EARLY DETECTION IS THE BEST PROTECTION

BREAST CANCER INITIATIVE OF EAST AFRICA, INC.

One Smartphone per Village Project: Comments and Suggestions

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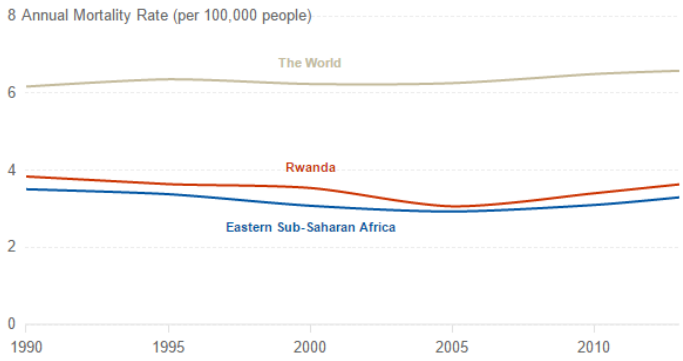
Disease Background

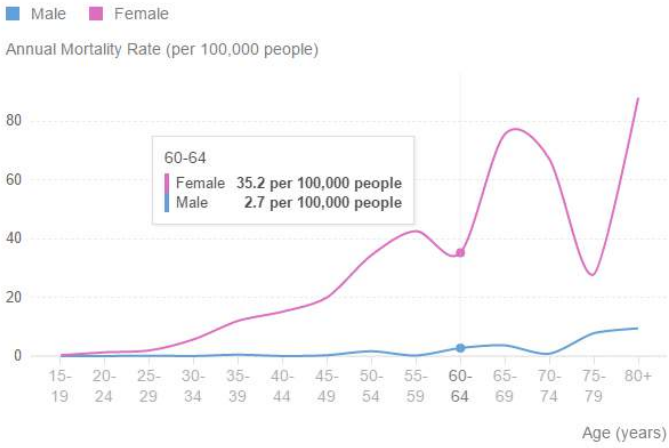


Breast cancer transpires when cells in the breast divide rapidly and uncontrollably. There are several types of cancer that can occur, both invasive and non-invasive. Treatment can comprise of a combination of surgery, chemotherapy, radiation treatment, hormone therapy, or biotherapy; the type of treatment depends on the type, size, and cause of the cancer.

In Rwanda, as it is in the rest of Africa, breast cancer is becoming a major health issue. Eighty five percent of breast cancer cases are presented in advanced stages of the disease; this is associated with of lack of awareness, fear, stigma and limited cancer care resources and infrastructure. For example, in the whole country, Rwanda only offers two oncologists, which can make it difficult for potential victims of the disease to receive professional care and proper treatment.

The average mortality rate for breast cancer in Rwanda is 3.6 per 100,000 people. The Annual Years of Healthy Life Lost is 126.9 per 100,000 people – down 6.9% from 1990 (Health Grove, 2017).

There are currently no oncologists in Rwanda, though plans are underway to train doctors in this field (Musoni, 2012). Rwanda does boast a state of the art cancer centre; however, it lacks a radiotherapy department. Currently patients requiring these services are referred to hospitals in other countries, such as the Mulago Hospital in Uganda (Musani, 2012). However, sometimes even that isn't an option, as the equipment in neighboring countries may not be running. Uganda's only radiotherapy machine for treating cancer broke beyond repair in April of 2016, and leaving thousands of people without access to potentially life-saving treatment, unless they were able to travel to other hospitals in other countries, such as neighboring Kenya (Anonymous, 2016). The machine was unavailable for use for a whole year, until it was finally replaced with a new machine which was to be installed in June of 2017 (Ainebyoona, 2017).



Statistics from Butaro Cancer Center of Excellence, RBC, CHUK Teaching Hospital, Rwanda Military Hospital, and King Faisal Hospital indicate that for breast cancer cases, as many as 57% are presented at late stages when treatment for the disease may be costly, difficult, or impossible (Kibugu-Decuir, 2017).

Organization Background

Breast Cancer Initiative East Africa (BCIEA) was created in 2008 to eliminate preventable deaths resulting from late stage presentations of breast cancer through awareness, education, survivorship, and research. BCIEA aims to improve cancer survival rates in Rwanda 50% by the year 2020 through equipping Rwandans with the skills and understanding of the importance of early detection as the primary defense against cancer. Awareness and education are the key. BCIEA's ultimate goal is to have a fully equipped Breast Cancer Center where women can access valuable information, training and professional support for survivors.

