

Sickle Cell Health Awareness, Perspectives, and Experiences (SHAPE) Survey: Findings on the Burden of Sickle Cell Disease and Impact on the Quality of Life of Patients and Caregivers in the UK

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Disclosures

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Introduction



Sickle cell disease (SCD) adversely affects the physical and emotional well-being of patients and their caregivers,¹ yet research on the impact of SCD on quality of life (QOL) is limited.^{2,3}



Approximately **14,000 people in the UK live with SCD**,⁴ and **1 in 2517 babies in England were diagnosed with SCD between 2019 and 2020**,⁵ warranting the need to identify and address the challenges faced by individuals with SCD and their caregivers in this region of the world.



The **SHAPE survey** aims to improve our understanding of the global impact of SCD on patients and their caregivers; this analysis reports **survey findings from the UK** within the context of insights obtained internationally.

Objective



To understand the impact of SCD on the QOL of patients and caregivers in the UK

SHAPE Survey Overview

Online, quantitative surveys of closed-ended questions to investigate:



- Circumstances and experiences of respondents
- Unmet needs of **people living with SCD** and of **those caring for** and **treating** people living with SCD



Patients, caregivers, and healthcare professional (HCP) respondents:



1. **Patients:** aged ≥ 12 years, diagnosed with SCD by an HCP













2. **Caregivers:** aged ≥ 18 years and caring for someone diagnosed with SCD



3. **HCPs:** practicing for 3 to 35 years with ≥ 10 patients with SCD under their care

Patient and Caregiver Population by Country

Of 919 patients and 207 caregivers interviewed globally,
151 patients and **30 caregivers** were from the **UK**.

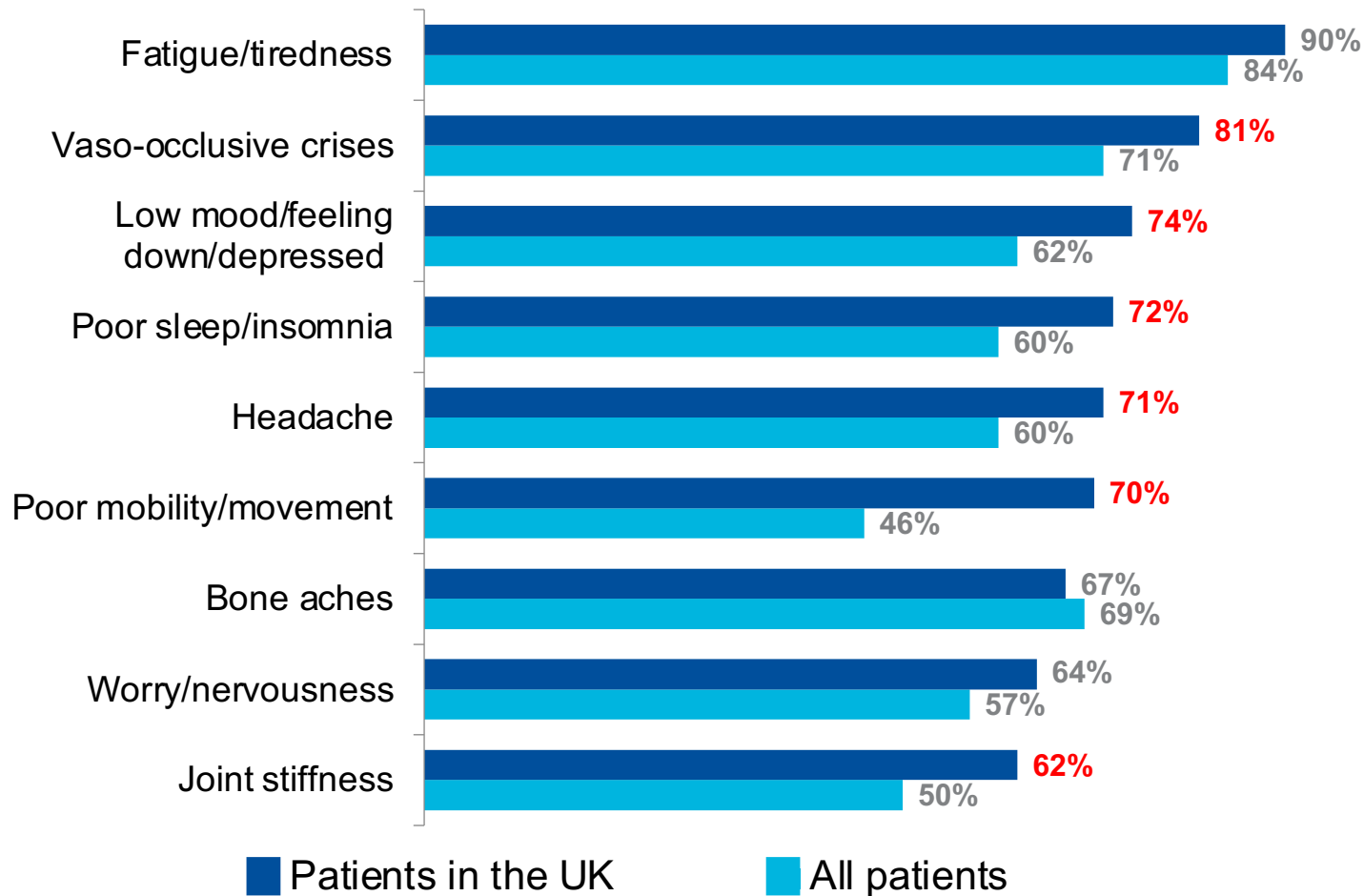
	USA 	UK 	Brazil 	France 	Saudi Arabia 	United Arab Emirates 	Canada 	Bahrain 	Germany 	Oman 	TOTAL
Patients	295 (32%)	151 (16%)	151 (16%)	122 (13%)	70 (8%)	46 (5%)	32 (3%)	19 (2%)	18 (2%)	15 (2%)	919
Caregivers	30 (14%)	30 (14%)	50 (24%)	29 (14%)	25 (12%)	17 (8%)	10 (5%)	8 (4%)	8 (4%)	0	207

