** is a test to see if a woman has the HPV virus that causes cervical cancer. The HPV test helps to identify who is at risk of



developing cervical cancer. However, a positive test means that the person will need to go through a procedure to remove the cancerous cells. If the woman that is tested is positive for HPV then she will need to have the VIA/Cryo procedure or the colposcopy and LEEP treatment. Women can do the HPV test by using a vaginal swab to take a sample of cells from inside the vagina. The samples are collected and run through a machine that is able to

tell if the vaginal swab is HPV positive or not.

4. The Pappaniculuou or "Pap- smear" is a test where cells from the cervix are collected and checked to see if they are normal, precancerous, or cancerous. However, a PAP smear test needs to be read and analyzed in a laboratory making them less commonly used in developing countries. If a woman's pap smear is positive then the patient will need to have a second procedure to remove the cancerous cells.

### **Treatment**

Breast and Cervical cancer are treatable diseases if you visit the doctor and get screened early. There are different ways of treating breast and cervical cancer. The most common ways are through chemotherapy, surgery and radiotherapy.

If the person arrives with a very developed cancer, the doctors will not be able to eliminate the cancer from the person sody completely. It is possible to give the person chemotherapy to slow the growth of the tumour through palliative care. The chemotherapy will make them feel better and will also extend their life. People can live with advanced and metastatic cancer if they follow the treatment correctly.

**Chemotherapy** is a medication given through the vein to treat cancer. It works by killing the bad (cancerous) cells that



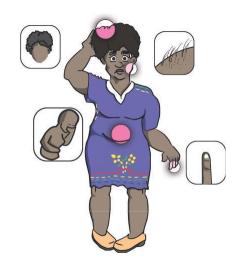
multiply quickly and to prevent any more from coming back. In this way it also can make a tumour smaller. However, chemotherapy attacks all cells in the body that multiply quickly, not just the bad cancer cells. The cells that multiply most quickly in our body are in our hair, in our nails, and also in our stomach. This is why our hair and nails grow so quickly. However it also means that during chemo a patient may experience:

- 1. Hair loss
- 2. Changes in nail color
- 3. Nausea and vomiting
- 4. Skin changes

Most of the time, once chemo has finished, these side effects go back to normal.

While doing chemotherapy treatment, patients experience:

- 1. Hair loss
- 2. Nail discolour
- 3. Nausea
- 4. Skin changes



Once the chemotherapy is completed, most secondary effects go away.

The patient who is receiving chemotherapy needs to visit the doctor"s at precise intervals to receive the chemotherapy medication under the supervision of the doctors and nurses. Most cancers can be treated in outpatient clinics. This means that the person with cancer will go to have their chemotherapy treatment at the

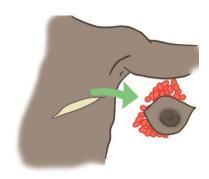
clinic or hospital and can return home after the session. The patient has to follow an itinerary (plan) of chemotherapy

sessions established by the doctor.

Surgery. An operation to remove the cancer growth from the person"s body can be life saving. Surgery is done while the patient is asleep, and so they feel no pain during the operation. Most often,

these surgical interventions are in the place where the cancer is growing.

If a women has breast cancer they will need to have a lumpectomy or a mastectomy depending on how advanced the cancer is. If the breast cancer tumour is small, the doctor might be able to do a lumpectomy, which means removing only the cancerous area of the breast. With advanced breast cancer, the doctor may



need to remove the entire breast. This is what is known as a mastectomy. If the patient refuses to undergo the mastectomy the cancer will continue to grow and will eventually cause the person to die.

Some facilities also offer a mastectomy surgery with reconstruction. This means that the breast that is removed can be replaced with an implant or other fat and skin from another part of the body.

If a woman has advanced cervical cancer the doctor may need to do an operation to remove the uterus (organ where a baby can grow). This is called a hysterectomy, and means that the surgeon will remove the cervix and attached uterus.

**Radiation.** Radiotherapy uses high-energy rays to treat both breast and cervical cancer. It can be given both externally and internally.

