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**PROGRESS IN THE IMPLEMENTATION OF THE AFRICAN REGION
SICKLE-CELL STRATEGY 2010–2020**

Information Document

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BACKGROUND

1. The Sixtieth session of the WHO Regional Committee for Africa (RC60) adopted the document entitled “Sickle-Cell Disease: A Strategy for the WHO African Region”.¹ The aim of the strategy is to reduce the incidence, morbidity and mortality of sickle-cell disease (SCD) in the Region through: (i) identifying priority interventions for Member States to develop and implement programmes and policies for SCD prevention and control at all levels; (ii) providing a platform for advocacy to increase resource allocation for the prevention and control of SCD; (iii) establishing mechanisms for monitoring, evaluation and research on SCD and applying the findings in policies and programmes.

2. From November 2018 to March 2019, WHO assessed the implementation of the regional SCD strategy in 26 Member States,² including the 23 high-burden Member States. The high-burden Member States have sickle-cell trait (SCT) prevalence ranging between 20% and 30%. A validated self-administered questionnaire was sent to all the WHO country offices in the Region, for completion by ministries of health. The questionnaire was meant to assess the available policies, programmes and health service infrastructure for SCD prevention and management in countries.

3. The response rate from high-burden countries to the questionnaire was 92%. Some Member States with low SCD prevalence indicated that they did not have an SCD programme, so they did not complete the questionnaire. In addition to the questionnaire, WHO conducted deep-dive missions to some of the high-burden Member States, to further validate the responses and get more details on available resources for SCD and the challenges Member States were facing in the implementation of the Regional strategy. The assessment revealed that implementation of the SCD strategy had been generally inadequate in comparison to the targets adopted in the regional strategy.

4. At the Sixty-ninth session of the WHO Regional Committee held in Brazzaville from 19 to 23 August 2019, a high-level side meeting was organized to strengthen commitment to the strategy and agree on ways and means to scale up SCD prevention and control in the context of universal health coverage (UHC). At the end of the high-level meeting, agreement was reached on actions to rapidly increase access to essential diagnostic technologies and medicines for SCD prevention and control in Africa.

5. This report summarizes the actions taken and progress made by Member States against the set targets as well as issues and challenges. The Regional Committee is invited to examine the report and adopt the proposed next steps.

PROGRESS MADE/ACTIONS TAKEN

6. Functionality of national SCD control programmes in high-burden Member States: All high-burden Member States have established a designated unit for SCD in their respective ministries of health. They have also included SCD in their current national health plans except for Burundi, Comoros, Mauritania, Senegal and Sierra Leone.

¹ Sickle-Cell Disease: A Strategy for the WHO African Region, World Health Organization, Regional Office for Africa, 2010 (AFR/RC60/8)

² Angola, Benin, Burkina Faso, Burundi, Cameroon, Central African Republic, Chad, Côte d’Ivoire, Democratic Republic of the Congo, Gabon, The Gambia, Ghana, Guinea, Kenya, Liberia, Mali, Mauritania, Madagascar, Niger, Nigeria, Senegal, Sierra Leone, South Sudan, South Africa, United Republic of Tanzania, Togo, Uganda, Zambia, Zimbabwe

7. **Resource allocation for prevention and control of SCD:** Allocation of funds for prevention, early diagnosis, management and surveillance of SCD is an important barometer of progress in implementing national SCD control programmes. The Regional strategy targeted 50% of the 23 high-burden countries implementing clearly defined national SCD control programmes; however, funding from the annual State budget is allocated for health promotion for SCD in only eight Member States³ and for newborn screening or mass screening for SCD only in Burkina Faso, Kenya, Liberia, Niger and Nigeria. Only Burkina Faso, Liberia, and Nigeria reported allocation of funds in the national budget for surveillance, monitoring and evaluation of SCD activities. Seven Member States⁴ had funding allocated for capacity building for prevention and management of SCD. Only Benin, Burkina Faso, Liberia, Mali, Togo and Zambia had funding allocated in their national budget for research related to SCD.

8. **Newborn screening and early diagnosis of SCD:** Newborn screening for SCD is an important component of surveillance and determination of SCD prevalence. It is being practised in 12 Member States⁵ at subnational level, out of the expected target of 50% of all Member States. Furthermore, the services are generally provided only in tertiary health facilities except in Mali, Democratic Republic of the Congo, Uganda and Ghana where samples for newborn screening are collected at all levels of the health system and transported to the tertiary facilities. In Burkina Faso and Uganda, SCD newborn screening is integrated into HIV screening programmes. In six other Member States,⁶ newborn screening for SCD is integrated into reproductive, maternal, newborn and child health (RMNCH) programmes. These linkages improve early detection and management of SCD.

9. **Adoption of comprehensive health-care management of SCD:** The related Regional Strategy target is for 25% of African Member States adopting the concept of comprehensive health-care management of SCD. The levels of implementation of comprehensive health-care management of SCD patients of all ages vary across Member States. National guidelines for SCD management were indicated to be available in 11 Member States.⁷ Folic acid prophylaxis for SCD patients is available in all Member States that responded except in Angola, Burundi, Central African Republic and Gambia, while availability of hydroxyurea was reported in 11 Member States.⁸ The prevention, diagnosis and management of SCD are often centralized in secondary and tertiary health facilities.

10. **Strategic information, surveillance and research:** The related target of the Regional strategy is for 25% of the high-burden sickle-cell trait (SCT) Member States to establish SCD surveillance. However, most Member States in the Region had no accurate information on SCT prevalence. Only 10 Member States had data on SCT prevalence in newborns and adults.⁹ However, eight Member States¹⁰ have included time-bound national targets for SCD screening and management and five Member States¹¹ have defined national indicators to facilitate the development of national frameworks that will improve surveillance, reporting and accountability.