Sociodemographic Information for Patients and Caregivers

Characteristic	Patients		Caregivers	
	UK (n=151)	Total (N=919)	UK (n=30)	Total (N=207)
Age, mean, years	34.0	32.3	44.3	39.1
12 to <18, n (%)	20 (13)	64 (7)	0	0
18 to 39, n (%)	83 (55)	648 (71)	10 (33)	111 (54)
≥40, n (%)	48 (32)	207 (23)	20 (67)	96 (46)
Gender identity, n (%)				
Male	34 (23)	257 (28)	7 (23)	55 (27)
Female	117 (77)	659 (72)	23 (77)	149 (72)
Other/prefer not to say	0	3 (<1)	0	3 (1)
Current employment/educational status, n (%)				
Working	81 (53)	465 (51)	22 (73)	143 (69)
Full-time	46 (30)	257 (28)	14 (47)	83 (40)
Part-time or self-employed	35 (23)	208 (23)	8 (27)	60 (29)
Student	32 (21)	170 (18)	3 (10)	7 (3)
Retired	5 (3)	34 (4)	1 (3)	7 (3)
Unemployed/not working	40 (26)	274 (30)	4 (13)	54 (26)
Don't know/prefer not to say	1 (1)	11 (1)	0	0

Symptoms Experienced by Patients in the Past Year

Occurring in $\geq 60\%$ of Patients in the UK

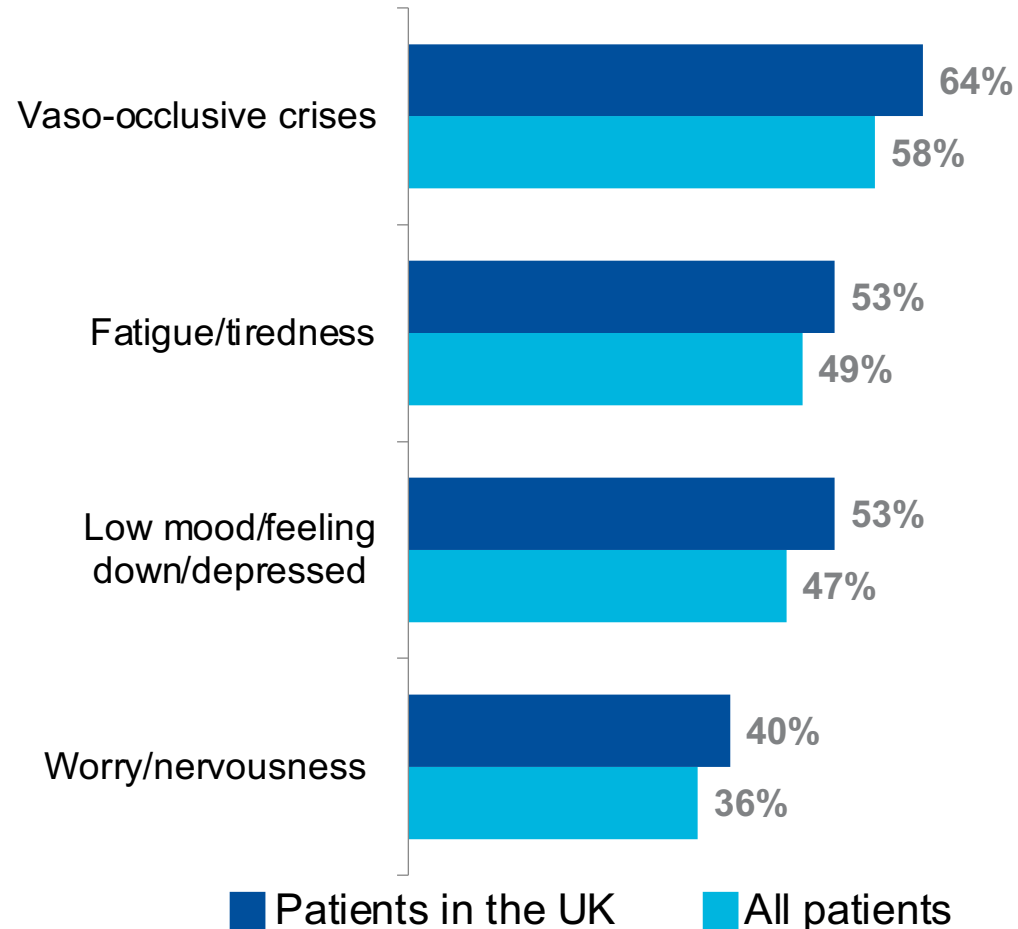


- **Fatigue/tiredness** was the symptom most frequently experienced by all patients and by patients in the UK in the past year.
- Compared with all patients, a **significantly higher percentage of patients in the UK** experienced:
 - Vaso-occlusive crises (VOCs)
 - Low mood/feeling down/depressed
 - Poor sleep/insomnia
 - Headache
 - Poor mobility/movement
 - Joint stiffness

Red indicates a significantly higher percentage of patients in the UK versus all patient respondents.