- External radiotherapy aims high-energy x-rays at the affected area using a large machine.
- Internal radiotherapy involves having radioactive material placed inside the body.
- Radiotherapy works by destroying cancer cells in the area that"s being treated.

At this current time radiotherapy is not available in Uganda, but is available in neighbouring countries.

### **Community and Family Support**

Women with cancer are often victims of abuse and abandonment and this makes it more difficult for them to talk to their partner, husband and relatives about cancer. Many women hide their disease for fear of repercussions and this means that they come to the doctor with advanced disease that is more difficult to treat.

In order to encourage women to go for screening and follow their treatment, they need a living environment that is supportive.

As experts in the field of cancer treatment and support in Uganda, we have observed how social and familial support is crucial to patient's wellbeing and recovery.



### **Test Module 1: True of False?**

- 1. Cancer is a disease that happens because cells multiply and do not stop:
- 2. Cancer can happen only on the outside of the body:
- 3. Cancer happens because something or someone hits the body:
- 4. Body fat increases your chances of getting cancer:
- 5. You can only have a screening for breast cancer at the doctor"s:
- 6. Unusual bleeding is the main symptom of cervical cancer:
- 7. Chemotherapy treatment has side effects, one of these is hair-loss:
- 8. If you have cervical cancer you have to have surgery to treat the disease:
- 9. Palliative treatment is given to make cancer go away entirely:
- 10. Women are often victims of abandonment because of their cancer:

### Module 2: What you need to know about stigma and women's cancer

### Stigma and Women's Cancer

Stigma comes from Latin and Greek sigma, stigma which means prick. In this sense it means to mark or label.

To stigmatize means to print something on the person, an indelible mark.

According to Goffman (1963), stigma is described as a dynamic process of devaluation that discredits an individual in the eyes of others.



### Cultural aspects of stigma

Stigma is seen as a belief about, or discarding of, a person or persons who are also perceived as going against cultural norms of social groups. Stigma also reinforces the fear of facing excluded and vulnerable groups, like migrants of people with HIV. Stigma is born from misinformation and stereotypes about a given topic and manifests as a severe criticism of what one considers morally reprehensible.

Stigma leads to social rejection and the segregations of vulnerable groups.

### Stigma and discrimination

Stigma and discrimination are closely related and are mutually reinforcing. Stigma leads people to participate in discriminatory acts and behaviours that put others at risk. Discrimination can be defined as the application of stigma.

### Stigma in Uganda

Women with cancer are often stigmatized. The stigma is ted in individual and societal attitudes and results in behaviours that violate the rights and dignity of people who have cancer. These

constitute barriers to research, care and to personal and collective commitments towards the cancer treatment process.

Stigma can have negative effects on the person with cancer"s self esteem when they are already in a vulnerable state. As with HIV / AIDS, there are many taboos and cultural perceptions born from lack of knowledge about the disease and treatment. For example, some people falsely believe that hitting the breast causes breast cancer; others falsely believe that cancer of the cervix is a disease that only affects sex worker.

### Impact of a non-supportive community on a person with cancer

If a person is stigmatized, treating the disease will be difficult because their external environment will have a negative impact them. Stigma itself is as a major challenge in the fight against cancer because it:

- Undermines prevention efforts against cancer;
- Makes women fearful to discover if they have cancer;
- Prevents women from learning about ways to reduce the risks of cancer metastasising and adopting safer behaviour;
- Prevents patients from coping with the side effects of the disease;
- Impacts women"s empowerment;

Fear of stigma also discourages women to reveal and treat their cancer. Women are driven to conceal their cancer from family members and sexual partners in order to avoid isolation, abandonment, unemployment and discrimination of their children. This can contribute the women developing metastatic cancer, because they are too fearful of the consequences of being diagnosed.

### Steps to combat stigma in the fight against cancer

We must address discrimination around cancer, especially women's cancer in Uganda. To do this it is also important to engage stakeholders at all levels (political and social) in advocacy and awareness raising.

