

METHODS NOTE · Peer-reviewed · Published · Live dashboard figures

Sickle Cell Disease Neglect: A Mismatch Between Burden and Research in Africa

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Abstract

In the burden-versus-investment landscape of African research, does the distribution of sickle cell disease trials reveal a systematic research gap, despite sickle cell disease affecting more Africans than any other genetic condition [1,2]? This cross-sectional audit used ClinicalTrial.gov records through April 2026, covering 23,87 African and 190,644 United States (US) interventional trials registered. We computed the rate ratio comparing Africa to other regions as primary outcome using metadata for each nation.

Africa recorded 9 sickle cell trials (0.0% of its portfolio) compared with 574 in US, indicating a 0.02-fold disparity in per-population investment. The Theil index of 1.288 indicated high between country inequality, with decomposition showing most disparity arising from inter-regional gaps. These findings suggest research activities do not align with disease burden, with Africa receiving minimal trial attention relative to need.

These results may be limited by the reliance on a single trial registry (ClinicalTrial.gov), which may omit locally registered African studies.

Interactive dashboard figures

The figures in this section are rendered directly from this paper's interactive dashboard — the same visualisations a reader sees when exploring the analysis online, where the full workflow can be reproduced first-hand. **Interactive dashboard:** <https://mahmood726-cyber.github.io/africa-e156-students/health-disease/dashboards/sickle-cell-neglect.html>

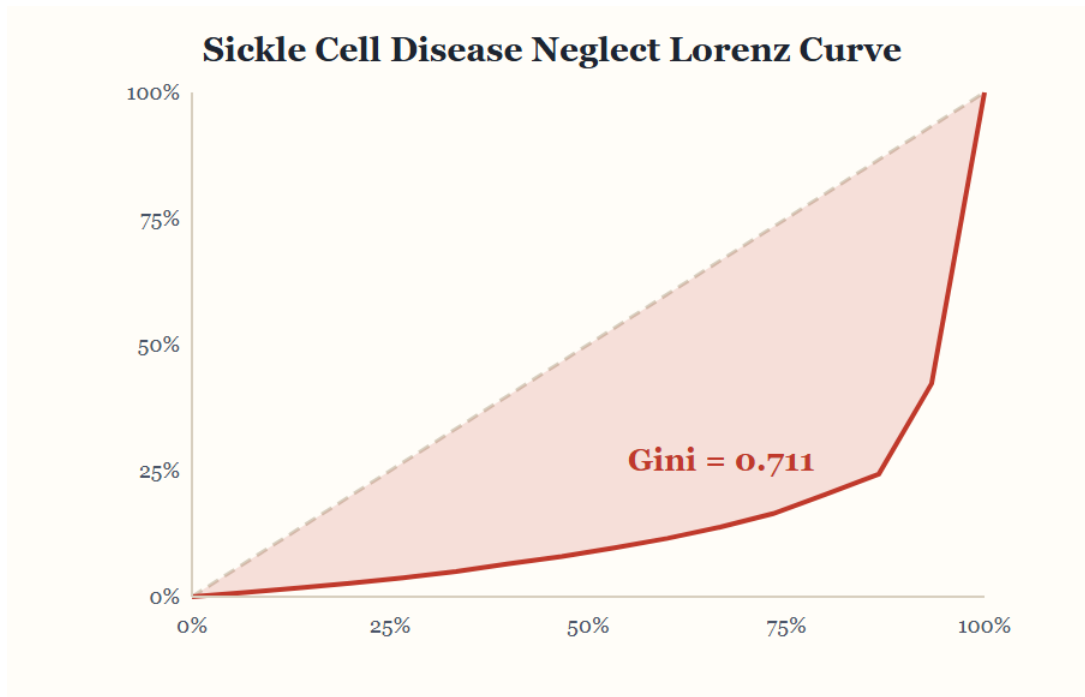


Figure 1. Sickle Cell Disease Neglect Lorenz Curve Rendered directly from the article's live interactive dashboard.