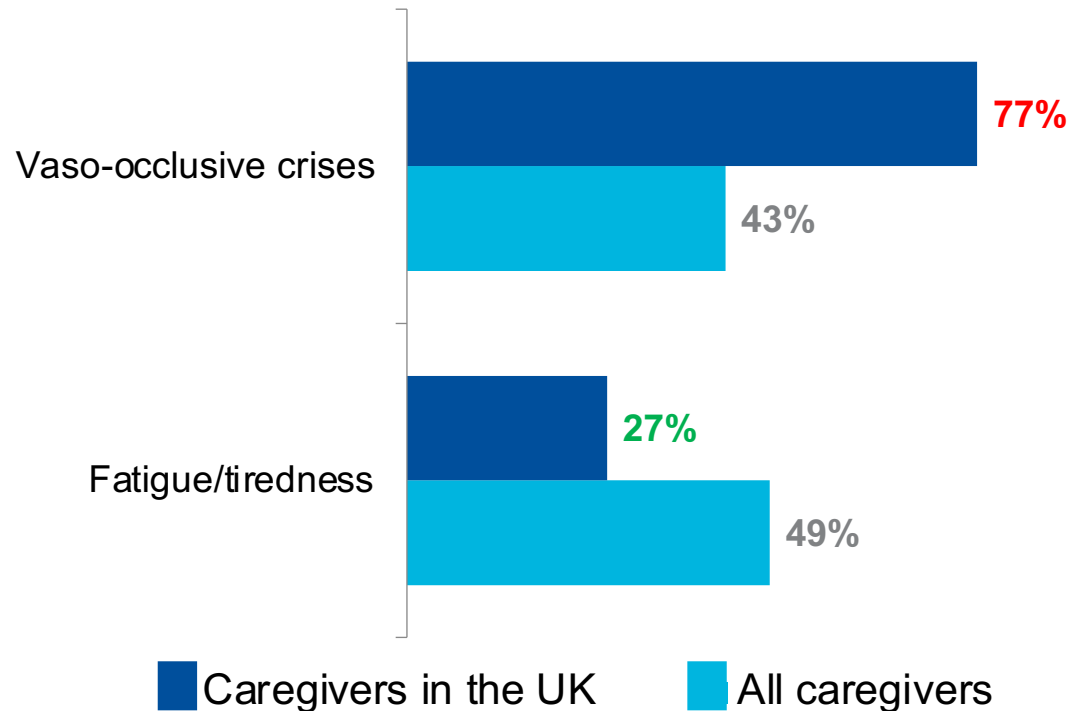
Self-Reported Patient Symptoms With the Greatest Impact on All Areas of Life

Occurring in $\geq 30\%$ of Patients in the UK



- Patients in the UK reported **VOCs** as the symptom having the **greatest impact on their lives**.
