



**Date of Publication: July 18, 2020**

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**Title: Raising cancer awareness through an automated telephone system: early lessons from the Uganda Cancer Institute**

We have all heard the adage “Knowledge is power”. In healthcare knowledge can mean the difference between life and death or suffering. Knowledge of health related issues, such as signs and symptoms of ill health, causes and preventive measures, or where to get proper care when one is ill, empowers people to seek appropriate care in time, follow or adhere to treatments, and to take actions that reduce disease risks. [Health literacy](#) is the term used to describe the ability to obtain, process and understand healthcare information, and use it to make appropriate health decisions and follow treatment instructions. Health literacy is especially important for cancer control and prevention because cancer is a complex disease. In this blog we highlight the need for raising awareness on cancer and an innovative intervention by the Uganda cancer institute to address this gap. Early lessons are promising and scaling up this innovation will contribute to early presentation and subsequently better treatment outcomes

### **Health literacy in cancer**

There are many different types of cancer, each with different signs and symptoms; with no single cause but rather a variety of risk factors (sometimes none can be identified); treatments are complex and take a relatively long time. Consequently, patients often delay to seek care because when they develop cancer symptoms – which are often non-specific and vague in the beginning – they think of other, easily understood or more common illnesses. For example, many patients with cancer of the stomach will have sought treatment for (peptic) ulcers for several months before the cancer diagnosis is considered. Other patients shy away from seeking cancer treatment even after diagnosis due to fear, denial, or previous dissatisfaction with the quality of care received from the healthcare facilities. Such patients are often hoodwinked by alternative healers who promise more than they can possibly deliver, and unfortunately the patients end up at cancer treatment facilities in late stages after spending a lot of money on futile treatments. The chronic and complex nature of cancer and its treatments also often results into treatment abandonment and loss to follow up.

*“It is a long journey. You spend a lot, you get different advice, spend money with witch doctors because you think you are being bewitched. People advise you to go here and there” – A cancer patient at the Uganda Cancer Institute talking about her experience.*

### **Cancer awareness in Uganda and access to cancer information**

Cancer awareness in Uganda is low, and access to cancer information is limited. A [study](#) of 545 adult men aged 18-71 residing in Kampala showed that only 10.3% had good knowledge of the symptoms of prostate cancer and only 9% knew about serum prostate specific antigen (PSA) testing which is used in screening for prostate cancer. A [survey](#) on cervical cancer among women in Eastern Uganda found relatively higher knowledge about

the illness, especially among those living in urban areas, those with high incomes, and those who had previously had an HIV test. However, this study still found that many women lacked information on cervical cancer screening, and held wrong perceptions, for instance, that nothing could be done once someone is diagnosed with cervical cancer, that cervical cancer patients could transmit the disease, or that long-term use of contraceptives could cause cervical cancer.

Often accurate health information in Uganda is obtained from health workers, e.g. during a hospital visit, a community outreach, or from a health show on radio or TVs. The limited number of cancer experts and cancer care centers in Uganda implies limited access to cancer information. As a result, there are many myths and misconceptions about cancer. A diagnosis of cancer is one of the most dreaded, often considered a death sentence. Accessible and convenient interventions to raise cancer awareness are therefore needed.

### **An automated telephone system to disseminate information on cancer in Uganda**

Mobile phones are ubiquitous items across all demographics – rich and poor, young and old, rural and urban. Over 70% of Ugandans own a phone, and phone network coverage is countrywide. Ugandans are quite familiar with phones for basic calls and SMS, as well as relatively advanced functions such as mobile money transactions (money transfer, airtime purchase, bill payments) and internet access for those who are literate and own smart phones.

Interactive voice response (IVR) systems are also commonplace, especially in telecoms, banks, digital TV providers, or large corporations. They are the automated, pre-recorded responses you hear when you call the customer care line of the company before you can speak to a person. Often they are used to filter callers and route them to the appropriate adviser.

The Uganda cancer institute (UCI) has implemented a similar system for provision of cancer information to callers. The UCI IVR system functions as the destination as opposed to filtering callers. That is, the pre-recorded messages are detailed enough to answer the callers' questions without having to speak to a person. This reduces the need to dedicate clinicians to the call center, allowing our already busy staff to attend to patients who are in hospital. Our IVR system gives a simple description of cancer, signs and symptoms, cancer types common in Uganda, risk factors and how to minimize them, cancer screening and diagnosis, cancer treatment, and what to expect when one comes to the UCI for treatment (including duration and cost). Following COVID-19 pandemic outbreak, we also added information that cancer patients should know about COVID-19. Lastly, the system has an option for callers to speak directly to a clinician if they have individualized questions as well as a voicemail function to leave a message or question in case the clinicians are busy and unable to answer the calls.

The information is currently in English and Luganda (the commonest local language), and the system is accessible 24/7 by calling a toll-free number (**0800100800**) from any network anywhere in Uganda. In the 6 months since go-live, over 3500 calls have been made to the system (totaling to over 7000 minutes) by over 1230 different numbers. Feedback from the callers is very positive, and we are currently translating the content to 5 additional languages. The service is supported by the Uganda Communications Commission.