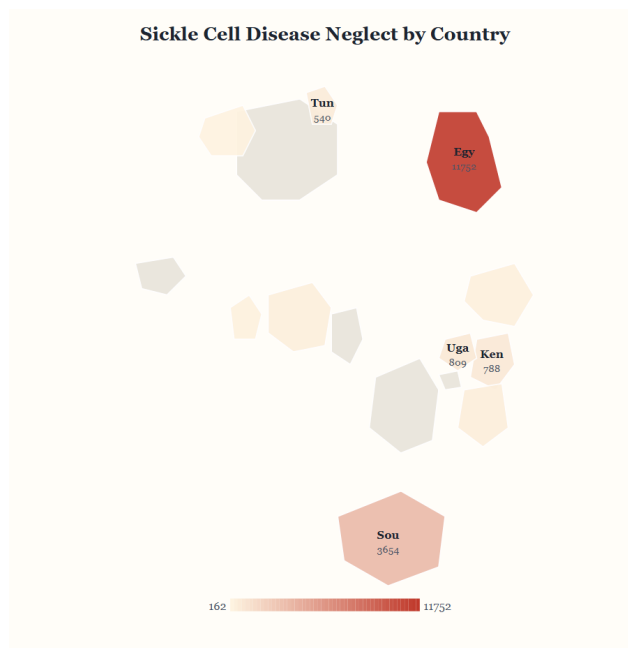


Figure 2. Sickle Cell Disease Neglect by Country Rendered directly from the article's live interactive dashboard.

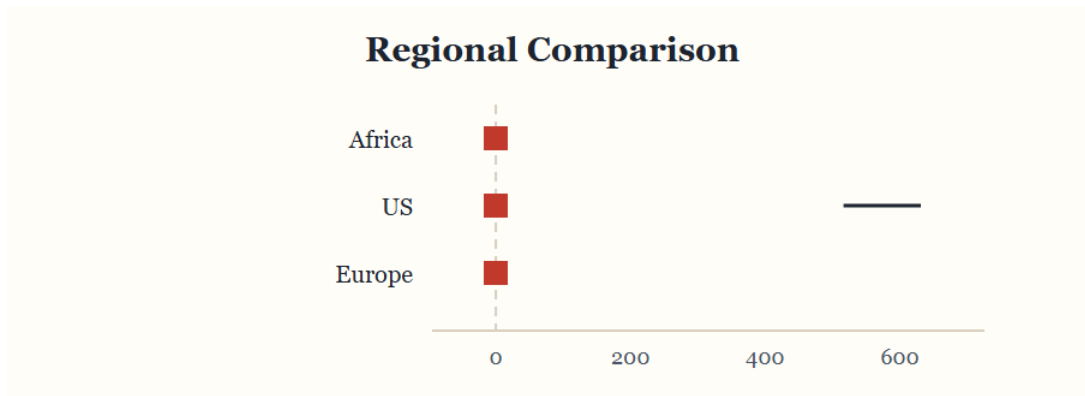


Figure 3. Regional Comparison Rendered directly from the article's live interactive dashboard.

