Project background
Sickle cell disease (SCD) is a genetic disease that affects the red blood cells. It is a serious and lifelong health condition and is a common cause of childhood mortality across Africa. Tanzania ranks fifth in the world for the highest number of SCD births annually and it is estimated that the disease accounts for 6.6 per cent of all deaths of children under the age of five each year. Yet deaths from the disease are not inevitable. Early identification of SCD through newborn screening (NBS) means that symptoms can be treated and managed promptly, increasing the chances of survival for children with the illness.

Project description
The Newborn Screening for Sickle Cell Disease programme was an innovative health intervention that previously had not been implemented in Tanzania. In addition to increasing the survival rates of children diagnosed with SDC, the pilot also aimed to improve the quality of reproductive and child health (RCH) services by training health workers on NBS theory and practice. The pilot was implemented as a routine RCH service in two public hospitals, Muhimbili National Hospital (MNH) and Temeke Hospital.

A blood sample was taken from a newborn baby within 48 hours of birth and screened for the disease. Babies who were found to be SCD positive were then given appropriate follow-on care while health-care workers educated parents about the disease, including its symptoms and treatments. Pregnant women were also made aware of SDC during their regular antenatal clinic visits.

Project results
Between September 2015 and August 2016, the NBS programme screened 4,002 newborns (12 months): 1,142 (29 per cent) at MNH and 2,839 (71 per cent) at Temeke Hospital. As a result:
- 31 newborns were diagnosed with SCD, 508 were identified as carriers of the SCD gene, 27 were diagnosed with other haematological disorders, and 3,436 were found to be SCD negative. All 31 babies who were diagnosed with SCD at birth were given comprehensive care.
- 160 nurses from MNH, Temeke, Amana, and Mwananyamala Hospitals and eight laboratory technicians were trained on SCD screening using Isoelectric Focusing (IEF) and High Performance Liquid Chromatography (HPLC) methods.
**KEY LESSON**

*Look for ways to adapt and enhance existing resources:* The success of the programme was mainly due to the approach of selecting public hospitals and integrating NBS services into existing government RCH services. Instead of training new nurses from scratch, the NBS programme worked with nurses who were already part of the government employment system and engaged in related services, such as HIV counselling for pregnant women and HIV tests for newborns. Consequently, they were already familiar with NBS-related practices and could apply their previous and ongoing experiences.

**NEXT STEPS**

The MUHAS Haematology and Blood Transfusion (HBT) department will continue to oversee the programme and retain the services of laboratory technicians trained in NBS to carry on conducting the tests. The HBT department has already started mobilising resources through developing and applying for research funds, developing partnerships with health programmes, and exploring a strategy for generating income by providing laboratory services.

Through the Newborn Screening for Sickle Cell Disease programme, MUHAS will continue to support MoHCDGEC to establish the NBS national steering committee, which will review NBS targets and redesign the national strategy based on learning from the programme. Pending support from MoHCDGEC and the availability of funds, MUHAS will also oversee the process of finalising NBS national guidelines, training materials, and standard operating procedures.

**PRINCIPLES FOR DIGITAL DEVELOPMENT**

*Design for scale:* By engaging with government health stakeholders and donors from the beginning, Muhimbili University of Health and Allied Sciences (MUHAS) has been able to influence and help shape the national agenda on NBS. For example, the programme supported the Ministry of Health, Community Development, Gender, Elderly and Children (MoHCDGEC) to develop the first draft of the country’s ‘National Newborn Screening Guidelines.’