With your organisation or group you must define an efficient and effective communication strategy to reach people in your area using all resources and means available to engage communities in the question of cervical cancer and breast

cancer. This is an important step in breaking the chain of discrimination and providing access to information and services for one and all.

### 1. Cancer, a natural disease

It is import to encourage people to understand that cancer is not related to sin or curse but rather a natural disease like any other disease. It is also not a punishment or a disease reserved for women. Everyone can have cancer.

### 2. Awareness

Persuade people that they need to observe any changes in their body. When anomalies appear, you must see a doctor to get tested and also seek necessary information from other people who are in the field. You should not fear reprisal or judgement for seeking treatment.

### 3. Treatment

Explain the treatment process and why patients and their families should maintain their self-esteem during and after this process. The more the community knows about the treatment process, the less they will fear the consequences.

### 4. Available Services

Connect people with facilities where women and their families can find the services available and how to access them. The more people who are successfully treated, the more this will help inform the population and change perception.

### 5. Respect for the dignity of cancer patients

It is important to make sure that people know that access to physical and mental health care is a human right and that this right is guaranteed by law. Everyone has the right to know his or her diagnosis and prognosis. All those who work to improve the living conditions of people who have cancer, especially women, must also take into consideration that they are often victims of violence (sexual, economic, emotional and verbal) because of their disease.

### 6. Family and Community Support

The family unit is recognized as an entity that has a strong influence on the person. Maintaining self-esteem in a difficult time depends on family solidarity.

Therefore, it is important to remind people that family and community support is helpful to empower women to seek diagnosis and treatment of cancer.

Remind people that if they need to discuss cancer in the family, they should discuss how to support the person and seek out people who have knowledge and information on the topic to clarify any questions.

The family is a chain and every link is important for balance. Empowering women is an important part of your role at RURAL COMMUNITY AMABSSADOR, and to sensitize the community towards women society and the need for greater gender and social equality.

### **Test Module 2: True or False**

- 1. Stigma is rooted in individual and societal attitudes and results in behaviours that violate the rights and dignity of people who have cancer.
- 2. To address stigma we should not involve other actors, it is a community-based issue.
- 3. It is easy for women with cancer to maintain self-esteem.
- 4. Stigma prevents women getting screening.
- 5. Stigma can be addressed by providing the community with information.
- 6. If a patient has a bad diagnosis we shouldn"t tell them.
- 7. It is important to look at the issues around cancer like violence and economic abuse.
- 8. Stigma prevents good treatment.
- 9. It isn"t important to empower women with cancer because the doctor will help with this.
- 10. RURAL COMMUNITY AMABSSADORs can have a very important impact on stigma.

### Module 3. Perceptions and what to tell people about women's cancer

Common Misperceptions about Cancer: Here are some common misperceptions that both men and women have about cancer in Uganda.

- 1. Having cancer necessarily means that the person will die.
- 2. Cancer is not a natural disease.
- 3. Cancer care is too expensive for me to afford.
- 4. If I have breast cancer I will have to have my breast cut off.
- 5. Someone, or something, hitting the breast or cervix is what causes breast cancer.
- 6. Cervical cancer is caused by rough sex or the position in which you have sex.
- 7. Breast exams need to be done by a doctor
- 8. Cervical cancer is treated by removing the cervix.

### Key messages

On the basis of some of these key perceptions, we have come up with a set of key messages that RURAL COMMUNITY AMABSSADORs, the media and community leaders should reinforce when talking about cancer.

### 1. Cancer is a disease that can be treated.

It is important to reinforce that Cancer is a disease that can be treated. If you are diagnosed with cancer this does not mean that you are going to die. However, when a person with cancer begins treatment they must follow what the doctors and nurses say.

2. Cancer is a disease that is caused by outside factors in the environment and by a person's family history (genes).

Cancer is not contagious so it cannot be transmitted from one person to the next. It is a disease that is caused by genetics and by what we eat and how we live.