- The **symptoms** with the greatest impact reported by patients in the UK were **similar** to those reported by **all patients**.

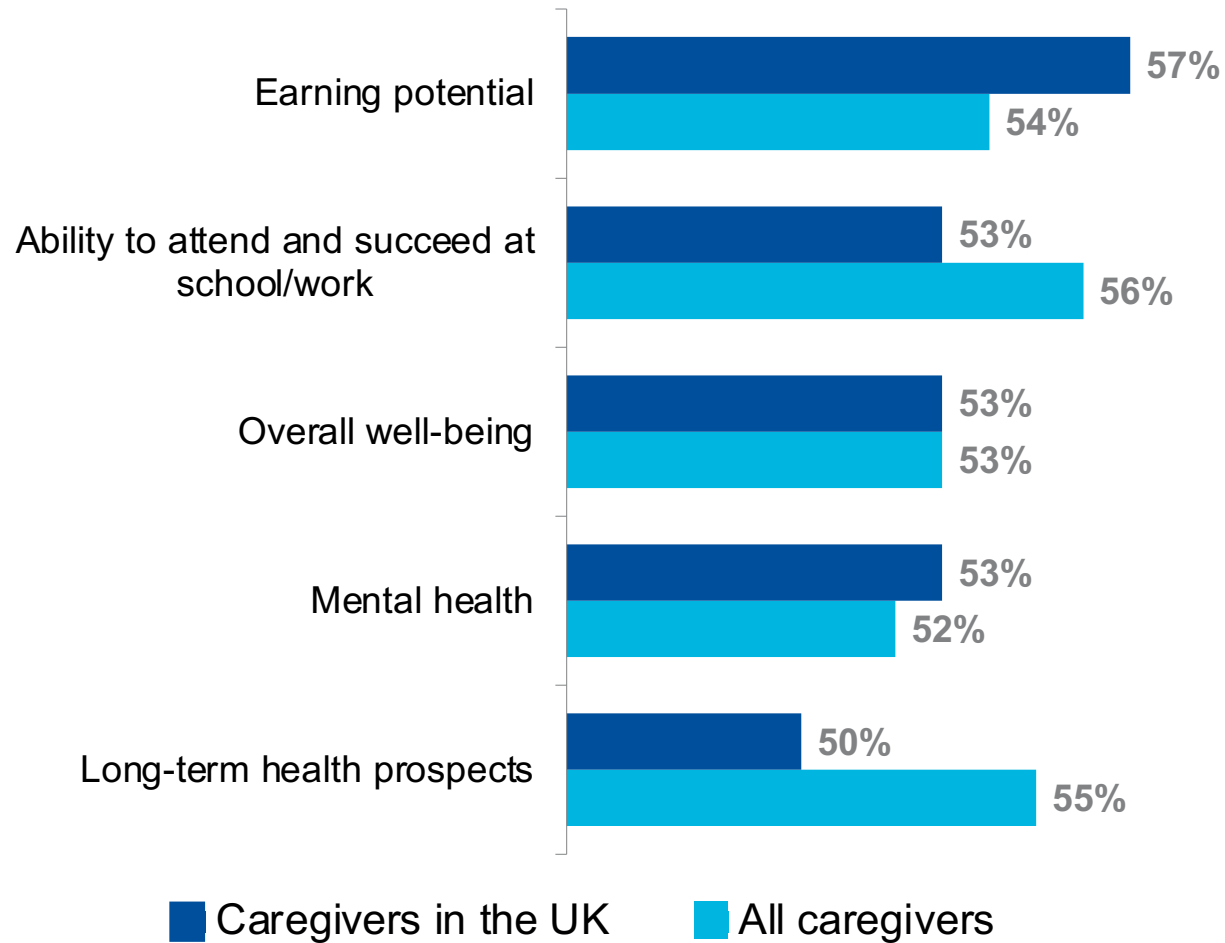
Symptoms Experienced by Patients That Have the Greatest Impact on Caregivers' Lives



