

“Changing a verdict of despair” – Ghana’s Public-Private Partnership with Novartis in the field of sickle cell disease



Sickle Cell Disease (SCD) is a global health problem, but the highest burden of disease is concentrated in sub-Saharan Africa (SSA), 80% of people with SCD live in this region. In resource-poor countries, more than 90 percent of children with SCD do not survive to adulthood. In Ghana, 15'000 babies are born with SCD every year. This essay aims to show how the Ghanaian government joined forces with the pharmaceutical company Novartis in a public-private partnership to offer a comprehensive approach to manage the disease, and to consider the African contributions of this partnership to global health. After looking at the sickle cell disease and what is a public-private partnership in general, it considers how this specific partnership is conceived and how SCD has not only a medical but also a cultural dimension which needs to be considered.

SCD is a major genetic, hereditary, and life-threatening disease causing ongoing vascular damage and injury to blood vessels and organs. The sickle shaped cells interconnect and can result in blood clots causing extreme pain in the back, chest, hands, and feet. The disrupted blood flow can also cause damage to bones, muscles, and organs. The illness takes a heavy emotional, physical, and financial toll on patients and their families. The World Health Organization (WHO) recognized SCD as a public health priority and a neglected health problem in SSA (Power-Hare & Ware 2020, 173). However, SCD is largely absent from the global health agenda.

A Public Private Partnership (PPP) is a term that describes a broad category of activities and structures involving public and private sectors. At minimum, a PPP involves one core public, non-commercial organization and one private or commercial organization that collaborate and share efforts and rewards. A PPP in health systems should contribute to improve the efficiency of and access to the healthcare system, decrease costs, and increase innovation for the benefit of vulnerable populations (Strasser 2021, 2).

The PPP between the Government of Ghana and Novartis to create a comprehensive approach to manage the sickle cell disease in Ghana, was officially launched in Accra, Ghana,

on November 11, 2019. In Ghana the institutions involved from the start were the Ministry of Health of Ghana, the Ghanaian Health Service, and the Sickle Cell Foundation. Novartis CEO, Vas Narasimhan, MD, placed this commitment in line with Novartis' new strategy to provide innovative medicines to more patients in SSA. Novartis was already present in Africa addressing malaria and leprosy. In 2019, it created the Global Health SSA unit shifting the focus away from sales performance and profits to parameters that strengthen health systems in the region (Novartis November 13, 2019). Further, it created the Novartis Africa Sickle Cell Disease program to implement PPP with local governments, as well as collaborations with universities, patient groups, and professional societies. Novartis entered in PPPs with Uganda and Tanzania in 2020 and plans to reach at least 10 countries in SSA.

One of the key pillars of the PPP in Ghana is the access to drugs which can help SCD patients. Ghana became the first country in Africa to offer the drug Hydroxyurea as from 2019, the global standard of care for people with SCD in countries of the Global North, but until then not present in SSA. The WHO had included Hydroxyurea both in its *Model List of Essential Medicines* and its *Model List of Essential Medicines for Children* (Power-Hayes and Ware, 2020, 178). Novartis registered the drug for the treatment of SCD in Ghana both for use in adults and children and committed itself to develop a child-friendly formulation for children unable to swallow capsules. The Sickle Cell Foundation of Ghana, a local partner in the PPP, together with a team of Ghanaian SCD experts, developed the Hydroxyurea dose adapted to the country. The team also developed, with the support of Novartis, a digital phone-based application (App) to ensure safe and effective use of Hydroxyurea by the health professionals. These activities are evidence of a partnership, where Ghanaian health experts bring in their essential know-how.

To ensure accessibility, Novartis entered a strategic collaboration with Olon, an Italian manufacturer, that supplied the first 12,000 of the active ingredients for the drug at no cost and by 2020 Novartis had delivered more than 60,000 treatments of Hydroxyurea (a treatment equals one month's supply for an adult patient). Further, the strategic collaboration of Novartis with Zipline, a drone delivery system, improved the accessibility of the drug to patients living in rural areas. In line with the other two key pillars of the PPP, namely the strengthening of the healthcare system and training of health professionals, the therapy is made available through 11 treatment centres which have been trained on using the drug.

"The nurses love having a mobile phone that has the App in it", said Prof. Ohene-Frempong, president of the Sickle Cell Foundation of Ghana (Novartis, Sickle Cell Disease 2019, You tube). He considers that screening babies is the most important public health activity because an early diagnosis allows appropriate care and preventive therapy which makes the disease milder. Novartis supported the Sickle Cell Foundation of Ghana to develop and roll out an App to facilitate collection and management of data in Ghana's national new-born screening program. The nurses type the information in the App, the laboratories receive the information and add the results which go back to the family and the treatment centres. Having digital and real-time information at hand helps to provide continuity of care and today more than 25,000 babies have been registered in the App. In an example of South-South circulation of knowledge, the application is being expanded to other countries in SSA. Novartis partnered

with Hemex Health to launch an affordable point of care diagnostic, improving not only access to SCD screening but also to genetic testing of adults.