- 3. Cancer care is available at low-cost or for free in Uganda at Mulago Cancer institute hospital. Make sure to reinforce that cancer care is available in Uganda and that some services even offer screening and treatment for free.
- 4. Breast cancer can be treated through chemotherapy and by removing only the cancer from the breast, if the disease is diagnosed early. Many women are scared of being screened for breast cancer because they think that they will have to have their breast removed if they are diagnosed with breast cancer. If you are diagnosed with breast cancer early then you may be able to only have a lumpectomy, which is a procedure to remove the cancer from the breast.
- 5. Something, or someone, hitting the breast, does not cause breast cancer. Many people in Uganda think that breast cancer is caused by a person or an object hitting the breast. Make sure to reinforce that this is not true.
- 6. Cervical cancer is caused by the HPV virus that is transmitted during sexual intercourse. Many people think that cervical cancer is caused by rough sex. Reinforce that it is not caused by rough sex but by contracting HPV, a sexually transmitted virus. The virus itself is not cancer but causes the calls of the cervix to become cancerous.
- 7. Breast exams can be done very effectively by women at home. You do not need to pay to visit the doctor to do this! Reinforce the fact that self checking is important and also free.
- 8. Cervical cancer can be treated by doing a 'see and treat' treatment.

  Doctors will remove the cervix only if the cancer is advanced, most of the time they will perform a "see and treat" procedure to remove any cancerous cells.

Make sure to reinforce these points in your discussions and in the way you communicate in the community.

## **Test Module 3**

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List five of the messages that you need to keep in mind what talking to the

### Module 4: How to Teach Self Breast Exams

Early detection of cancer is the single most important thing. Catching cancer at an early stage will mean that the person has a much better chance of recovery. For this reason, encouraging self-screening in the community is very important!

This is a practical guide to teaching people to do a self-breast exam. You should teach this in big as well as small groups by demonstrating the process step by step. Firstly, explain why self-breast exam is important and encourage women to do this while they are washing themselves or putting on their bra. It is important to give people advice about when and where to do the breast exam because it helps them remember to do it.

With the women following you, stand up and repeat the steps. Following the steps also makes it easier to remember the process:

**Step 1:** Looking at your breasts with your shoulders straight and your arms on your hips.

Here's what you should look for:

- Breasts that are their usual size, shape, and colour
- Breasts that are evenly shaped without visible distortion or swelling

If you see any of the following changes, bring them to your doctor's attention:

- Dimpling, puckering, or bulging of the skin
- A nipple that has changed position or an inverted nipple (pushed inward instead of sticking out)
- Redness, soreness, rash, or swelling

Use the cards to show the pictures to the group as you are demonstrating.

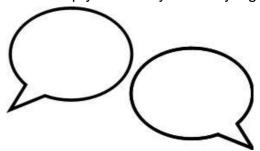
**Step 2:** Now, raise your arms and feel for the same changes, using your right hand to feel your left breast and then your left hand to feel your right breast. Use a firm, smooth touch with the first few finger pads of your hand, keeping the fingers flat and together. Use a circular motion, about the size of a coin.

**Step 3:** Alternatively, feel your breasts while lying down, using your right hand to feel your left breast and then your left hand to feel your right breast. Use a firm, smooth touch with the first few finger pads of your hand, keeping the fingers flat and together. Use a circular motion, about the size of a coin.

Once you have finished explaining, ask for one volunteer to come up and demonstrate what they have learnt.
Help them go through the steps one by one and correct any mistakes they make. This process is important for the whole group to understand and learn together.
Test Module 4: List the Steps
What is Step number 1?
What is <b>Step number 2?</b>
What is <b>Step number 3?</b>

### Module 5: What to do if you find women in the community with cancer symptoms

As a community health worker you may have to make very important decisions as part of your job. During your outreach sessions, you may come across women who have symptoms of breast or cervical cancer. This section of the training is a decision making guide to help you identify the early signs of women's cancer.



# Question 1: Have you checked your breasts this month for lumps or skin changes?

If the person says no: Explain to the person the importance of checking their breasts regularly and revisit the Self Breast Exam steps with them. Ask them to check their breasts and see if there are any changes. Alternatively they can travel to the nearest health centre/clinic to have it done.

