

Systematizing Sickle Cell Care: From Crisis to Routine

Establishing *Samhitā*: A population-based hemoglobinopathies Registry in the Chamarajanagar district of Karnataka



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Introduction

Sickle Cell Disease (SCD), a genetic blood disorder, presents a significant public health challenge in India, which bears the second highest global burden. Data gaps, especially from Karnataka, limit our understanding of its real distribution. Accurate community-level data is essential to assess disease burden, plan interventions, and guide policy. The lack of 'models of care' that are adapted to particular tribal population settings further exacerbates disease management in low-resource settings. A **disease registry for people diagnosed with SCD (PwSCD)** is a critical step toward systematic monitoring while enabling evidence-based strategies for the prevention and control of SCD.

Objectives

- To establish a SCD registry for tracking an individual patient's condition and her/his access and compliance to care within the existing public health system over a period of time
- To study access to care for haemoglobinopathy patients by monitoring their complications, treatment and outcomes, and in the long term their quality of life and survival

Study Area

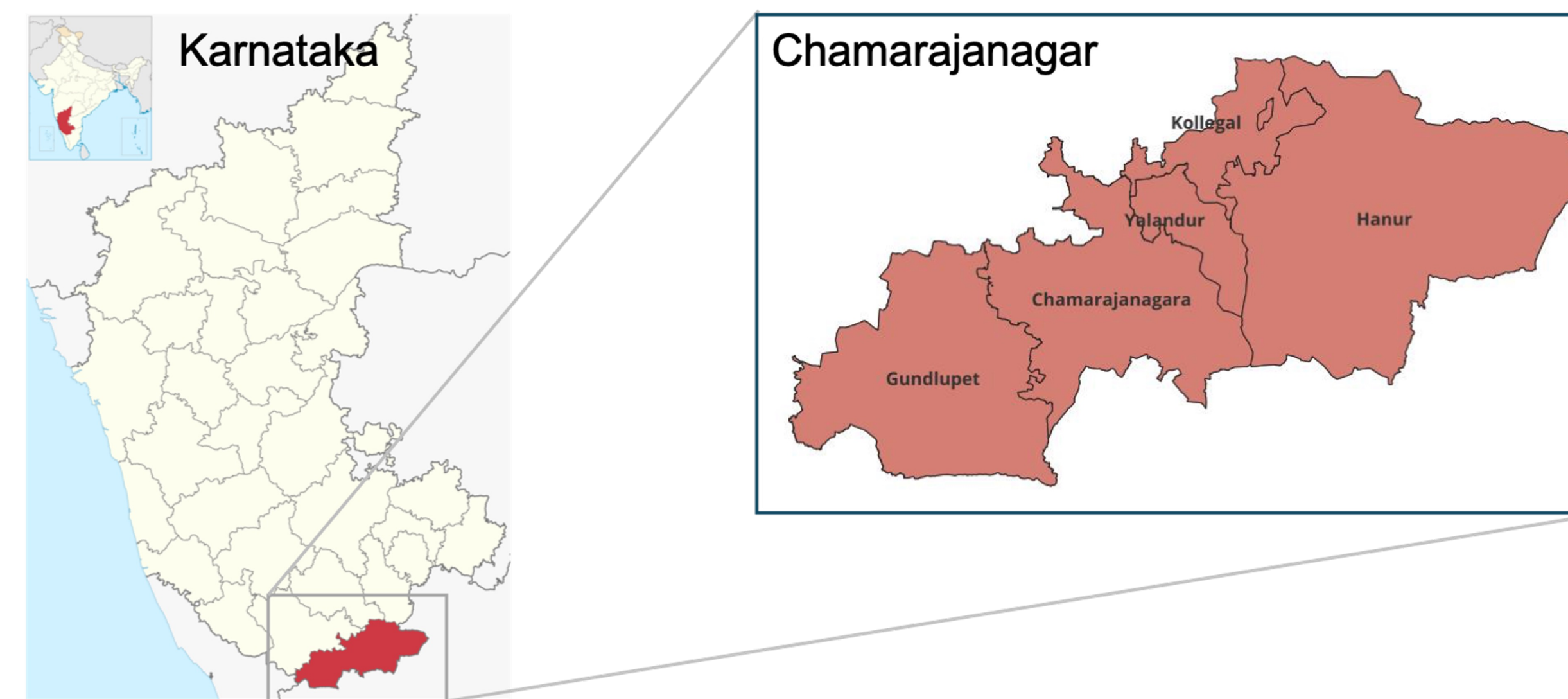


Fig1: Five blocks or talukas of Chamarajanagar district

Chamarajanagar district, a south-Indian Karnataka district with mixed rural tribal and non-tribal population