Using lessons learned, evidence-based materials, modified and translated, BCIEA developed a culturally appropriate curriculum targeting women age 16-70, families, caregivers and medical professionals. This program is implemented by trained survivors and/or volunteers in various settings, including: leveraging wide spread cellphone usage and innovative homegrown educational application, professional presentations, community outreach, training workshops and conferences, and health fairs/forums. BCIEA works within the communities of Rwanda to demystify and de-stigmatize breast cancer, replacing the fear with hope and empowering Rwandans to take charge of their health.

BCIEA focuses on early detection being the best protection, as their slogan states. They have three chants that they teach ambassadors and community members: Ikunde (Love yourself), Imenye (Know yourself), Isuzumishe (Get checked). These chants become outcomes, and with each encounter made in villages, the impact and awareness spreads.

One Smartphone per Village

According to studies, 76% of Rwandans own and/or use cell phones; however, many lack access to life-saving information, such as information about breast cancer. The One Smartphone per Village Project intends to put that knowledge into the hands of community members who act as village ambassadors. It is believed to be far more likely that someone may believe information given to them by a neighbor, family member, or friend.

One Smartphone per Village aims to increase breast cancer awareness easily and in a cost-effective manner. The project encourages leadership and ownership of the burden of cancer in

Rwanda. There is a mobile application that provides information and educational materials in English, with a printed guide available in Kinyarwanda.

A member of the village is chosen to act as a village ambassador; this ambassador is preferably someone who has been impacted by breast cancer in some way, either as a survivor or as a friend or family member to a victim of the disease. They are then trained on the basics of breast cancer, including how to promote awareness and utilizing proper communication skills. BCIEA makes sure to include a standard disclaimer that the ambassador is not a health worker and cannot give official medical advice. The ambassador's role is to share information and if necessary, recommend follow-up if he or she thinks it may be beneficial.

The ambassador is given a donated smartphone, loaded with BCIEA Awareness/Educational mobile application.

BCIEA is working to translate the app into Kinyarwanda, which would remove the need for the written guide; the organization also intends to add a data collection function, as well as make the app available offline and accessible to more basic cell phones. This will allow the information to be available to a larger audience.

Village ambassadors use many platforms to share the message and promote awareness; trainings at schools, churches, and community centers, Umuganda, and Umugoroba w'Ababyeyi are a few examples. As of 2016, BCIEA had 23 ambassadors spread out around Rwanda. Data collected suggests that each ambassador reached a range of 120-700 people in their trainings.

The ambassador holds trainings in his or her community, informing attendants about signs/symptoms of breast cancer, risk factors, reducing risk by healthy lifestyle – i.e. no smoking/alcohol, diet/nutrition, exercise – types of treatment, and prevention. Also discussed is how to perform a self-exam. Ambassadors talk and teach about the importance of the exam and why it should be practiced regularly.

Clinical breast exams may be offered by a nurse through a collaboration with RAM. This nurse is paid, though BCIEA cannot afford to have a nurse at all outreaches; in addition, many trainings are held outdoors with little privacy to perform exams. Here is another example of the disparities of Rwanda – there is no mammography equipment for mass screening, and few health professionals who have specialized training.

Ambassadors may hold several trainings in communities throughout the year, in various locations such as schools, community centers, churches, and other platforms. There may be anywhere between 50 and several hundred people in attendance at the training, male and female, and any age range.

Rwanda has 14,847 villages, and BCIEA is committed to installing an ambassador in each one.

Observations

Between May and August, multiple trainings were held in various communities around Rwanda. I had the opportunity to attend three of them, in three separate communities around Rwanda.

Each training was held in Kinyarwanda, though the option of being trained in English was offered each time.

1. Gahini: May 14, 2017
    a. 222 school-aged girls in attendance
    b. Held mid-late afternoon
2. Musanze: June 3, 2017
    a. 218 school-aged children and teenagers, a mix of boys and girls
    b. Held around mid-day
3. Musha: June 19, 2017
    a. 203 school-aged children and teenagers, a mix of boys and girls
    b. Held mid-afternoon

At the end of each training, the ambassadors or BCIEA representative was approached by one or two individuals who wished to discuss concerns. Most trainings appeared to hold the community's attention, and when several members were interviewed after the conclusion, they indicated that they would use what they had learned in the future, bringing the knowledge home to their families, and felt better prepared to protect themselves and their loved ones. There was better attentiveness during the trainings that were held in the afternoon; the one training held around noon appeared to have many kids losing interest as they had not eaten lunch yet.

