

## Africa Storytelling Challenge— Notable Submissions: In Christine Wanjiru Mburu's Words

Committed to championing scientific innovations and advancements, Mburu is affecting change in her community and throughout Africa—and this year's judges of the Africa Storytelling Challenge lauded these impressive efforts. Recognized as a runner-up in this year's contest, Mburu shares her essay submission below.

I am passionate about using my technical skills to assist women in low-income settings to use readily available Information and Communication Technologies (ICTs) to access healthcare. Since 2013, I have been working in marginalized areas around Africa to design and deploy m-health systems that help Community Health Workers (CHWs) to educate mothers on maternal and child health care. In 2016, I met a woman who had undergone a traumatic preterm birth (less than 37 completed weeks of gestation). From that harrowing experience, the woman suggested that it is essential for researchers to investigate how technologies can support mothers of premature infants' cope with the stressful premature birth phase. The challenge intrigued me, and I became curious to learn whether there exists research knowledge that focuses on using technology intervention to support mothers of premature infants. Unfortunately, none existed in the developing world context and I felt compelled to explore this sensitive field of maternal health.

At the start of the year 2017, I enrolled for a doctoral degree at the University of Cape Town. I am currently collaborating with renowned experts in both Human-Computer Interaction (HCI) and neonatology field to explore this under-researched topic. This research is being conducted at Groote Schuur Hospital (GSH). We are currently working with Neonatal Intensive Care Unit (NICU) staff and mothers of preterm infants from low-income settings to understand the challenges that mothers face in the NICU. Most mothers live in informal housing settlements in Cape Town city periphery where overcrowding, unemployment, crime and poverty is rife.

These mothers are stressed by their infants' uncertain health conditions as well as the intimidating environment at the NICU. It is an uphill task for these poverty-stricken mothers to create time and raise the fare to needed to visit and nurse their infants. They are forced to rely on staff to update them on their infants' health status when they are unable to visit the unit. However, the NICU staff are usually overwhelmed with daily NICU duties and they can only communicate with the mothers when the infant's condition is critical or when the mother has been away for a long time. There is evidence of

communication breakdown because mothers lack essential information that will help them make prompt decisions over their infants' care thus exacerbating their level of emotional stress.

To ensure we design an intervention that will overcome the communication challenges in the NICU, we focus on engaging both the NICU staff and mothers in the co-design process to ensure that their needs are captured and incorporated in the final solution. This is a sensitive study that involves participants who are vulnerable to stress and possess limited exposure to technology and design skills therefore we focus on exploring the appropriate techniques that will empower both mothers and staff to fully participate in the design process without aggravating their emotional stress levels.

To familiarize with the NICU environment and build work relation with the participants, we volunteered to work in the unit where we helped the nurses and mothers to feed and clean the infants. Through this process, we were able to understand the challenges that both staff and mothers face while the infant is hospitalized to the NICU. Later we conducted one-on-one interviews with 10 staff and 15 mothers to deepen our knowledge of the existing challenges. We analyzed our data and identified that mothers need constant communication with staff to help them alleviate the stress related to premature birth. The NICU staff mentioned that technology could be used to educate mothers on parental roles and neonatal status of their infants. To clarify the information collected during the interview sessions, we conducted four separate focus group sessions with neonatologists, nurses, mothers and lastly a joint focus group with all participants.

We employed the empowered design process that recognizes that participants regardless of their limited exposure to technology, are experts of their own lives and when empowered, they are capable of shaping technology solutions to meet their own needs. Through these sessions, we allowed the participants in their separate groups to generate design ideas and sketch workflows and prototypes of solutions that were feasible in this context. During the joint focus group session, participants narrowed down the design ideas to the most viable solutions. They agreed that a motivational system could be used to sensitize the mothers who are not able to visit the NICU to continue expressing breastmilk for their infants as well as educate them on the benefits of exclusive breastfeeding. The participants generated the system workflow to visualize its functionalities. In addition, digital videos were proposed as the appropriate solution for educating mothers on common health complications that are related to prematurity.

This study is still a work in progress. In the next co-design activity, we plan to engage the participants in prototyping sessions. We will use both low and high-fidelity prototypes to allow the participants to turn their design ideas into testable and tangible artifacts, which they can interact with to discover the potential issues that may exist in the workflow before we develop the system. The final tool will be deployed at the hospital where we will monitor its usage and effectiveness in supporting mothers. We will also create digital video which we will share with mothers as well as display them at the NICU I to afford the mothers opportunity to learn about premature birth and complications related to it.

This is ground-breaking research and the first of its kind in the developing world context. We hope it will serve as the reference to future researchers who might venture in building on this work with an aim of supporting low-income mothers as they adjust to the maternal role while their infants are hospitalized in NICU. The complete work is envisaged to inform the effectiveness of using ICTs in NICU context, the appropriate methodologies while working with mothers who are vulnerable to stress and challenges related to this study.

The content and views presented here are those of the individual Challenge participant.

## **About the Africa Storytelling Challenge**

The inaugural <u>Champions of Science—Africa Storytelling Challenge</u> took place between May and August 2018. Open to all scientists doing innovative work in Africa, the contest drew more than 100 submissions. An independent selection committee of scientists, policymakers and science journalists reviewed the applications and selected the winners. Each winner will be awarded \$5,000 and will have the opportunity to share their stories at the 2019 American Association for the Advancement of Science (AAAS) annual meeting in Washington, D.C.