If the person says yes, no changes: Make sure you commend them checking and encourage them to do it again next month.

If the person says yes, they felt a change: Commend them for checking and ask if you can feel or see the part of their breast they are concerned about. Connect them with one of the treatment centres listed at the end of this training course.

### Question 2: Have you ever had a cervical cancer screening?

If the persons says no: Explain that the cervical cancer is non-symptomatic (doesn"t have any signs or symptoms) and that they should have a cervical cancer screening at least once every three years. Then, help connect the person with a facility where they can have a screening done.

**If the person says yes:** Reinforce that this is a positive step and ask how long ago they had the screening. If it is more than three years explain that cervical cancer is often non-symptomatic and that women need to be screened every 3 years. Help the person connect with a screening facility if needed.

### Module 6: Taking care and supporting cancer patients in the community

Throughout your work you may need to follow-up on women in the community who are being treated for cancer. Here are a few important things to know in order to support them.

Women who are being treated for cancer are often abandoned by their partners or husbands, so they often face the treatment alone. Although they may receive support from their family, they will benefit from

peer-support and encouragement, especially if they are looking after their children alone. Fostering community support for women with cancer through churches or local organisations is important for their recovery.



Women who are undergoing treatment for cancer feel sick and can benefit from home visits during this time. Chemotherapy can be very hard on the body so visiting patients at home is a good way to support women with cancer. Your organisations can help you identify these people for your follow-up.

After a woman has had her operation they may need assistance keeping their wound clean. Home visits to ensure that the wound is being properly cleaned can speed up a woman's recovery and reduce the chances of infection.

Women who are going through treatment loose their hair and often have a breast removed. It is important that family members and other members of the community understand this and are supportive of the person. Encourage them to speak about their treatment in church and ask for the communities support.

Supporting women in the community who have metastatic breast or cervical cancer is very important. Women who have metastatic cancer may be undergoing palliative care. This means that they are having chemotherapy to reduce their symptoms and make them feel better. But they will never be cured from cancer because is it too advanced. Supporting these women through home visits is just as important as supporting women who are in curative treatmen

### **Test Module 6: True or False?**

- 1. Women often need support for health workers because they are abandoned when they have cancer.
- 2. Chemotherapy doesn"t make women sick.
- 3. Health workers can help take care of women's wounds after an operation.
- 4. Women must stay inside when they have lost their hair and not participate in the community.
- 5. Women with metastatic cancer are going to die so we don't need to support them.

## Module 7: Where are cancer screening and treatment facilities?

Kibaale health center IV Mulago Cancer institute All private health facilities

### **Module 8: Activity Guide**

Motivating the community to adopt positive behaviours requires the RURAL COMMUNITY AMABSSADOR to make home visits, small group education sessions, as well as larger sessions. RURAL COMMUNITY AMABSSADOR interactions with the community are critical. RURAL COMMUNITY AMABSSADORs can help calm fears about cancer; they can also and provide information and support.

Community members trust messages delivered through people they know. RURAL COMMUNITY AMABSSADORs should work with community figureheads, informal leaders, parents, traditional healers and other community partners to deliver



messages and organize activities. Conversations can occur in small group settings or one-on-one and should include activities along with information. After a session, RURAL COMMUNITY AMABSSADORs should also encourage members of the community to share what they have learnt with others.

### **Mobilizing the Community**

Community mobilization is an action that aims to encourage citizens to participate in collective activities and to meet community needs. This participation is designed to positively impact both the individual and the community.

The community must mobilise in the fight against Cancer, in order to fight stigma, build the self-esteem of women who are affected by cancer and encourage the community to help engage other members.

### Why is mobilization important?

All members of a community have a right to feel and to be safe. Community participation encourages collective life skills and helps to develop the communities potential.

When this is understood and defended by all, it is possible to bring about positive and significant changes to community structures, policies and attitudes that shape

collective life. Women's right to safety, emancipation and integration is also shaped in this context.

Mobilising the community in the fight against cancer means increasing engagement with health education, health services and working towards respecting the rights and dignity of women who are affected by cancer.