- Total population (~10 lacs)
- 12% of population is tribal (1,20,000)
- 2% Adivasis (~30,000)
- Majority of tribals living in or near the forest area
- Historical neglect by public services and systems

Intervention

Operational Model

- Screen population with point-of-care testing methods
- Confirm diagnosis with High-performance Liquid chromatography (HPLC) before enrolment in Registry
- Upon enrolment, baseline clinical proforma completed by an expert doctor
- Quarterly follow-ups by home visit
- Annual follow-up at SCD health camp organized at the tertiary hospital offering comprehensive tests and treatment.

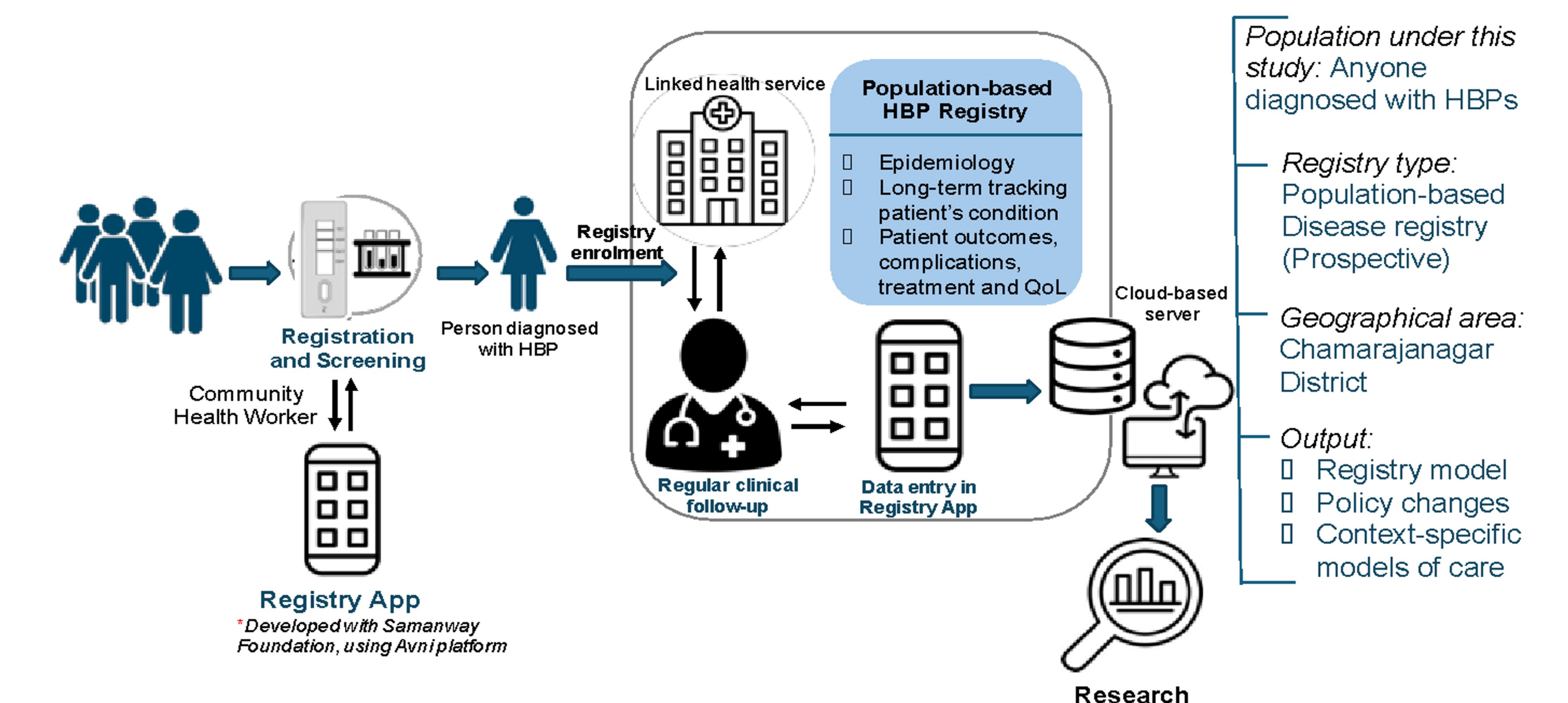
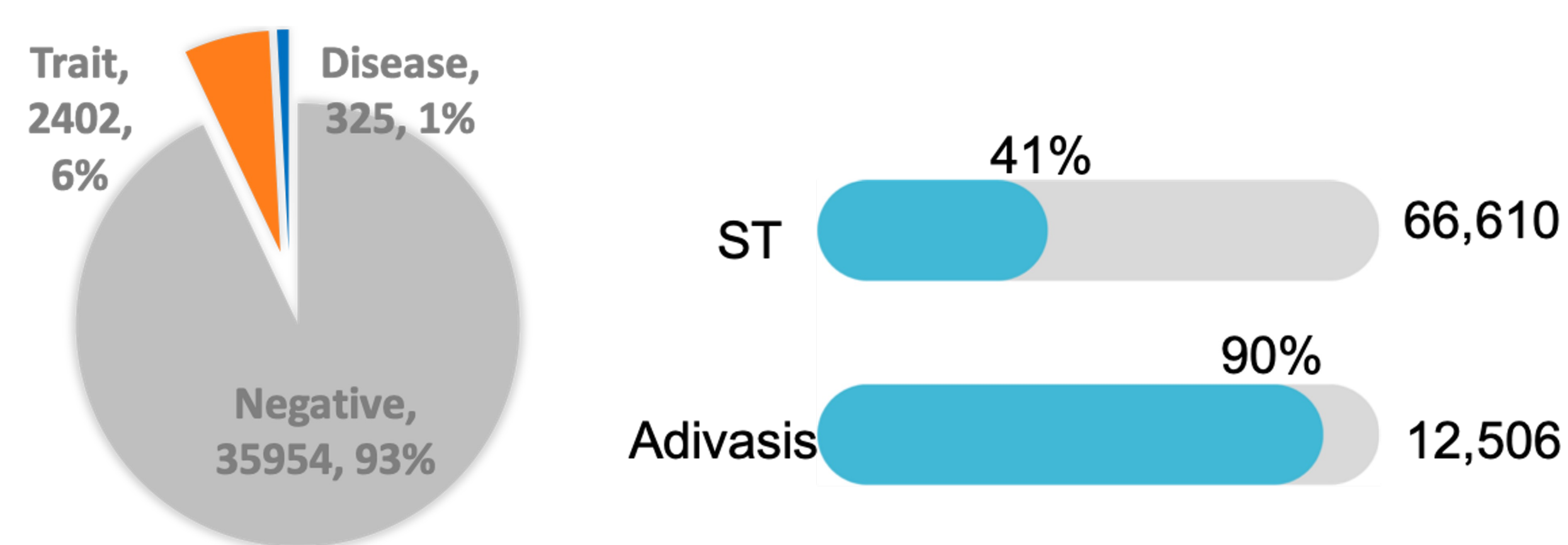