Trainings were all documented by photographs, with several video interviews being conducted at the conclusion of the training in Musha, asking questions such as what they learned and how they would use that knowledge in the future.

I believe continuing to document trainings in this way will prove beneficial; interviewing participants and asking specific questions such as those that were asked after the training in Musha will assist BCIEA in determining the level of impact within the communities. In addition, asking for any additional questions they still had at the completion of the training may help to further focus and improve future trainings.

Interviews

Interviews with current ambassadors were conducted, gathering information on perceived successes, as well as areas for improvement and suggestions for additions to the organization and the One Smartphone per Village Project.

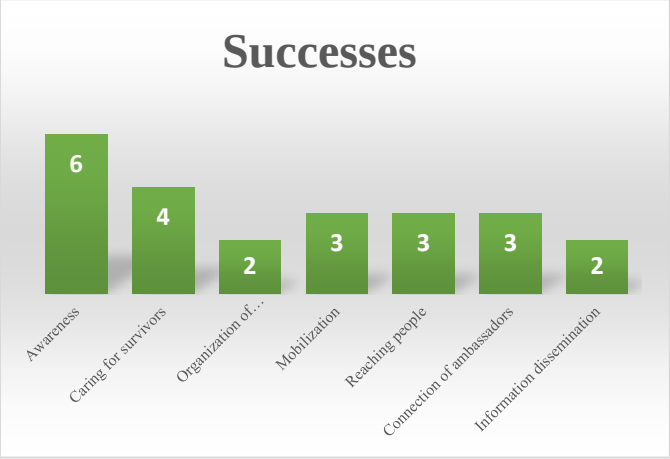
The ambassadors gave testimony concerning their own experiences with BCIEA, and how they hope to improve and expand in the future.

"The Initiative has helped me to survive," says one ambassador, a breast cancer survivor herself. "It gave me the advice and how can I eat or drink, etc. to help. [It] helped me to think positive – not about always thinking I'm going to die, but how to live."

The ambassadors are committed to changing the stigma and increasing awareness, through education and training. One ambassador shared her struggle. When she got cancer, her husband and family, they said 'don't lose our money. She will die, so let's not go to the hospital.' She felt sick, but her family couldn't help her. She tried to self-medicate. No one would help. She went to Kenya to get treatment, but had to go by herself. No one would help her. Her husband still will not help her and her children. The feeling is that if you get cancer in Africa, they say you will die, they can't help you. Her husband says the same thing: don't help them because they will die. This is the attitude that BCIEA works diligently to change.

Interview with a village ambassador, at a school training in Musanze, Northern Province

Successes



BCIEA has had great success thus far, working with ambassadors in villages located in all provinces in Rwanda (Kigali Province, Western Province, Eastern Province, Northern Province, Southern Province).

When one ambassador was asked about her thoughts, she replied that BCIEA needs to "keep going in schools. When the kids go home, they will tell their mothers. [It's a] good way of spreading message – to themselves, to the mothers. Not only high school, but also secondary schools. Kids go home and tell stories."

Note that many ambassadors indicated more than one success of the organization.

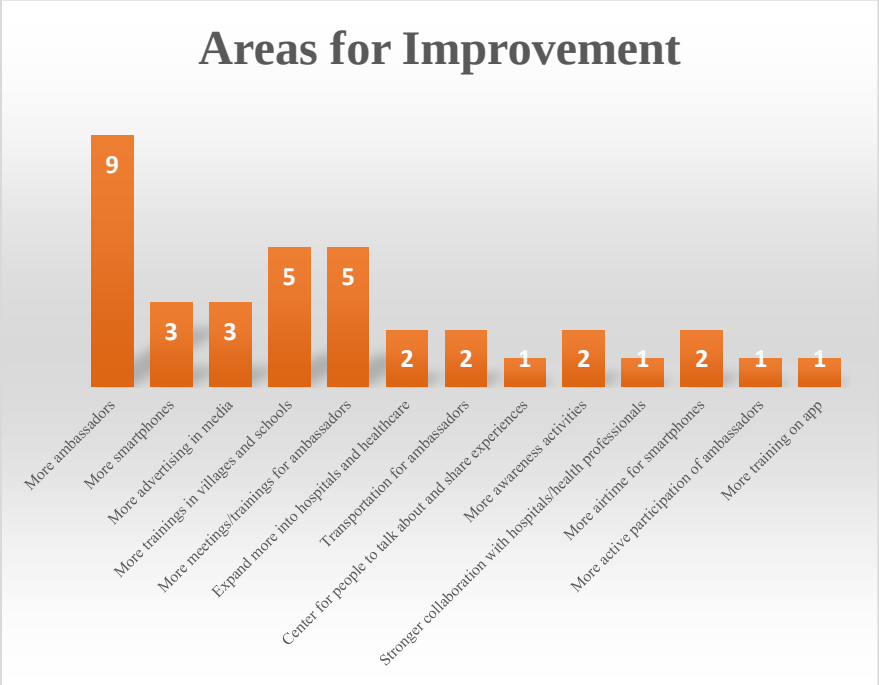
- *Awareness*
    - Many interviewees commented on the success BCIEA has had in increasing and improving awareness of breast cancer in Rwanda. By holding trainings in