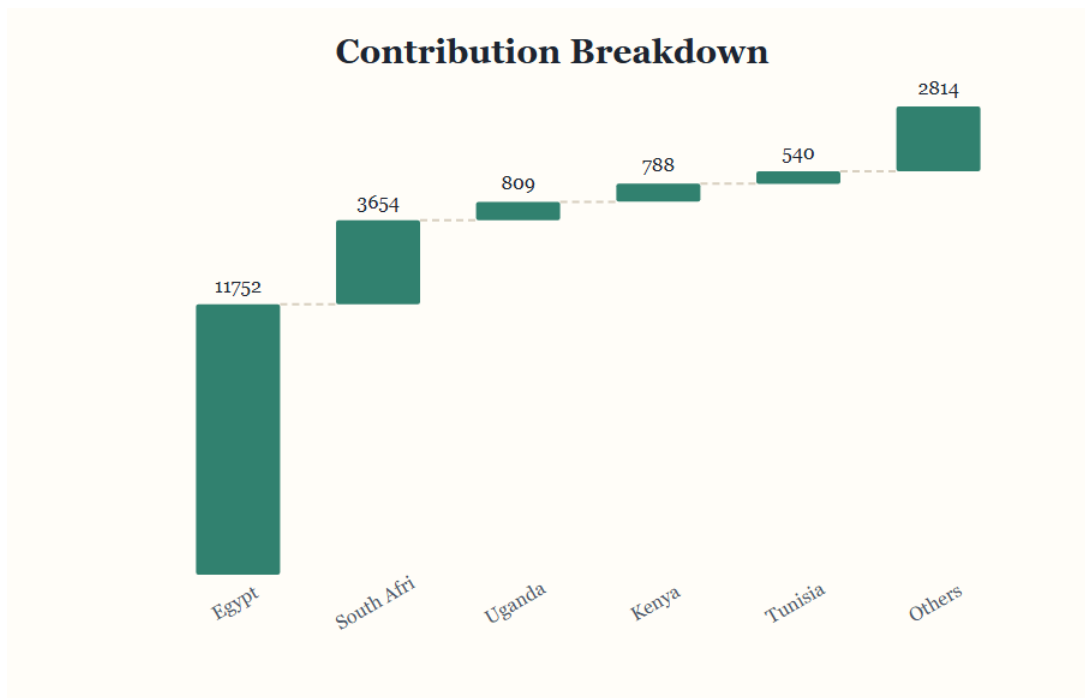


Figure 4. Contribution Breakdown Rendered directly from the article's live interactive dashboard.

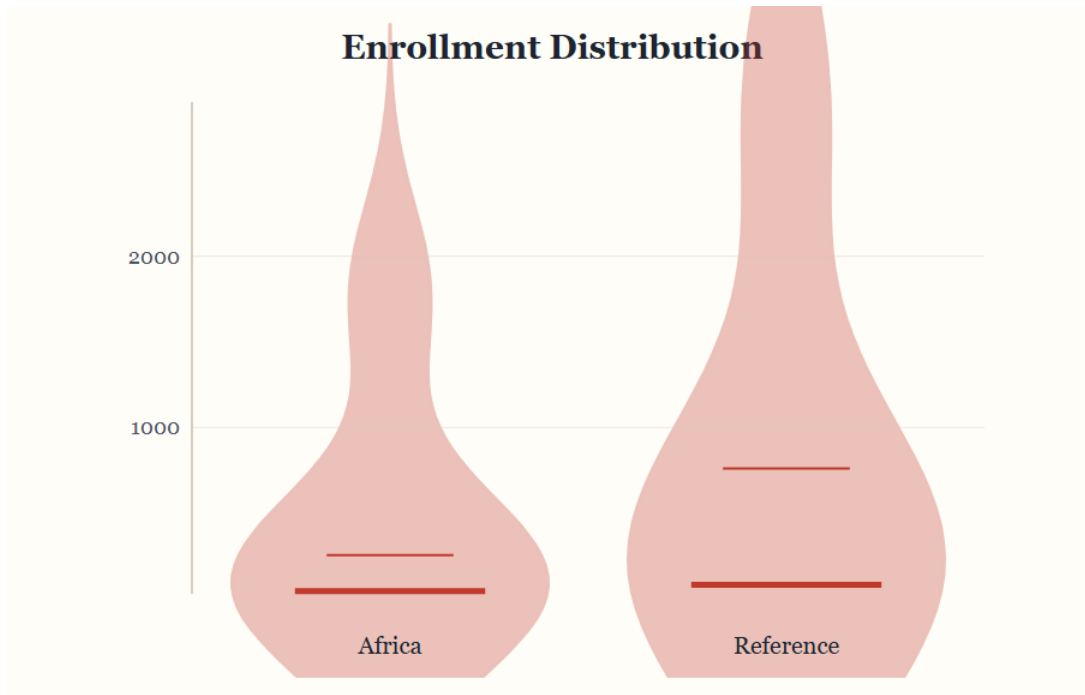


Figure 5. Enrollment Distribution Rendered directly from the article's live interactive dashboard.