Fig 2: The concept model of SCD Registry

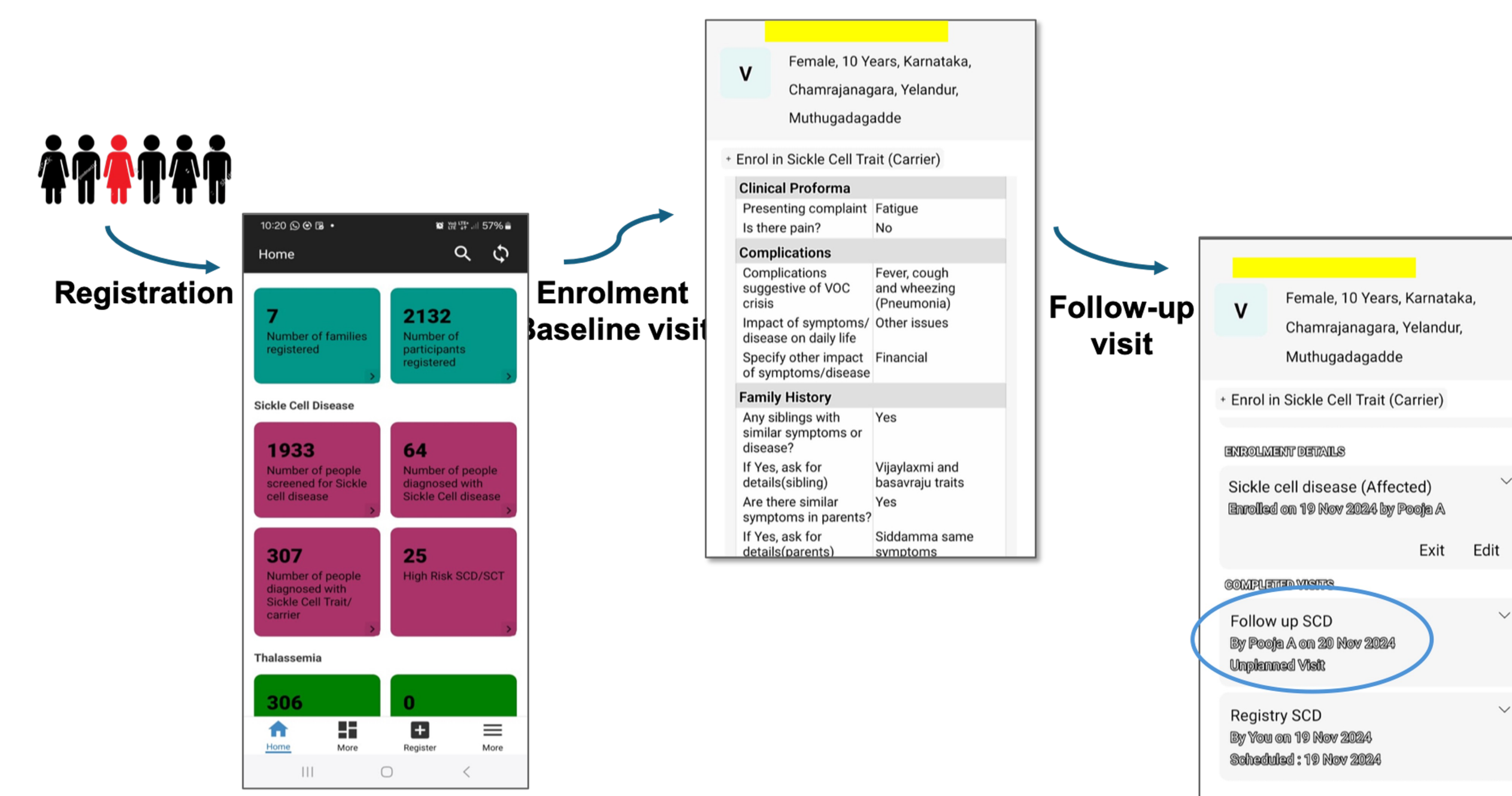
Results

SCD screening in Chamarajanagar under NSCAEM



- More than 90% of the Adivasis and 40% of the ST population screened by December 2024 under the National mission
- 1 in 100 found to be affected by the disease, and 6 among 100 are carriers.**
- District healthcare staff (MO, CHO, ANM/GNM, ASHA) capacity was built with multiple trainings and hand-holding sessions for screening, diagnosis, and disease management
- Patients with crises are successfully linked to tertiary healthcare services by referral and tele-consulting.

- 64 patients enrolled in the Registry** (4 are sickle-thalassemia cases) are routinely followed up.
- 25 among 64 are high-risk patients and required blood transfusion and hospitalization** in the last 3 months. 58/64 are out on hydroxyurea treatment.
- A real-time dashboard is developed to systematically track the PwSCD health



Registry App: Tracking PwSCD health in real-time

Conclusion

The SCD burden in the district of Chamarajanagar (1%) is more than double the national average (0.38). Given the socio-cultural vulnerabilities of Adivasis communities, a context-specific 'model of care' is established in the form of a real-time disease registry. The impact of the registry in terms of reducing crises episodes, hospitalization and mortality is under study.

References

- Raman V, Seshadri T, Joice SV, N Srinivas P. Sickle cell disease in India: a scoping review from a health systems perspective to identify an agenda for research and action. *BMJ Glob Health*. 2021 Feb;6(2):e004322.
- Government of Karnataka. Human Development: Performance of Districts, Taluks and Urban Local Bodies in Karnataka, 2014-Snapshot. 2014.
- India - Census of India 2001 - Series 12 - Karnataka - District Census Handbook, Part XII - A & B - Mysore [Internet]. [cited 2025 Mar 6]. Available from: <https://censusindia.gov.in/nada/index.php/catalog/43804>
- Piel FB, Colah R, Jain DL. Casting light on the national mission to eliminate sickle cell disease in India. *HemaSphere*. 2024 Oct;8(10):e70033
- Babu BV, Sharma Y, Surti SB, Bhat D, Sridevi P, Ranjit M, et al. Indian sickle cell disease registry for surveillance and patient management: Development and implementation. *Int J Health Plann Manage*. 2023 Sep;38(5):1483-94
- Health Camp held for sickle cell patients. <https://www.thehindu.com/news/national/karnataka/health-camp-for-sickle-cell-patients-held-in-chamarajanagar/article68656003.ece>

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