- Compared with all caregivers, a **significantly higher percentage of caregivers in the UK reported VOCs** as the patient symptom having the **greatest impact on their lives**.
- Compared with all caregivers, a **significantly lower percentage of caregivers in the UK reported fatigue/tiredness** as the most impactful symptom.

Red indicates a significantly higher percentage of patients in the UK versus all patient respondents.
Green indicates a significantly lower percentage of patients in the UK versus all patient respondents.
VOC, vaso-occlusive crisis.

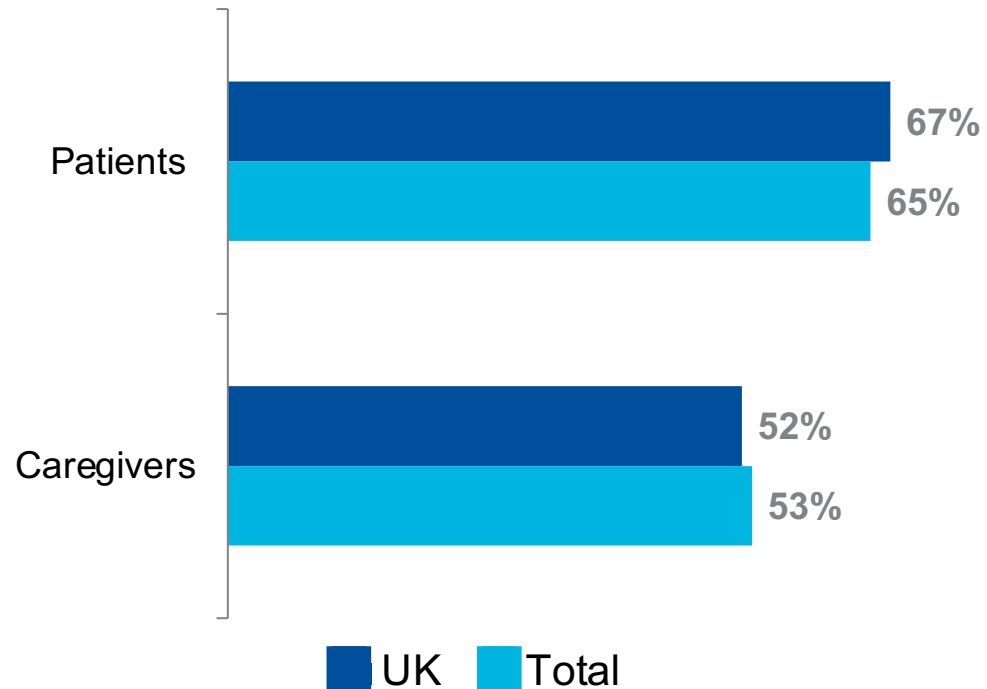
Areas of Caregivers' Lives Most Impacted by Patients' Symptoms



