Cameroon Townhall for Healthcare Professionals

Meeting Minutes, March 9, 2024

Host: Cameroon Townhall for Healthcare Professionals

Date: March 9, 2024

Chair: Dr. Munoh Kenne Foma

Co-Moderators: Elvis Ndansi (lead moderator), Dr. Katte Jean-Claude (Q&A moderator), Dr. Bryan Tegomoh

Guest Speaker: Dr. Yauba Saidu, MD (Faculty of Medicine and Biomedical Sciences, Yaoundé), master's degree in vaccinology, PhD in public health, Country Director, Clinton Health Access Initiative (CHAI), Cameroon

Distinguished Guests: A paediatrician in the United Kingdom, Franklin Maloba, microbiologist and immunologist in the United States, Dr. Ronald Gobina

Title: Roadmap to Sickle Cell Disease Elimination in Cameroon by 2060: Strategies, Action and Policy Priorities

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Agenda Items:

1. Welcome and opening remarks by Elvis Ndansi, Dr. Bryan Tegomoh, Dr. Katte Jean-Claude and the Chair
2. Introduction of the speaker by Elvis Ndansi
3. Presentation by Dr. Yauba Saidu on a roadmap to sickle cell disease elimination in Cameroon by 2060
4. Reactions from the moderators and the Chair, including on gene therapy
5. Discussion and Q&A moderated by Dr. Katte Jean-Claude
6. Closing

Opening Remarks:

- Elvis Ndansi welcomed participants and said the town hall had about 2,350 members across about 36 countries, meeting every two weeks. He recalled the previous session on the malaria vaccine by Dr. Boghuma Kabisen Titanji.
- Dr. Bryan Tegomoh said he looked forward to the speaker's vision for the ambitious goal of eliminating sickle cell disease. Dr. Katte Jean-Claude, joining from the

United Kingdom, said the disease is strongly associated with people of African descent and needs a response on the continent.

- The Chair said Cameroon has no strategic plan for sickle cell disease, that the disease evolved alongside malaria, and that he treated more patients and gave better care in New York than in Cameroon; outside Africa, the Bronx has the highest concentration of patients. He noted the toll on infant, child and maternal mortality.
- Elvis Ndansi introduced Dr. Saidu, Country Director of CHAI in Cameroon, describing his work on medical oxygen during COVID-19, on malaria, and on negotiating prices of cancer medicines with the government.

Presentation Points:

Presentation by Dr. Yauba Saidu: "Roadmap to Sickle Cell Disease Elimination in Cameroon by 2060: Strategies, Action and Policy Priorities"

1. The disease and what prevents complications:

Dr. Saidu outlined sickle cell disease as a single amino acid change (glutamic acid replaced by valine at position six of the beta globin chain) that causes haemolysis, anaemia and vaso-occlusion, with complications in the lungs, brain, kidneys, eyes and spleen. Vaccination against pneumococcus and other encapsulated bacteria, eye screening, pain management and disease modifying drugs such as hydroxyurea prevent much of the harm, but uptake is low, morphine is hard to obtain, and gene therapies remain out of reach.

2. Burden and the link with malaria:

Over 500,000 children are born with the disease each year worldwide and 50 to 90% in Africa do not reach their fifth birthday. The distribution of the trait mirrors malaria because carriers (AS) are protected against Plasmodium falciparum. Haplotypes differ, and the speaker and the Chair said the Bantu and Cameroon haplotypes found in Central Africa are linked to more severe disease than the Senegal or Arab-Indian types. Because the burden is concentrated in Africa, market incentives for new diagnostics and drugs are weak.

3. Governance and screening gaps:

His team reviewed 106 Cameroonian publications, interviewed stakeholders and analysed newborn screening pilots. Cameroon has a management guideline (last updated in 2021), but its availability and use in facilities are uncertain, and only a small, largely non-functional unit in the Ministry handles sickle cell disease. Systematic screening is almost absent: the largest pilot screened about 60,000 newborns in 2015 to 2016, out of about 1.1 million births a year, and the median age

at diagnosis is about four years. The national reference laboratory in Yaoundé offers discounted testing for children under 15, but families elsewhere pay 7,000 to 20,000 FCFA. About 7,000 children are born with the disease each year in Cameroon.

4. Care, workforce and psychosocial support:

Dedicated sickle cell units are few and concentrated in tertiary urban hospitals. A study of about 200 Cameroonian physicians found only about 14% had adequate knowledge, as pre-service training is limited. Psychosocial support for families is essentially absent, and families face stigma, including accusations of witchcraft. He called for care integrated into primary health care at health centre level and more haematologists and paediatricians trained in the disease.

5. Data and financing:

The district health information system (DHIS2) has no sickle cell indicators, so deaths and their causes go unrecorded. Most spending is out of pocket and can push families into poverty. A study found 82% of children with the disease had not received recommended pneumococcal and meningococcal vaccines. He proposed adding screening and care to the universal health coverage package, a budget line with tracking of disbursement, and noted the health budget had fallen from about 6% to about 5% of the national budget against the 15% target.