Participatory development communication is the use of media and traditional, interpersonal means of communication that empowers communities to form objectives and discover solutions to their issues.

Participatory communication, a technique used for community mobilization especially for education and awareness raising, has proven to change behaviour, reduce tensions and build community solidarity in the community for women's cancer. Women in Uganda are exposed to high levels of violence. Participatory communication techniques, that take into account all different groups and levels of trust and are used to meaningfully problem solve issues around women's cancer.

# In order to ensure participatory communication around women's cancer, you must identify:

- 1. The people affected directly and indirectly.
- 2. The most important messages to convey
- 3. Information Channels
- 4. Information means
- 5. Awareness / Communication tools

### How can I identify people who are directly and indirectly concerned?

- **1-** People who are directly concerned actors are the women who have cancer and their families.
- **2-** People who are indirectly concerned are the other actors such as health facilities, town councils, women's organizations and other international organizations working in the domain.

### What are the different types of information?

- **1-** Information about available treatment services and ways to facilitate access.
- 2- Information on the quality of available services.
- **3-** Standard messages commonly defined by patients and families and organizations involved in the field especially women's organizations in the community.

#### What are the channels?

- 1- Press (media)
- 2- Community Radio
- 3- School and Church and the Marketplace
- 4- traditional work Arrangements (Corvees, Konbit, esquades).

### What are the means of raising awareness?

- **1-** Mass Communication or communication to the general public that is to say used matches Foot Ball, recreational days/ patronal festivals / garden parties.
- **2-** Interactive communication such as: dialogue groups, intergroup encounters and discussion clubs

### What are the tools?

**1-**Communication tools such as: Booklets, fact sheets, picture cards, banners, and evaluation cards

### **Community Involvement in Women's Cancer**

Commitment of different stakeholders is the fight against cancer yields the best results. This means involving health institutions, schools, churches, grassroots organizations, social clubs (culture, sports, education ... etc.) and even political parties in an awareness movement.

### Some tips for community mobilisation:

- Learn about local seasonal calendars:
- Prepare a plan and follow it;
- Form partnerships with other groups that operate in the field of women's health:
- Convey clear and accurate messages;
- Learning about the timing of major events;
- · Ability to listen and be listened to

 Remember to identify you"re the people who are directly and indirectly concerned with the issue.

This section of the book provides examples of activities, important topics to cover, and strategies for RURAL COMMUNITY AMABSSADORs to use when mobilizing community members in the fight against cancer. It is important for RURAL COMMUNITY AMABSSADORs to work across settings to have a broad reach in the community. RURAL COMMUNITY AMABSSADORs should be positive and listen to community concerns, problem solve, and avoid simply lecturing. RURAL COMMUNITY AMABSSADORs should use different strategies to support behaviour change. In order to help you to pass on the information we have made an activity guide for you! Some of these activities may be more appropriate for your organisation than other so please feel free to choose what is most appropriate for your ne

### Activity 1: Invite a Survivor or Woman living with Cancer to talk in the Community

Now that you have learnt about cancer, you can start thinking of ways to communicate with the community. Here is one way to do peer-to-peer communication.

From our experience, breast cancer survivors are great communicators and their stories are amazingly motivational. They are able to educate and persuade others of the value of screening and treatment by talking about their stories. Those who listen will laugh and cry but will also connect with people who have lived with cancer in a human way. You can invite a woman from IHI's support group or the Group de Support Contre le Cancer to talk in your community!

- Locate an appropriate space in the community to hold the session. The most appropriate spaces will be in a church or social club.
- 2. Find a survivor that can come and talk at the gathering by contacting the GSCC or IHI.
- 3. Organise an appropriate day for the event to take place. During church service is always a good option.
- 4. Facilitate the arrival of the speaker and their introduction to the community
- 5. Make sure to pass out any education material you have after the session.



## **Activity 2: Discuss Cancer Prevention in the Market Place**

Sometimes it is difficult to teach prevention strategies. Cancer is a disease that is linked to the way we eat, why not use the marketplace to do some education?

