

# The Sickle Cell Health Awareness, Perspectives and Experiences (SHAPE) Multinational Survey



## What was the SHAPE survey?

The SHAPE (Sickle Cell Health Awareness, Perspectives and Experiences) survey was a multinational, patient, caregiver and healthcare professional (HCP) survey. It was developed by Global Blood Therapeutics (GBT) in partnership with sickle cell disease (SCD) experts and advocates.

**The aim of the survey was to better understand the experiences and unmet needs of people living with SCD, as well as of those caring for and treating people living with the condition. The survey explored the broader and longer-term implications and outcomes of SCD including e.g.**

+ The misunderstood reality of life with SCD and the impact on quality of life

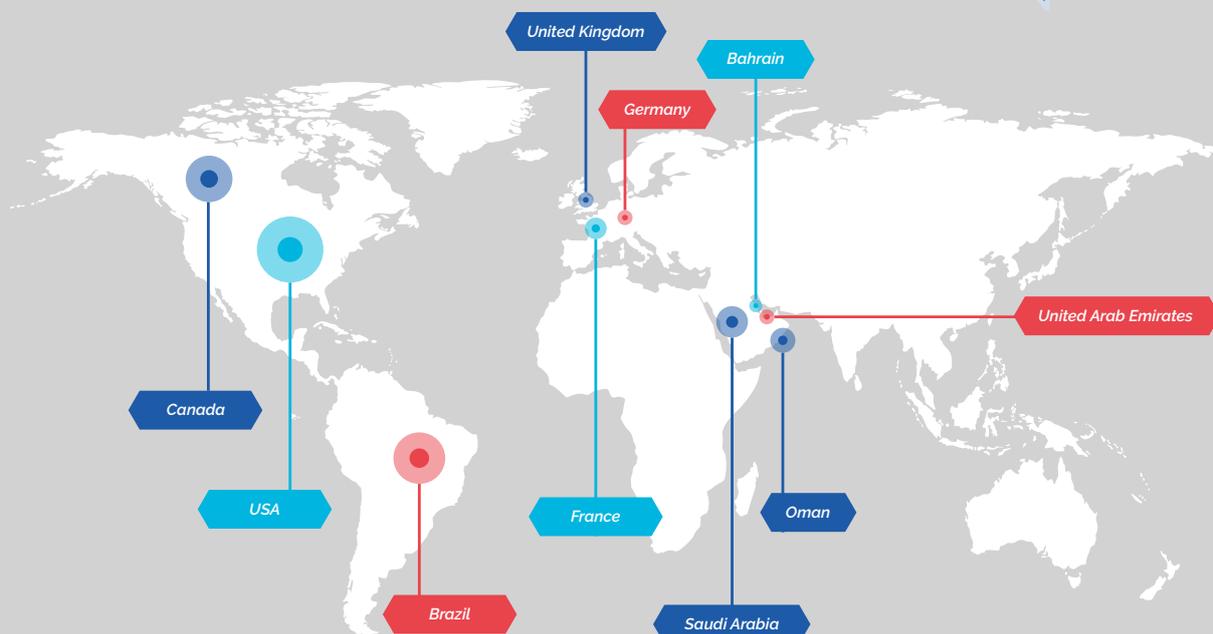
+ The need to start a new conversation around SCD to help overcome health inequities

+ Improving the clinical experience for the SCD community

## How was the SHAPE survey conducted?

It was commissioned by GBT and surveys of patients, caregivers, and HCPs were conducted in 10 countries, with fieldwork conducted between September 2021 - February 2022. A different sized sample of respondents was included from each country.

Survey participants were required to answer a range of closed-ended questions about their circumstances and experiences during a 12-minute online survey (except in the GCC region where face-to-face is considered more appropriate).



The SHAPE survey was developed in partnership with global SCD experts, including patient association representatives (both patients and caregivers) and HCPs from around the world.

### HCP Steering Committee

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### Patient Association Steering Committee:

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- Dianaba Ba  
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- Elvie Ingoli  
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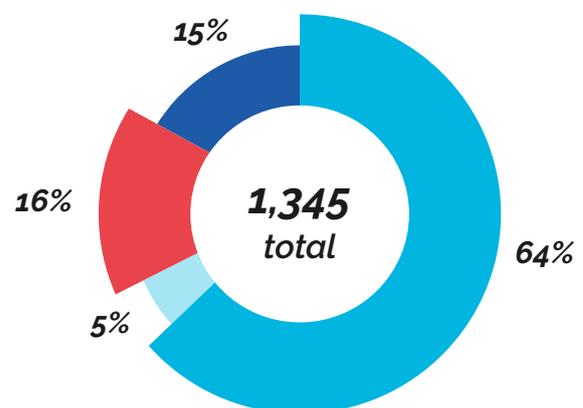
- John James  
Sickle Cell Society UK

- Biba Tinga  
Sickle Cell Disease Association of Canada

### How many people participated in the SHAPE survey?

In total there were 1,345 people involved in the SHAPE survey. This included:

- 855 people living with SCD aged 18+
- 64 people living with SCD aged 12-17
- 207 carers
- 219 HCPs



### Who completed the survey?

#### Patients

(Average age of 32)

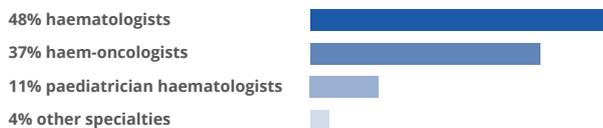


#### Carers

(Average age of 39)



#### HCPs



### How will the SHAPE survey results help to improve the lives of those with SCD?

The SHAPE survey will help us to better understand the perspectives and challenges faced by those living with this debilitating, life-long condition and those that care for them. In partnership with SCD experts, GBT seeks to ensure it is working on solutions that align to the needs of the SCD community.

Please visit [www.gbt.com/shape](http://www.gbt.com/shape) to learn more about the SHAPE survey

