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Profile

Sophie Uyoga—reducing sickle cell stigma in Africa



For more on **G6PD deficiency and malaria** see **Articles**
Lancet Haematol 2015;
2: e437–44

For more on **sickle cell disease in Kenya** see **Articles**
Lancet Glob Health 2019;
7: e1458–66

For more on the **TRACT trial** see
Vox Sang 2019; **114**: 340–48

Although there were no scientists in Sophie Uyoga's family, she had the full support of her mother in pursuing a career in science. Born and raised in Mombasa, Kenya, she studied biological sciences at Jomo Kenyatta University of Agriculture and Technology (Nairobi, Kenya). Unlike her peers, who mostly went into sales at pharmaceutical companies, she knew she wanted to pursue a career in academia. She was able to do an informal internship at the nearby Kenya Medical Research Institute (KEMRI, Kilifi, Kenya), studying the immune responses of pregnant women to malaria. After returning to university to complete her studies, KEMRI offered her a full-time job. She remains working there as of September 2020, as a research fellow at the KEMRI-Wellcome Trust Research Programme, "This really opened the door to my career", says Uyoga, who started as a lab technician in the team of Tom Williams (Imperial College, London, UK and KEMRI-Wellcome Trust Research Programme). She then received funding to do a Masters' degree in immunology through distance learning at the University of Manchester (Manchester, UK), and was, subsequently, thrilled to obtain a Marie Curie Fellowship to do a PhD at the University of Torino (Torino, Italy), where she found it very easy to blend into a cosmopolitan laboratory with many nationalities working together. During these years, she worked in both Torino and Kilifi, transferring the laboratory-based experiments on mechanisms of severe anaemia in malaria to the field.

Uyoga's initial research described a genetic polymorphism prevalent in people contracting malaria in sub-Saharan Africa: glucose-6-phosphate dehydrogenase (G6PD) deficiency correlated with severe malaria and malaria-specific mortality, with G6PD heterozygous girls showing protection against severe disease. She has also worked extensively on sickle cell disease, work that has expanded her profile in Kilifi. Working with Williams and colleagues, and using data from over 15 000 children registered in the Kilifi Health and Demographic Surveillance System from 2006 to 2011, her team showed that mortality in children with sickle cell disease was 24 times higher than those without; however, mortality was 74% lower in children with sickle cell disease registered with an outpatient clinic compared with those who were not. "The children registered were invited to the clinic for vaccines, drugs to prevent malaria and infections, and for monitoring of their symptoms during regular check-ups. However, we still don't have newborn screening for sickle cell disease, which could make a big difference", explains Uyoga. Another project she has been involved in is the TRACT transfusion trial in Malawi and Uganda. This study focused on children with anaemia who needed blood and described what type of blood and

how much blood they got, and their outcomes. "We found that sometimes, perhaps due to simple labelling issues, some physicians were not sure exactly what blood products they were giving", explains Uyoga. To disseminate the findings, Uyoga helped set up a meeting in Kampala, Uganda in February, 2020, attended by heads of transfusion centres across Africa. "Many of the issues could be solved with better training and communication, making it clear what blood product needs to be given and why", explains Uyoga. She feels the study and meeting have helped improve the transfusion system in Africa, including reducing wastage.

Among Uyoga's most rewarding work is an animated story book aiming to reduce stigma for children with sickle cell disease and families. The book was launched to commemorate World Sickle Cell Day on June 16, 2020. Uyoga helped conduct focus group discussions and in-depth interviews with patients and their families to help put together an accurate picture of the disease. "Some families do not understand the disease, while others believe it is a curse", explains Uyoga. "Children are treated as weak and bullied." The book, called *Sickle Cell Heroes*, was put together using a range of characters. "The book is not only meant to highlight the experiences of the affected families but also give hope and answer some of the questions that the patients and parents can struggle with. I wanted the message to be communicated in a way that would be entertaining to the younger patients", explains Uyoga. "At the moment, it is only available in English and Swahili, but we want to have it translated into other languages used across the African continent", she adds.

At the time of writing, Uyoga has found her work diverted to assist in the COVID-19 pandemic, conducting seroprevalence studies to establish exposure to the disease. Since the pandemic, she has been working from home most of the time, which has fuelled her Netflix addiction. "My main concerns are around funding for various projects that has stalled due to the pandemic", she says. "And like many people around the world, I don't really know what work will look like post-pandemic. Can we ever share offices and spaces again like we did before?"

"Sophie Uyoga is a fantastic asset to our research programme in Kilifi and to African science more broadly," says Williams. "Just being smart is not sufficient to succeed in a career in science: you also need the kind of passion, ambition and tenacity, together with the confidence to support younger colleagues, that Sophie has in abundance. The future looks bright with colleagues like Sophie navigating the way."

Tony Kirby