# Mapping the global burden of sickle cell anaemia

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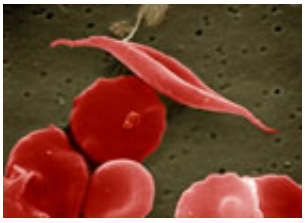

The first rigorous study to assess the global burden of sickle cell anaemia in recent times is reported today in the *Lancet*, giving an up-to-date view of the distribution of the disease. Accurate estimates of the numbers and geographical distribution of those affected are vital for effective prevention and treatment policies to be put in place.
The study estimates that in 2010 around 300 000 babies were born with sickle cell anaemia, a serious blood disorder that can be fatal if untreated, and 5.5 million newborns inherited the sickle cell gene. The 5.5 million who only inherit the gene will usually not present any clinical complications, but they could still pass this gene on and give birth to children with sickle cell anaemia.

The research by the Malaria Atlas Project, a multinational team of researchers funded mainly by the Wellcome Trust, maps the contemporary geographical distribution of sickle haemoglobin - a genetic disorder causing sickle cell anaemia. It also estimates the number

of newborns affected by this condition.

Historically, the sickle cell gene (haemoglobin S, or HbS) was common in people of African, Mediterranean and Indian origin; however, following human migrations, it is now much more widespread. The MAP team's estimates suggest that about half of the affected newborns are born in Nigeria, the Democratic Republic of the Congo and India, but important uncertainties remain in large parts of these countries owing to a lack of data.

Dr Fred Piel from Oxford University's Department of Zoology, who led the research, said: "Sickle cell disease has now been studied intensively for more than a hundred years, but our knowledge about its current distribution and burden is really poor.

"Our aim was to use available evidence-based epidemiological data from the literature combined with modern mapping and modelling methods to come up with the best maps and estimates. In the future, we hope that accessing additional data, including from national screening programmes, would help further refine these results."

This study provides the first rigorous assessment of the contemporary distribution of this disorder and uses state-of-the-art methodology to estimate the number of newborns affected globally, regionally and nationally. The team was inspired by work conducted by Frank B Livingstone in the 1970s and 1980s. Despite its age, his global database on inherited blood disorder frequencies still represents a unique resource.

There is growing awareness about the burden of genetic blood disorders - sickle cell disease in particular - and it is crucial for public health policy makers to access evidence-based quantitative epidemiological data allowing the assessment of the current situation and to measure

changes in the future. The data will be released in open access on the Malaria Atlas Project website.

Professor Sir David Weatherall, who has shared his unique expertise in the field and provided exceptional support to this project, said: "The inherited haemoglobin disorders, notably sickle cell disease and the different forms of thalassaemia, are by far the commonest monogenic diseases, and the vast majority of births affected occur in low- or middle-income countries.

"Previous work suggested that their distribution varied considerably even within short geographical distances and data regarding their true frequency is extremely difficult to obtain. Hitherto, they have been largely ignored by the international health community, and it is absolutely vital that better information is obtained regarding their true frequency so that their control and better management can be achieved, particularly in the low-income countries where they are so common.

"The impressive work described in this paper provides an invaluable base for future work of this kind."

**More information:** Piel FB et al. Global epidemiology of sickle haemoglobin in neonates: a contemporary geostatistical model-based map and population estimates. *Lancet* 2012 (epub ahead of print).

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