communities, the ambassadors are able to improve knowledge, and help women understand how to take care of their own health.

- *Caring for Survivors*
    - BCIEA does not stop at providing knowledge of how to perform a self-exam. The organization also provides information on nutrition, which foods to eat and which to avoid, and activities that can improve health. BCIEA continues to care for survivors long after the original information training and referrals to specialists.
- *Organization of Meetings/Trainings*
    - Interviewees commented on the usefulness of holding meetings and trainings for ambassadors, and praised the organization of these sessions.
- *Mobilization*
    - Another successful area that many interviewees commented on was mobilization of resources. BCIEA has become skilled in moving into communities and having their ambassadors
- *Reaching People*
    - Interviewees commended BCIEA in reaching people in the community. The organization does well in outreach and providing opportunities for communities to learn about breast cancer.
- *Connection of Ambassadors (Smartphone project)*
    - The One Smartphone per Village Project was praised for its ability to connect ambassadors together. The app allows ambassadors from different villages to reach out to each other for support, assistance, and support.
- *Information Dissemination (Smartphone project)*
    - The mobile application was also applauded for being able to disseminate information on a wide scale. It allows ambassadors to give information on breast cancer prevention and screening, as well as providing information on further steps that may be needed, should a community member require it.

Areas for improvement

Interviewees also indicated many areas where BCIEA could improve the organization and the One Smartphone per Village project.



Many ambassadors spoke passionately about their ideas for improvement. "[There are] so few [ambassadors] in country, it hinders large communication of spreading breast cancer awareness – we need to increase the number of phones. Hand in hand, we also need to increase volunteers – each village should have at least two ambassadors."

"Not all participants are active," said another ambassador. Though 23 ambassadors were trained, only 17 are active on regular basis. "If participants could be more active, the goal could be more easily reached. Very few ambassadors participate on the group in the smartphone app. More help with reports – to track data collection, [such as] how many referrals, etc." There could be many reasons why ambassadors don't currently participate. "[It] could be personal. More training on the app could help ambassadors be more active."

Note that many ambassadors indicated more than one area for improvement.

- *More Ambassadors*
    - The most often suggested area for improvement given by interviewees was to increase the number of ambassadors in communities. All ambassadors want to see BCIEA spread throughout the country, and believe that each village should have at least one ambassador. Some suggestions were made that there should be at least two ambassadors in villages, to increase their ability to disseminate information.
- *More Smartphones*
    - Alongside increasing ambassadors, many indicated that more smartphones were also needed, to provide more opportunity for giving out information to community members.
- *More Advertising in Media*