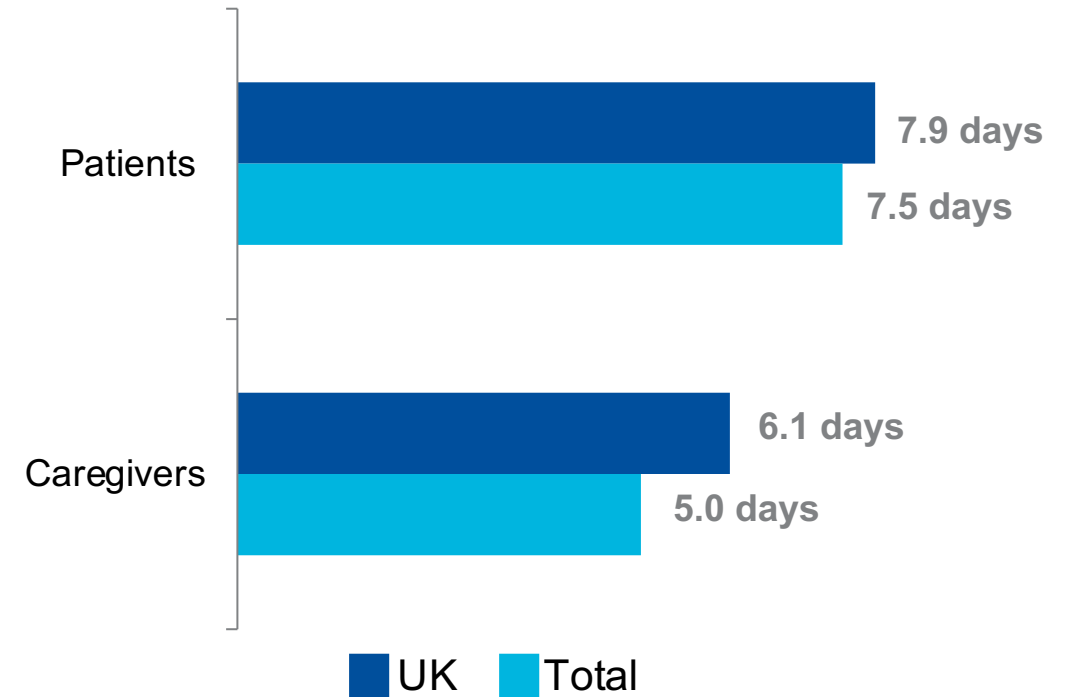
- More than half of the caregivers in the UK felt that **caring for someone with SCD affects** various aspects of their lives, including their **earning potential, education and career, and overall well-being.**
- Compared with caregivers from all 10 countries, a **similar percentage of caregivers in the UK** felt that caring for someone with SCD impacted their lives.