³ Benin, Burkina Faso, Guinea, Liberia, Mali, Nigeria, Togo and Zambia

⁴ Benin, Burkina Faso, Congo, Liberia Mali, Nigeria and Senegal

⁵ Benin, Burkina Faso, Cameroon, Democratic Republic of the Congo, Ghana, Kenya, Liberia, Mali, Nigeria, Senegal, United Republic of Tanzania and Uganda

⁶ Democratic Republic of the Congo, Gabon, Ghana, Guinea, United Republic of Tanzania and Uganda

⁷ Burkina Faso, Congo, Democratic Republic of the Congo, Ghana, Liberia Mali, Mauritania, Senegal, Nigeria, United Republic of Tanzania, Uganda

⁸ Congo, Ghana, Kenya, Mali, Mauritania, Mauritius, Nigeria, Senegal, United Republic of Tanzania, Togo and Uganda

⁹ Benin, Gabon, Ghana, Kenya, Mali, Niger, Nigeria, Senegal, United Republic of Tanzania and Uganda

¹⁰ Benin, Ghana, Gabon, Liberia, Mali Nigeria, Togo and United Republic of Tanzania

¹¹ Benin, Mali, Nigeria, United Republic of Tanzania and Togo

ISSUES AND CHALLENGES

11. **Poor availability of services at the district and subdistrict levels:** Most of the services across the continuum of prevention, early detection and management of SCD are not offered at district and subdistrict primary health care (PHC) facilities despite the fact that the Declaration of Astana on PHC of 2018 and the UN high-level meeting on UHC of September 2019, reiterated the central role of PHC in achieving UHC. Capacity for newborn screening is limited in most Member States. In most subdistrict PHC facilities in the Region, the available complement of human resources is not maximized to offer comprehensive SCD services through decentralization/delegation of diagnosis and management services.

12. **Poor access to medicines and medical equipment:** Since the adoption of the Regional strategy in 2010, there have been a number of innovations and technological advances in prevention, early diagnosis and management of SCD. These includes routine use of hydroxyurea that has been shown to significantly improve survival and the quality of life of SCD patients, use of transcranial Doppler ultrasound which is available in 16 Member States,¹² and other technologies that improve diagnosis and management of SCD. These are not widely available and, even when available, are not affordable to most of the people that require them.

13. **Insufficient budgetary allocation for prevention and control of SCD:** Progress in the implementation of the SCD strategy in Member States has been slow due to inadequate budgetary allocation to cover all planned SCD prevention and management activities and interventions at national and subnational levels.

14. **Weaknesses in health service organization:** SCD is poorly integrated into existing public health programmes such as HIV and RMNCH. The significant investment in the development of laboratory infrastructure for diagnosis and management of HIV across the Region has not contributed to improved availability of diagnostic procedures for SCD. In addition, although RMNCH programmes offer a platform for integrating SCD interventions including genetic counselling, newborn screening and early diagnosis, in most Member States, these capacities are not optimally utilized. Linkage of the SCD screening programme to the RMNCH programme is available in only six Member States.¹³ Moreover, community health care extension workers who can potentially reach more babies through the primary health care centres if adequately trained, are not involved in the process of newborn screening in any Member State.

15. **Lack of accurate and reliable data on SCD:** Due to the absence of national-level newborn screening programmes and SCD surveillance across most Member States, there is lack of accurate and reliable data on the national prevalence and burden of SCD. In addition, data collection for SCD is not included in most national population-wide surveys such as STEPS and demographic health surveys. The non-availability of accurate data has an impact on the prioritization and allocation of adequate resources for SCD.

¹² Benin, Burkina Faso, Democratic Republic of the Congo, Gabon, Ghana, Kenya, Mali, Mauritius, Niger, Nigeria, Congo, Senegal, Togo, South Africa, United Republic of Tanzania, Uganda.

¹³ Democratic Republic of the Congo, Gabon, Ghana, Guinea, United Republic of Tanzania, Uganda.

NEXT STEPS

16. Member States should:

- (a) Allocate to the SCD programme a budget that is commensurate with the national burden for screening, diagnosis, treatment, surveillance, and research;
- (b) Include hydroxyurea in the National Essential Medicine List and ensure its availability;
- (c) Integrate SCD prevention and management in the PHC service package, and specifically newborn screening and early intervention programmes for SCD in maternal and child care programmes;
- (d) Strengthen the referral system to improve access of SCD patients to specialized services when needed;
- (e) Develop and implement policies on genetic counselling for SCD;
- (f) Include SCD prevention and management (including genetic counselling) into the pre-service curriculum of all cadres of health service providers to increase their capacity to deliver comprehensive care to SCD patients;
- (g) Include SCD in routine population-based national surveys.

17. WHO and partners should:

- (a) Update the Regional strategy on SCD with deliverables and targets that are aligned with recent global and regional developments and reporting;
- (b) Provide technical assistance to Member States for the formulation, costing, implementation and monitoring of national policies and action plans on SCD;
- (c) Conduct high-level advocacy and resource mobilization for SCD at national and regional levels;
- (d) Engage with partners and national programmes to investigate the barriers to accessing hydroxyurea with a view to negotiating a reduced and affordable price;
- (e) Ensure that SCD remains high on national, regional and global health agendas through fostering collaborations and partnerships on SCD;
- (f) Establish an African Network on Sickle-cell Disease to serve as a platform for advocacy, generation and dissemination of research and best practices on SCD.

18. The Regional Committee noted the progress report and endorsed the proposed next steps.