

## Patients' and Health Care Professionals' Perspectives on Treatment Goals in Sickle Cell Disease – A UK Perspective: Results From the International Sickle Cell World Assessment Survey (SWAY)

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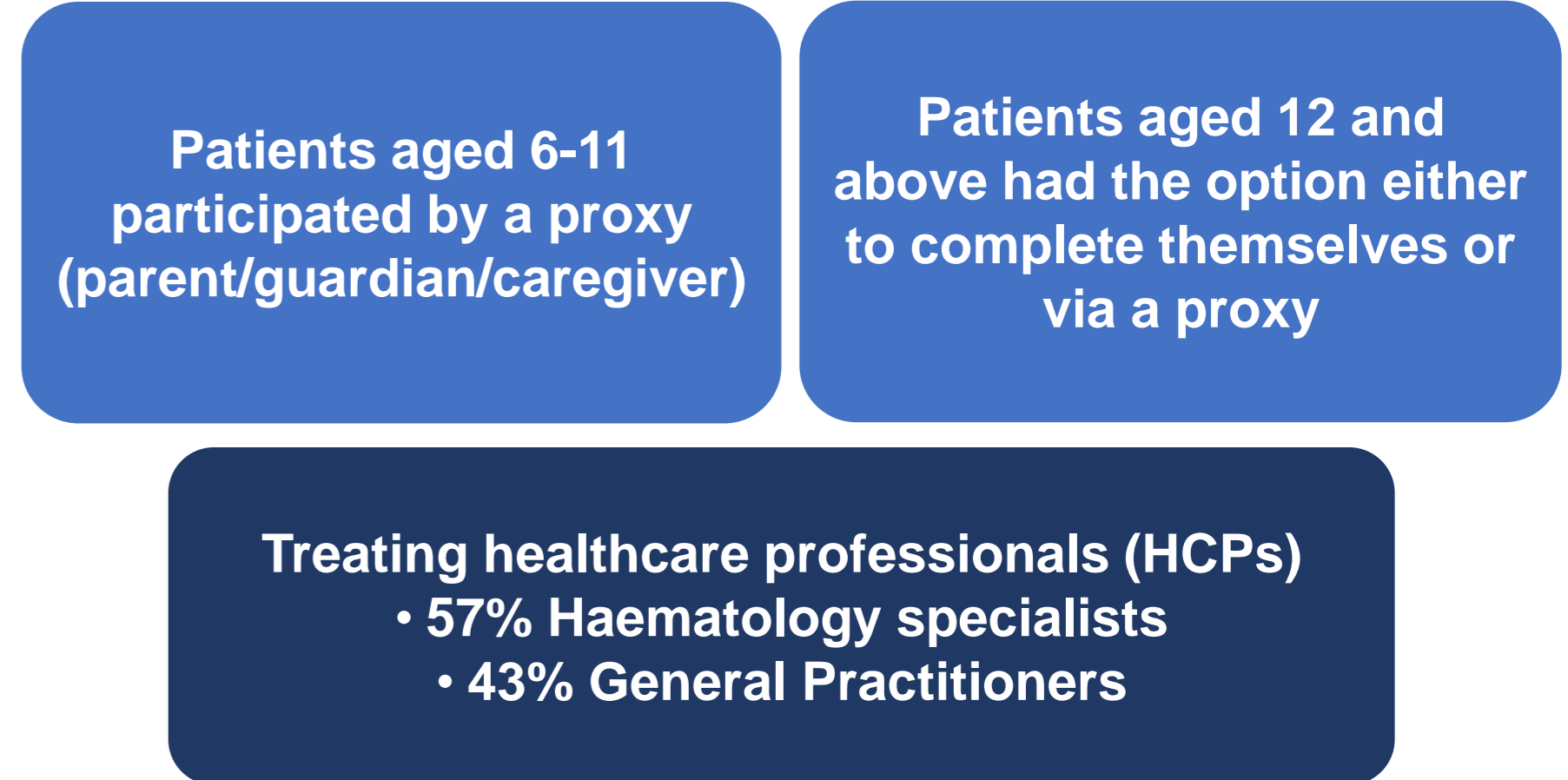
### INTRODUCTION

- Treatment of Sickle Cell Disease (SCD) focuses on the prevention and treatment of symptoms and complications<sup>1</sup>.
- However, the treatment goals of patients and their treating healthcare professionals (HCP) have yet to be explored.
- Here we describe these goals from both the patient and HCP perspective in the UK.

### AIM & METHOD

- SWAY was a cross-sectional survey of 2,145 SCD patients and 365 HCPs across 16 countries.
- Here we present data from 299 UK patients and 30 HCPs. Patients and HCPs were independently selected, no matching was conducted.
- Patients aged 6 years and up were eligible to participate with data collected using self-completed or proxy surveys.
- Patients and HCPs were asked: 'Other than a cure for SCD, what are your 3 most important treatment goals?', with 1 being the treatment goal considered the most important.
- Agreement and satisfaction questions were asked based on a 7-point Likert scale with high agreement and satisfaction scores = 5-7.