6. Opportunities:

He pointed to the WHO AFRO sickle cell strategy, a new point of care test giving results in about five minutes for about $2 to $3, school health clubs, premarital screening through religious, traditional and municipal authorities, the Lancet Commission on sickle cell disease, and funding from Open Philanthropy. He said volume guarantees could encourage manufacturers to supply hydroxyurea at low prices, and that existing programmes (community health workers, antenatal care, HIV, the Expanded Programme on Immunization, oxygen, CHAI sentinel sites for malaria and congenital syphilis) could add screening and care at little extra cost, including a life course vaccination platform for boosters after 15 months.

7. Three steps to elimination:

His roadmap: first, 'close the tap' by helping people know their haemoglobin genotype from school age and before marriage so that couples can make informed choices, preventing many of the 7,000 annual births with the disease; second, prevent deaths in children who are born with it through vaccines, nutrition, eye care, hydroxyurea, morphine and safe blood; third, introduce curative therapies when affordable. He asked that town hall talks be turned into short videos for TikTok and WhatsApp in simple English, French and Pidgin, citing Dr. Titanji's Pidgin video on

the malaria vaccine, and said he writes sermons on health for religious leaders. He named Dr. Makia Christine Masong, Françoise Nwabufo and his colleague Michael among a growing group of advocates, and said a manuscript and a call to action were being prepared from the presentation and the discussion.

Discussions and Q&A Session:

- **Dr. Tegomoh: what does the recent US approval of gene therapies mean for Africa?** The Chair said two therapies were approved, one using CRISPR gene editing and one a lentiviral vector, at about $2.4 million to $3 million per patient, and that even in the US few can afford them. At the American Society of Hematology meeting the main question was who would pay. Only three centres in Africa (in Nigeria, Namibia and South Africa) were said to perform bone marrow transplants, and gene therapy also requires chemotherapy conditioning. He said this is not the way forward for Cameroon now.
- **Dr. Katte Jean-Claude: how does the new point of care test work?** Elvis Ndansi said it is a finger prick rapid test, similar to an HIV test, that distinguishes AA, AS and SS in minutes for less than $2, with trials reporting 100% sensitivity. Dr. Saidu added that it also estimates the proportion of haemoglobin, which can guide decisions on transfusion at primary care level.
- **A paediatrician in the United Kingdom: is 'elimination' the right goal, when median survival in the UK is close to that of the general population and results from African laboratories are often wrong?** The paediatrician said people should know their status to make informed decisions, but advising people not to marry or have children raises ethical questions, and the focus should be on better care. Dr. Saidu said that in Cameroon the disease is still largely a death sentence, with about 90% of affected children dying before five, and that his proposal is informed choice through counselling, not a ban. He invited the paediatrician to document how often African test results are reversed in the UK. The Chair said his oldest patient is 88, that survival varies by haplotype, that Cameroonian laboratories mostly use basic haemoglobin electrophoresis while the UK uses high performance liquid chromatography and genetic testing, and that he estimated median survival at about 18 years in Nigeria and 19 in Cameroon. In the UK, all pregnant women and newborns are tested.
- **Dr. Tegomoh: which partnerships matter most for scaling up screening? And what did the American Society of Hematology say about priorities for Africa?** Dr. Saidu named government, civil society, patient and family groups (citing the role of HIV patient movements), philanthropic and women's and children's organisations, manufacturers, religious and traditional institutions, and development banks shown the economic cost of the disease. The Chair said sickle cell disease became a

priority for the American Society of Hematology from 2017 and that US public funding had supported several new drugs, but manufacturers rarely prioritise Africa.

- **A question from the chat (Dr. Ronald Gobina): how is malaria related to sickle cell disease?** The Chair explained that the mutation arose many times, but in Africa falciparum malaria favoured carriers (AS), while AA children died of malaria and SS children of sickle cell disease. As malaria is eliminated the advantage disappears and the trait slowly declines, as seen in Brazil, but this takes a very long time, so screening and informed choice are needed.
- **Franklin Maloba: how can an AA mother have a child with sickle cell disease, and does bone marrow transplant change the stem cell niche?** The Chair said such cases usually involve an untested thalassaemia trait (sickle beta or alpha thalassaemia) or other haemoglobin variants, which basic testing misses, and that many doctors in Cameroon are not aware of this. He described haemoglobin C, E and other variants and referred to the research of Prof. Ambrose Wonkam.

Call to Action and Closing:

- Elvis Ndansi thanked the speaker for a presentation of about 90 minutes that kept about 50 to 55 participants throughout, and noted that the town hall meets every second Saturday at 1 p.m. Eastern Time (7 p.m. Cameroon time).

Recording: https://www.youtube.com/watch?v=ilMUxPT5gmQ

Submitted by: Co-Moderators, Cameroon Townhall for Healthcare Professionals