

Breast Cancer Awareness Month – breast cancer survival in sub-Saharan Africa

Questions and Answers

1. Please describe the study, how it is being done, and at what stage you are.

The African Breast Cancer - Disparities in Outcomes (ABC-DO) study enrolls women newly diagnosed with breast cancer and follows their entire breast cancer journey. We interview women at diagnosis, to collect information on first signs and symptoms, sociocultural and lifestyle practices, and how they entered and navigated their health systems to reach the hospital. All breast cancer-related clinical information is extracted from medical records, and each woman is actively followed up with phone calls every three months to document such things as alternative treatments, quality of life, recurrence, and of course her vital status. We are currently two years into the recruitment phase and have just stopped recruitment at our first site in Namibia, where we have more than 500 women being followed. More than 1600 women with breast cancer are now in the study.

2. Why did IARC decide to conduct the first multi-country sub-Saharan African study of breast cancer survival?

The burden of breast cancer in sub-Saharan Africa is going to increase dramatically – it is projected to double in the next 20 years just from population growth alone. In addition, lifestyles are changing, especially reproductive patterns, which will likely further affect breast cancer burden. Current breast cancer survival data are sparse in sub-Saharan Africa and, furthermore, suffer from large losses to follow-up – something we are trying to address with active regular follow-up in ABC-DO. The data that do exist suggest that survival rates are some of the lowest worldwide.

3. The study will look at socioeconomic factors, cultural practices, and health attitudes that affect breast cancer survival in these countries. Can you give examples of what these are and how they affect women?

There are so many of these that affect women, especially relating to early diagnosis. The most obvious is cost; in many cases, women have to return to their homes/villages in order to raise money for their diagnostic tests and/or treatments. There are also far more complex issues; for instance, some women report to a local health clinic, but are not referred, or don't have the support or funds to reach referral hospitals hundreds of kilometres away.

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4. What are the greatest challenges in conducting this research?

Staying in touch with the women – even though mobile phone usage rates are extremely high in sub-Saharan Africa, most people have several SIM cards and change numbers often. Charging phones can also be a challenge for women, especially in more remote areas. We have a great research team of nurses, who are very persistent and do a fantastic job of keeping in touch. We also ask for contact details for friends and family who we can contact if we lose touch.

5. You will use health technologies such as mobile phones. Is this something new in this type of study, and how will that work?

I do not think it's new to use phones or tablets to collect study data, but we have extended this and also use them for study management. As you can imagine, it would be difficult for our nurse to know who to phone every day when she is following up 500 women, who need to be called every three months. Our specialized mobile application adds the woman's personal folder to the app each time a call is due (her folder will also appear when she has clinical information due to be entered), and calls can be launched directly from the app, as well as data entry.

6. What are the expected results, and how will these results help countries to better tackle breast cancer?

We expect to see settings that have better survival prospects than others, and demonstrate ways to avoid deaths from breast cancer in sub-Saharan Africa. We designed ABC-DO to have a within-Africa focus so that we compare more similar settings with each other, none of which have population-based screening. Differences that exist between sub-Saharan African countries then become realistic targets for improvements.