Figure 1. Participant Categories:



### RESULTS

#### Demographics

- 299 patients from the UK completed the survey; 56% were female, mean (SD) age was 29.2 (12.4) years, with mean (SD) age at diagnosis 6.6 (8.0) years.
- Patients were primarily diagnosed by their Paediatrician (38%) or Specialist doctor (22%).
- Overall, 58 paediatric (<18) and 241 adult patients completed a survey.
- 30 HCPs from the UK completed the survey; 23% were SCD-centre based, with a mean (SD) current SCD patient caseload of 76 (138) as shown in **Figure 2**.

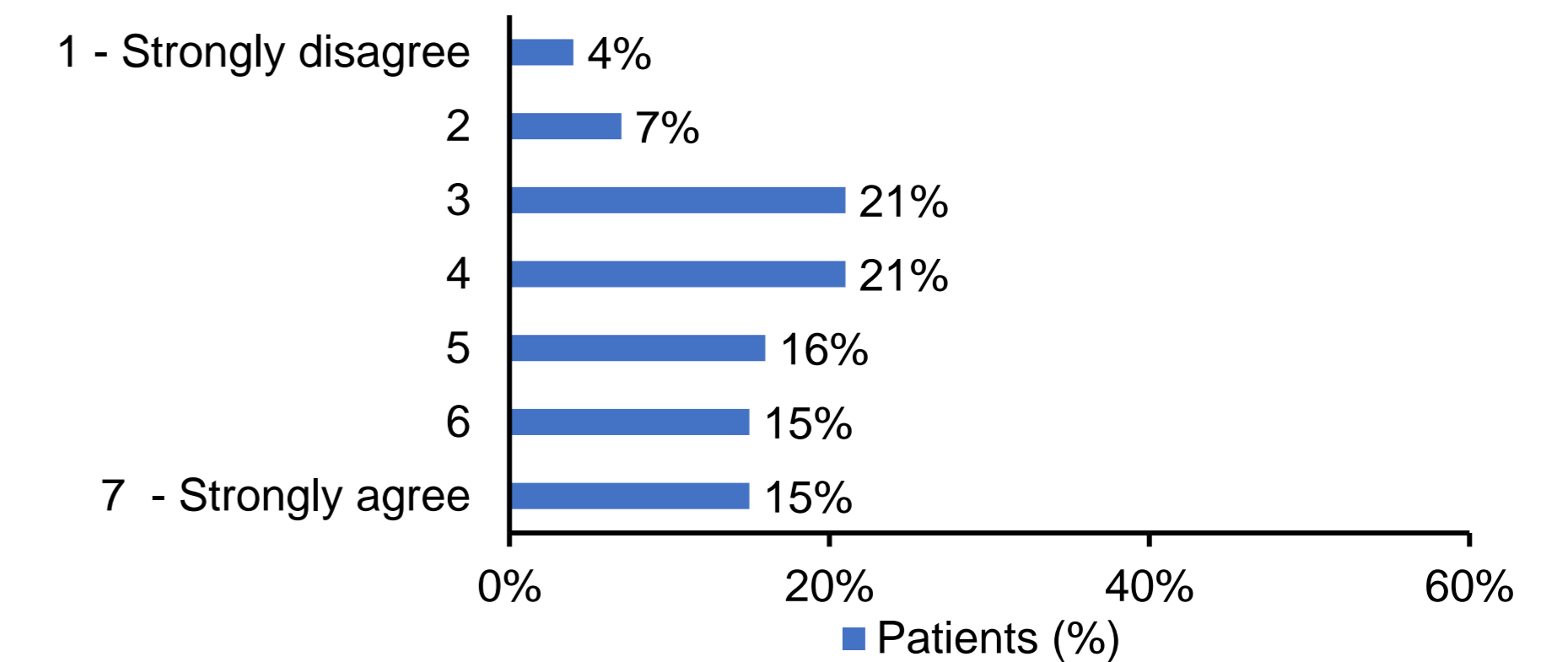
Figure 2. HCPs' Patient Caseloads

	Total patient caseload	Number of SCD patients currently under care	Number of SCD patients under care in past 12 months	Newly diagnosed SCD patients (under care) in past 12 months
Mean	460.3	76.3	59.9	7.2
SD	438.32	137.95	93.61	9.33

#### Goals for SCD management and treatment

- 46% of patients selected high agreement that their main HCP had similar management and treatment goals to them, as shown in **Figure 5**. However, 32% felt that they were not aligned, in contrast to **Figure 6b**.