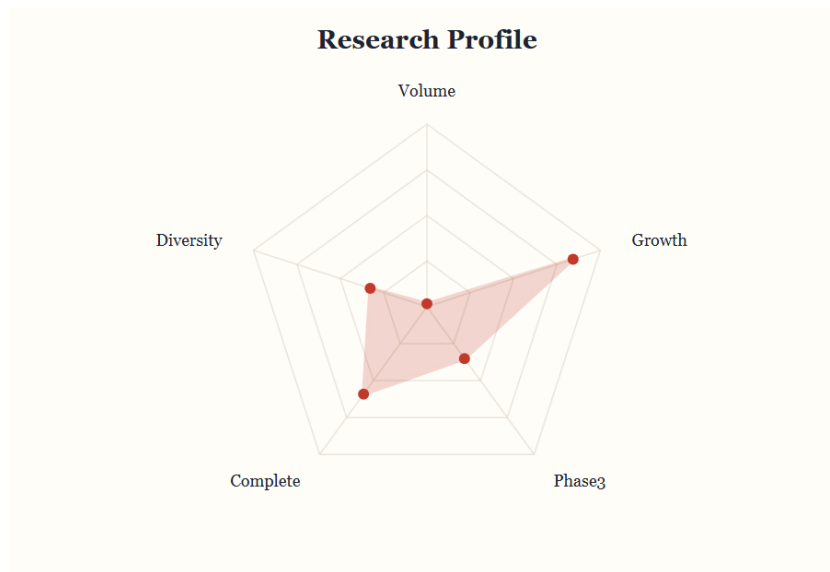


Figure 6. Research Profile Rendered directly from the article's live interactive dashboard.

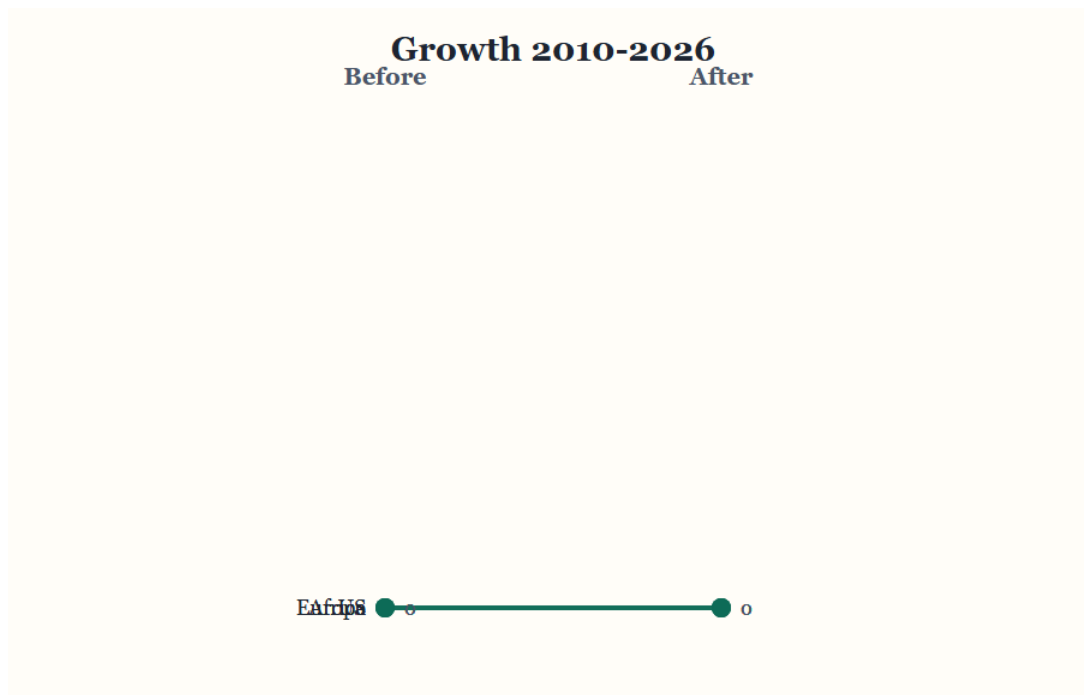


Figure 7. Growth 2010-2026 Rendered directly from the article's live interactive dashboard.

HOW TO CITE

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