An important aspect of drug accessibility is the economic burden on families affected by SCD. On June 19th, 2021, the World Sickle Cell Day, the government of Ghana announced the provision of Hydroxyurea and the associated laboratory testing for people with SCD through the National Health Insurance Scheme. Thus, the Ghanaian government stood to its commitment to ameliorate the access to SCD biomedical therapies.

Drug development is another key pillar in the PPP. Dr Cornelis Winnips, Novartis Head of Global Program Clinical Trials said in an interview with Christian Burri and Eric Nebié, that SSA Africa is “a great place to do clinical research.” Dr Winnips underlined that patient recruitment and motivation to participate in clinical trials in Novartis’ antimalaria drug development had been in all sites above expectations. In relation to SCD, Novartis announced plans to conduct two clinical trials in Ghana and Kenya for a novel treatment for SCD with crizanlizumab, making it the first time that a biologic therapy which is not a vaccine, would have multicentre clinical trials in SSA (excluding South Africa). This biologic therapy reduces the number of pain crises, and has been approved by the FDA in the USA in 2019. As the interview with Dr Winnips underlined, clinical trials in SSA represent an important African contribution to global health.

Novartis joined forces with partners from around the world, in the belief that no single pharmaceutical company or government can do it alone. The partnership of Novartis with Zipline and Hemex Health have already been mentioned. Novartis is deeply involved in Research and Development in the field of gene therapy which aims to treat diseases by replacing, inactivating, or introducing genes into cells — either inside the body (in vivo) or outside of the body (ex vivo). In SCD, the genetic cause has been known for long, but a gene therapy remains a goal. Novartis entered into a grant agreement with the Bill & Melinda Gates Foundation to discover and develop a novel gene therapy to cure the clinical manifestations of SCD. This in vivo gene therapy would be administered directly to patients, allowing shorter hospital stays and requiring less specialized infrastructures. Already back in 2007, Vink-Kim Nguyen suggested in relation to AIDS, that data from clinical research carried out in developing countries would be of increasing strategic importance to the pharmaceuticals industry as research costs escalate in the Global North relative to the number of research subjects available (Nguyen, 2007, 139). The Novartis engagement in SCD in SSA, could bring Novartis further know-how applicable in all other regions with SCD, for example the Americas, and India, but also Europe.

The fifth key pillar in the PPP is an innovative approach to the cultural dimension of SCD. While traditionally pharmaceutical companies saw their role in research and development of drugs and selling them profitably, this partnership recognized that the stigma attached to SCD required a change in the cultural response which is not brought about with a pill, a vaccine, or a gene-therapy. According to Nancy Rose, historians can use fiction as a source to acquire an insight of the cultural dimension in society. In the case of SCD, I refer to the novel *Stay with Me* by Adebayo (2017). “Do you know about sickle-cell disease? [...] Your son has sickle-cell disease” (Adebayo, p. 169). The medical verdict is one that brings despair to the young mother Yebide. Yebide and the biological father of her children carry the sickle cell gene and transmit

it to their children. Yebide is devastated when she sees her daughter Olamide suffer terrible pain and die, and her hope that her young son Sesan will be healthy crumbles down when he suffers the same fate – no hospital, and no ‘scientific’ medicine can save them. Moomi, Yebide’s mother-in-law, related the death to *Abiku*, the superstition of a child in an unending cycle of births, deaths and re-births, children who die prematurely, only to arrive again with the birth of the next child. (Akiyode 2006, 227). Moomi enforced the tradition of ritually marking the dead child’s body to recognize a new-born baby as the re-birth who comes back to torment the mother (Adebayo 2017, 203).

In real life, frequent illness, painful episodes, and stunted growth cause children to struggle to do well in school. Misconceptions and social stigma are in part related to the legacy of inexplicable early deaths afflicting certain families. It is not unheard of for children to be outcasted because their villages believe that witchcraft is behind their symptoms. To address understanding Novartis makes education a priority, developing educational content and partnering with the Global Alliance for Sickle Cell Disease Organizations (GASCDO) to strengthen the skills of patient associations.

In conclusion, the PPP of the government of Ghana with Novartis in the field of SCD is an example of Africa’s contribution to global health with a comprehensive approach taking into consideration the biomedical and the cultural dimension, to “change a verdict of despair.” Ghana is a relatively small country, but its government committed itself to invest in improving the health of its people partnering with Novartis to make SCD a manageable disease. SCD is not confined to Ghana and thus improvement in the treatment of SCD patients in Ghana could bring a circulation of knowledge not only within the Global South but also in direction of the Global North and could encourage other PPP in healthcare.

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