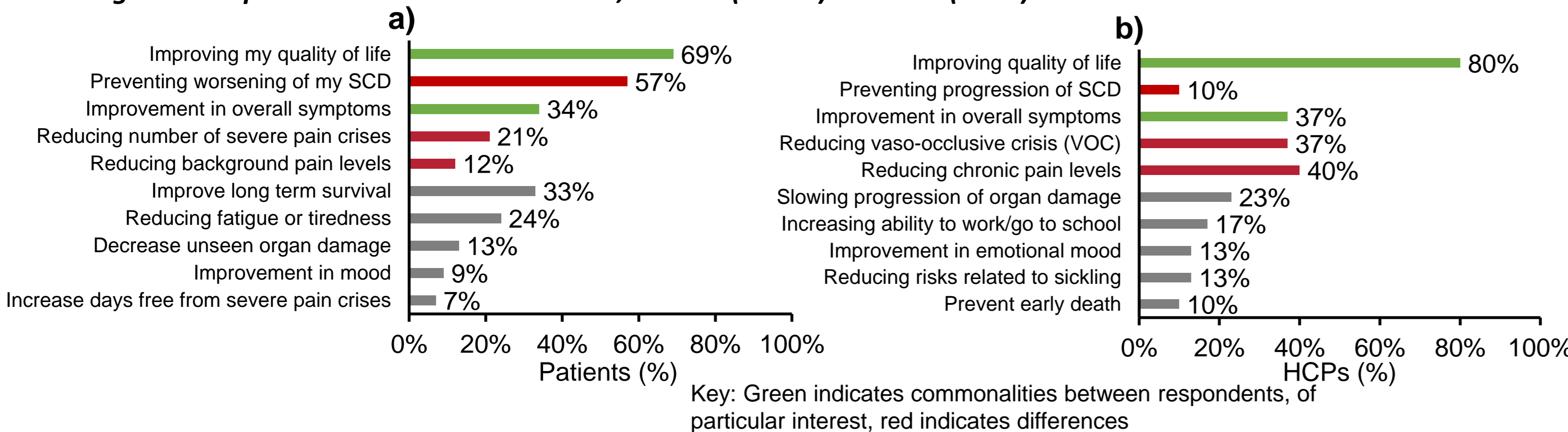
Figure 5. Patients and HCPs Have Similar Management and Treatment Goals (n=299)



#### Treatment Goals

- The most common treatment goal for both patients and HCPs was 'improving quality of life', 69% and 80% respectively, whilst 'improvement in overall symptoms' was stated 34% and 37% respectively, as shown in **Figure 3**.
- However, there were some differences with 57% of patients selecting 'preventing worsening of my SCD' as being in their top 3 treatment goals compared to 10% of HCPs selecting the comparative statement; 40% of HCPs selected 'reducing chronic pain levels' compared to 12% of patients, and 37% of HCPs selecting 'reducing VOCs' compared to 21% of patient.