Fruit and vegetables are crucial to keeping our body health and well-functioning. There is also lot so fruits and vegetables that people in Uganda love to eat and could incorporate more into their diet. In the marketplace, why not show the sellers and people around which foods are good for preventing cancer? Those who listen will attribute news meanings to the food they buy while also learning. You could even discuss which Ugandan dishes are the best for preventing cancer?

- **1.** Locate an appropriate space in the marketplace to hold the session.
- **2.** Find a local seller in your community who is willing to participate in the education session with the customers by using their produce as discussion points.
- **3.** Organise an appropriate day for the event to take place.
- 4. Facilitate a Q&A with market-goers in which you address the issues around cancer prevention.
- **5.** Make sure to pass out any education material you have after the session.



# Activity 3: Use true or false cards to show and test knowledge.

# Women in the community learn best while doing! So why not use images and cards to help them?

In the mother's club you can educate about women's cancer with images. The objective here is to encourage screening. The ladies will most likely be the right demographic and can learn about cancer along with their reproductive health classes. After the session you can play the card game, true or false, with the card set with statements you can find in IHI's toolkit.

### STEPS TO TAKE:

- **1.** Decide with your organisation or clinic which days are appropriate to include cancer education in the club sessions.
- **2.** Conduct the education session by telling stories about women with cancer and to provide general health information.
- **3.** After the session, the health-•-worker holds the true or false cards in his hand. He will go around the circle asking each person a question and whether it is true or false. If the person gets it right, they are allowed to keep the card. The person with the most cards at

the end wins!

**4.** Make sure to pass out any education material you have after the session.



# Activity 4: Use Image Cards in a Group Education Sessions

### Follow the pictures, tell the story!

You can use group sessions to provide higher-level education to all people and especially to engage the community so that they support women with cancer. Group sessions should be mixed.

### STEPS TO TAKE:

- 1. Plan a group session where you will educate about cancer.
- 2. With the image cards you should follow the story of a lady in Uganda who has cancer.
- 3. After the story, use the images to teach each topic of the session, explaining them in relation to the story.
- 4. After the session, you can use the "True or False" playing cards to test their knowledge!
- 5. Make sure to pass out any education material you have after the session.

### Activity 5: Create a Peer-Support Group for Women with Cancer

Women who are going through chemotherapy and surgery can meet one another and build support networks.

Once you have identified some women that are going through treatment with Cancer you can create a support group for them. You can even find a person in the support group who is particularly active who can help you run it.



- **1.** Create a list of women who you know are going through cancer treatment in the community, with their names and telephone numbers.
- **2.** Call the women individually and set up a time for them to meet, either in your health centre/clinic or organisation.
- **3.** Facilitate conversation between the group members allowing them to tell their stories and voice their concerns.
- **4.** Although you can use these sessions as a way to educate, they are mostly for the purposes of psycho-social support. Answer the questions that are asked of you.
- **1.** Make sure to pass out any education material you have after the session.

## Activity 6: Recruit Women to Be Community Ambassadors

Empower women to be ambassadors in their community to help you in the fight against cancer.

Women who acts as Ambassadors in the community will help you persuade more women to be screened and treated. Finding women who have had some experience with screening or the disease is an important step in finding credible ambassadors.

- **1.** Identify a few women who have been screened or have received treatment and how are willing to speak for the cause.
- 2. Encourage them to speak to other women whenever they can about their experiences and help get rid of fear about screening or treatment
- **1.** Make sure to give them education material that you have available so that they can pass it on.



### **Activity 7: Community Film Screening**

# Watch short films of testimonials with members of the community.

Screening films that have testimonies of women who have had or are living with Cancer is a way to educate and build empathy.

- 1. Find an appropriate location to screen a film, it can be somewhere public or a church.
- 2. Try and locate a video player of a projector that you can use to screen the <ilms.
- 3. Screen the film with members of the community.
- Hold a question and answer session after the screening in which community members can raise queries and ask for clarifications
- 5. Make sure to distribute any education materials that you may have following the session.