    - Several interviewees believed that BCIEA should increase their presence in the media. More advertising of the organization, as well as promoting breast cancer awareness in the media, could allow more people to come forward if they have a concern for their own health or the health of someone they know. One suggestion made was for a weekly or bi-weekly radio show, to give out information on breast cancer, screening, and prevention techniques.
- *More Trainings in Villages and Schools*
    - Ambassadors believe that there should be more training offered both in villages, and in particular, in schools. By providing the information to children in schools, they can also bring the knowledge home to their families, which further spreads awareness.
- *More Meetings/Trainings for Ambassadors*
    - Though the organization of meetings and trainings for ambassadors was praised, several interviewees thought that they needed more. Providing more meetings also provides ambassadors more opportunity to meet with each other and learn from each other's experiences. Meetings and trainings allow participants a chance to learn not only from BCIEA employees, but also from fellow ambassadors.
- *Expand More into Hospitals and Healthcare*
    - Several interviewees recommended expanding more into hospitals. By training more doctors and healthcare professionals, it could increase collaboration and decrease some of the fear and stigma that community members have, believing that a doctor will not help them if they go to a hospital.
- *Transportation for Ambassadors*
    - One of the biggest challenges for ambassadors is transportation; it is very difficult to get places because transportation costs are expensive. Many interviewees recommended this as an area for improvement.
- *Center for People to Talk About and Share Experiences*
    - A recommendation was made to provide a center where survivors could gather to talk and share their experiences. This center would also provide support and allow a chance to share suggestions and ideas for staying healthy.
- *More Awareness Activities*
    - An interviewee suggested more activities that provide awareness of breast cancer. The Ulinzi walk was highlighted as an example, and the interviewee recommended having similar walks in other parts of the country.
- *Stronger Collaboration with Hospitals/Health Professionals*
    - Increasing the collaboration within hospitals and other health professionals could help to combat the stigma and fear many community members face. BCIEA could help to improve this aspect by setting up and executing more trainings with doctors in hospitals, as well as working with professionals in nutrition and sports

fields. BCIEA already provides information on foods they should eat and those they should avoid, and activities that can be performed to improve health. Collaborating with professionals in these fields could improve knowledge and increase collaboration.

- *More Airtime for Smartphones (Smartphone Project)*
    - Though ambassadors are given smartphones to disseminate information, many would like to have more airtime available, so that they can use services like Google to look up more information as needed. This would allow them to further help their community, in particular those community members most in need of the assistance.
- *More Active Participation of Ambassadors (Smartphone Project)*
    - Not all ambassadors are active on the mobile application, which can hinder other ambassadors, as it limits the information they are sharing with each other. BCIEA should work to increase participation of all ambassadors on the app. This can include more training (see below), and working with ambassadors to determine the biggest hindrance for each of them, and working to overcome it.
- *More Training on Mobile Application (Smartphone Project)*
    - An interviewee recommended that ambassadors receive more training on the mobile application, as many may not understand how to fully utilize it. This could be a reason for the low participation. BCIEA should build a session on the app into each training it offers to ambassadors. This will ensure that ambassadors understand how to use the app, and offering this guidance at each training provides repetition and continuously guarantees ambassadors have not forgotten any part of the app.

Suggestions from similar projects

Mobile Health (mHealth) is a rapidly growing field across the globe, particularly in rural areas of underdeveloped countries, where the number of people using mobile phones for internet access far outstrips the number who use desktop or even laptop computers. There are many projects currently being piloted, tested, and expanded, that deal with a variety of health-related issues. Several ideas already in place to promote awareness in various public health causes could be adapted by BCIEA to be used to do the same for breast cancer.

- **RapidSMS**
    - RapidSMS is a free messaging mobile application that can be used to collect data even in rural communities, and allows recipients to receive information from organizations with whom they are in contact. It is a free, open-source programming framework that allows developers to build their own SMS-based applications. Organizations can use SMS mobile phone technology to customize

applications for data collection, logistics coordination and communications operations. RapidSMS has already been deployed in several countries around Africa, including Uganda, Zambia, Kenya, and Ethiopia. Within Rwanda, the application has been applied to a project that tracks nutritional information of pregnant women and children under the age of two.

- RapidSMS uses a phone's WiFi or data to send and receive messages, while also offering organizations more features – such as a computer desktop interface – to allow for greater versatility. While the organization interface may include additional fees, there are no added costs to the community member or recipient who receives the communication.

Adapting strategies to BCIEA

- *Nutrition program – Rwanda*
  - Rwanda's nutrition program tracks weight and height for children under two in all villages around the country (Gaju, 2013). It also gives feedback to Community Health Workers (CHWs) through notifications; the program offers CHWs help and advice to support mothers and families of malnourished children.
  - This system could be used by BCIEA ambassadors to track information on training sessions, referrals, doctor's visits, follow-ups, and other useful information. One of BCIEA's main concerns at this time is data collection and analysis. There are currently few strategies in place to gather data on the organization's success within communities, and while ambassadors are asked to track this information, they do not at this time do so with any regularity. Using RapidSMS could provide an easy way for ambassadors to send BCIEA this data.
- *Project Mwana – Zambia*
  - Project Mwana is an HIV project in Zambia that delivers test results for diagnosis in infants to rural clinics (UNICEF, 2012). This project also facilitates communications between clinics and community health workers, through the use of RapidSMS.
  - Project Mwana eliminated much of the turnaround time between testing and getting results. This is a similar problem that men and women face when testing for breast cancer. It takes time to go to the doctor for an initial visit; exams and testing takes more time, and then a return visit to get the results. Using RapidSMS to send ambassadors the results as soon as they are available could impact breast cancer in much the same way as it has done so for HIV among infants in Zambia – the initial results from Project Mwana indicated they improved the turnaround time for transmitting test results by more than 50 percent. While further research and testing is needed, these positive results indicate that a similar boost could be seen when utilizing this service for breast cancer.