Impact of SCD on School and Work

**Patients and Caregivers Who Missed School/Work in the Past Month:
UK and Total**

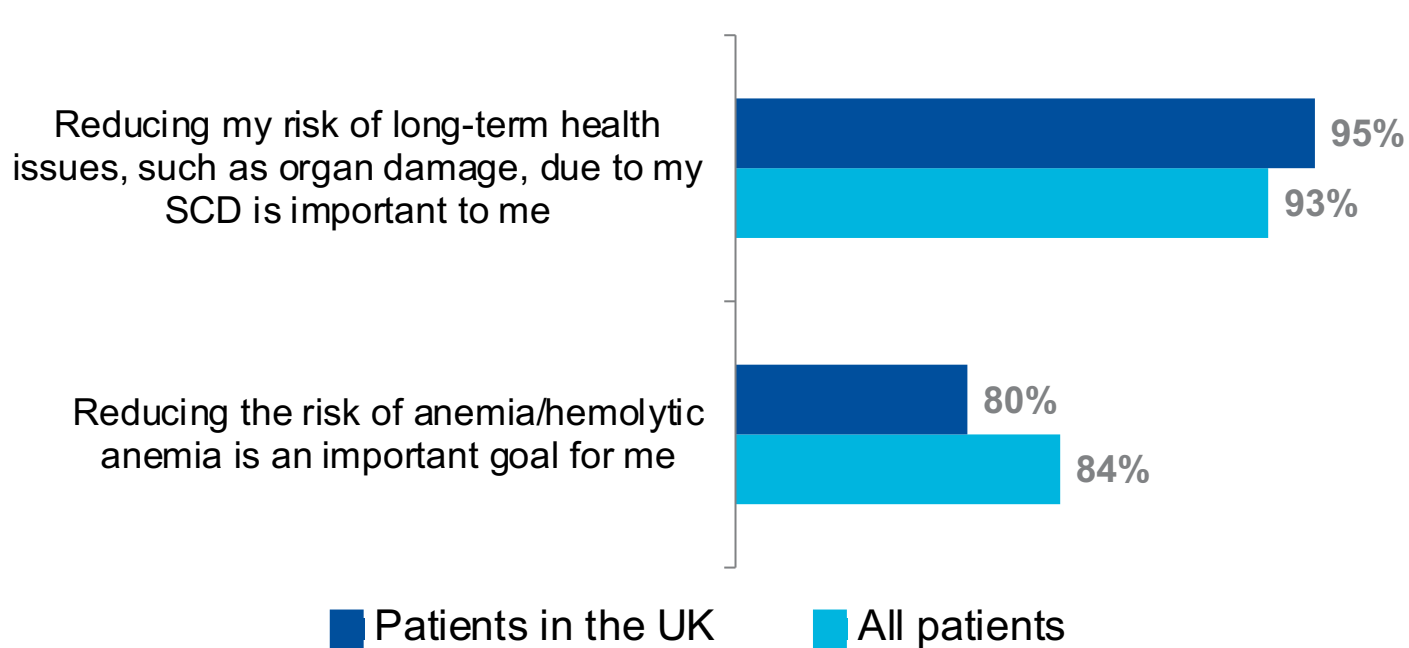


**Average Number of Days of School/Work Missed in the Past Month:
UK and Total**



Patient Perception of SCD Treatments

Patients Who Agreed^a With the Following Statements Regarding SCD Treatments

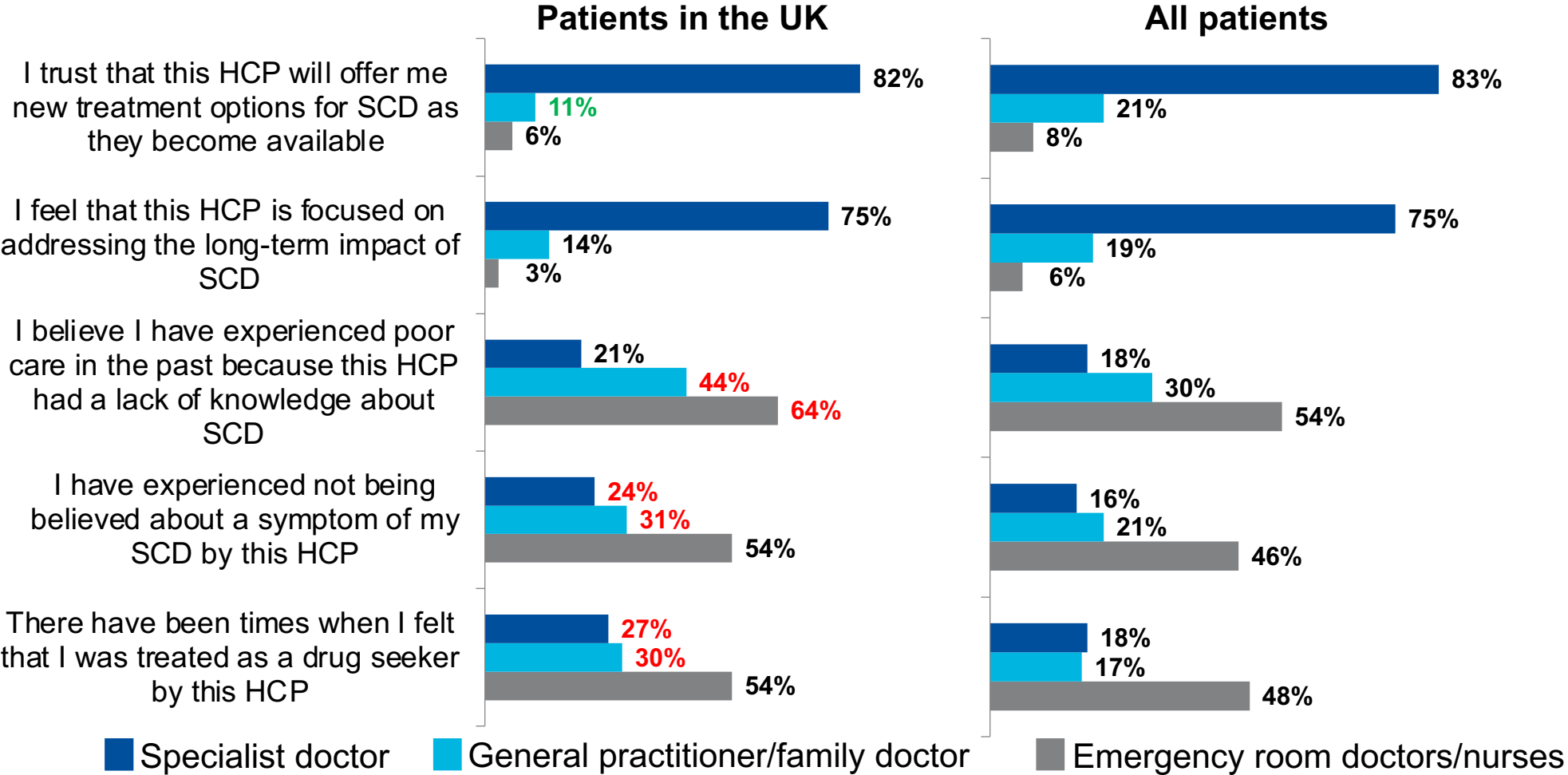


- Most patients agreed that **reducing** the risk of **long-term health issues** and **anemia/hemolytic anemia** is important to them.

^aPercentages reflect patients who answered “somewhat agree” or “strongly agree” to the statement.
SCD, sickle cell disease.

Patient Perception of Care Received From Different HCPs

Patients Who Agreed^a With the Following Statements



Red indicates a significantly higher percentage of patients in the UK versus all patient respondents. **Green** indicates a significantly lower percentage of patients in the UK versus all patient respondents.

^aPercentages reflect patients who selected the types of HCPs that this statement applied to regarding their experiences.

HCP, healthcare professional; SCD, sickle cell disease.

Conclusions



Findings reported in this survey emphasize the need for **targeted symptom management** to improve the **QOL of affected individuals in the UK**.



Compared with all caregiver respondents, a **greater percentage of caregivers in the UK** identified **VOCs** as having the **greatest impact** on their lives, **limiting their earning potential and ability to attend school or work**.



Patients with SCD in the UK on average **missed 7.9 days** of school or work in a **month** and **caregivers** lost **6.1 days**, highlighting the **immense burden of SCD** on the daily lives of patients and those who care for them.



Patient responses regarding SCD treatments highlight the **need for treatments that target the underlying disease pathology to improve both acute and chronic SCD complications**.

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