Conclusion

BCIEA has made significant strides in the last few years, to increase awareness and decrease stigmatization in Rwanda. Reports indicate that its

efforts are working; however, addition of data collection to tha app would improve the work being done by this organization. Based on my observations this summer, some ambassadors do not use the mobile application as much as they should, and they do not report details from their trainings in a timely manner. Updating the app to include data collection services would improve BCIEA and provide evidence to highlight the organization's successes, as well as to show any areas that need improvement.

There are some public health services in developing countries that use technology. BCIEA can look to these projects, such as Project Mwana and the Nutrition program in Rwanda, for ideas that can be transferred and used to improve the One Smartphone per Village project. Ambassadors have also given ideas on how to improve and make volunteering with the organization easier and more effective. Increasing ambassadors, providing more training, and working towards more collaboration with hospitals and healthcare professionals are just some of the ideas ambassadors have that could improve BCIEA.

Breast cancer is an increasing problem in many developing countries, especially Rwanda. But with organizations like BCIEA working on the ground in country, we can work together to combat all aspects of the disease – from the lack of awareness of the problem, to the stigmatization for people who have been diagnosed, and eventually all the way to the severe lack of specialized doctors and equipment needed to treat patients. BCIEA is committed to working within communities to overcome barriers and improve awareness and prevention.

References

1. Ainebyoona, E (2017, April 1). New cancer machine arrives in June. Retrieved from http://www.monitor.co.ug/News/National/New-cancer-machine-arrives-June/688334-3872436-j5snm4/index.html
2. Anonymous (2016, April 8). Uganda's radiotherapy machine for cancer treatment breaks. Retrieved from http://www.bbc.com/news/world-africa-35997075
3. De Tolly, K & Alexander, H (2009, March). Innovative use of cellphone technology for HIV/AIDS behavior change communications: 3 pilot projects. Retrieved from https://www.w3.org/2008/10/MW4D_WS/papers/kdetolly.pdf
4. Gaju, E (2013). The Use of RapidSMS in Nutrition: Mobile Technology to Track 1000 Days – presentation. Retrieved from www.moh.gov.rw
5. Health Grove (2017). Breast Cancer in Rwanda. Retrieved from http://global-disease-burden.healthgrove.com/l/33173/Breast-Cancer-BCIEA in-Rwanda
6. Kibugu-Decuir, P. (2017, April 14). Breast cancer fight: each one of us has something to give. *The New Times.* Retrieved from http://www.newtimes.co.rw/section/article/2017-04-14/210649/
7. Musoni, E. (2012, July 8). Clinton to open Butaro Cancer Centre. *The New Times*. Retrieved from http://www.newtimes.co.rw/section/Printer/2012-07-18/55188/
8. Newton, R, Ngilimana, P, Grulich, A, Beral, V., Sindikubwabo, B, Nganyira, A, & Parkin, D (1996). Cancer in Rwanda. *International Journal of Cancer, Volume 66*, pp. 75-81.
9. Niyitegeka, T (2016, February 5). Rwanda has only two oncologists. Retrieved from http://en.igihe.com/health/rwanda-has-only-two-oncologists.html
10. Partners in Health (2016, February 5). Faster, better care for breast cancer in Rwanda. Retrieved from http://www.pih.org/blog/faster-better-care-for-breast-cancer-in-rwanda
11. Rubagumya, F (2017, February 7). There's no worse disease than ignorance. *The New Times*. Retrieved from http://www.newtimes.co.rw/section/article/2017-02-07/207768/
12. UNICEF (2012). Project Mwana: Using mobile technology to improve early infant diagnosis of HIV. Retrieved from https://www.unicef.org/partners/Partnership_profile_2012_Mwana_Zambia_V2_approved.pdf