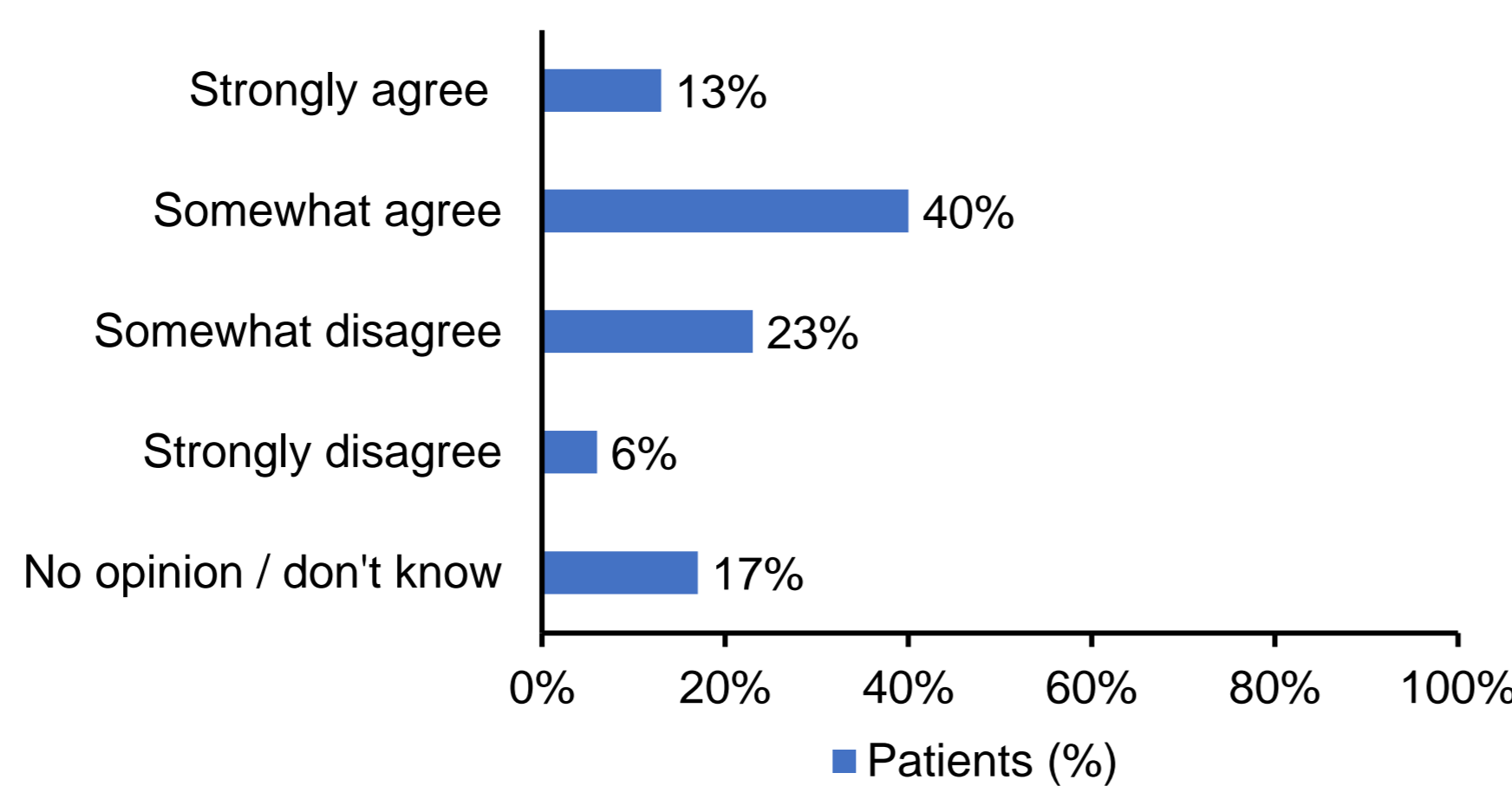
Figure 3. Top 10 Ranked Treatment Goals, Patient (n=299) and HCP (n=30)



#### Current Treatment Approach

- Overall, 53% of patients stated their agreement that their current treatment approach was helping them achieve their treatment goals, as shown in **Figure 4**. However, 29% of patients felt that the current treatment was not helping them reach their treatment goals. 17% of patients stated 'no opinion/don't know', suggesting that their therapy may be having low impact.

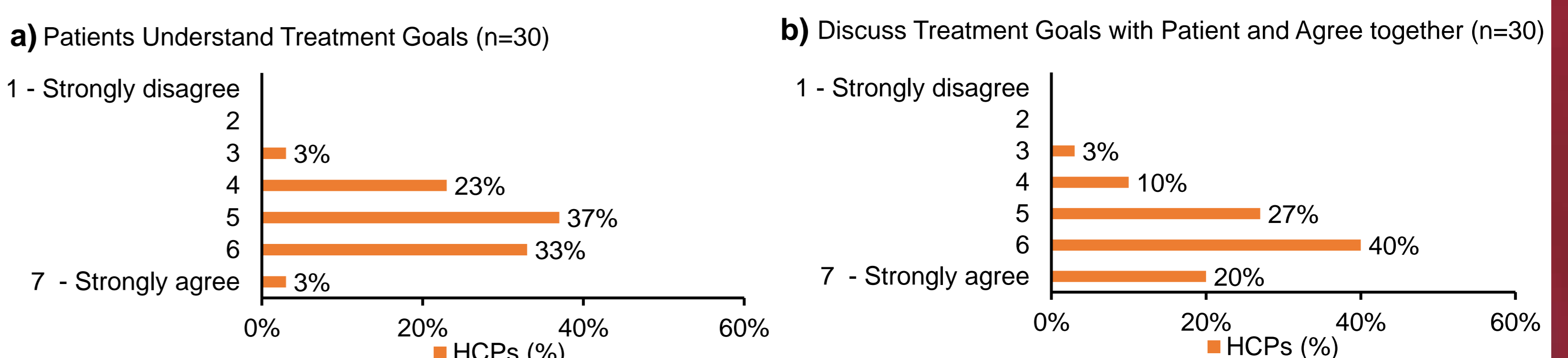
Figure 4. Current Treatment Approach Helping Reach Goals (n=299)



#### Patient Understanding of Treatment Goals (HCP perspective)

- Most HCPs (73%) felt that patients understood their treatment goals, based on a score of 5, 6, or 7 on the rating scale, as shown in **Figure 6**.
- 87% of HCPs selected high agreement that they discuss/agree on treatment goals with patients.

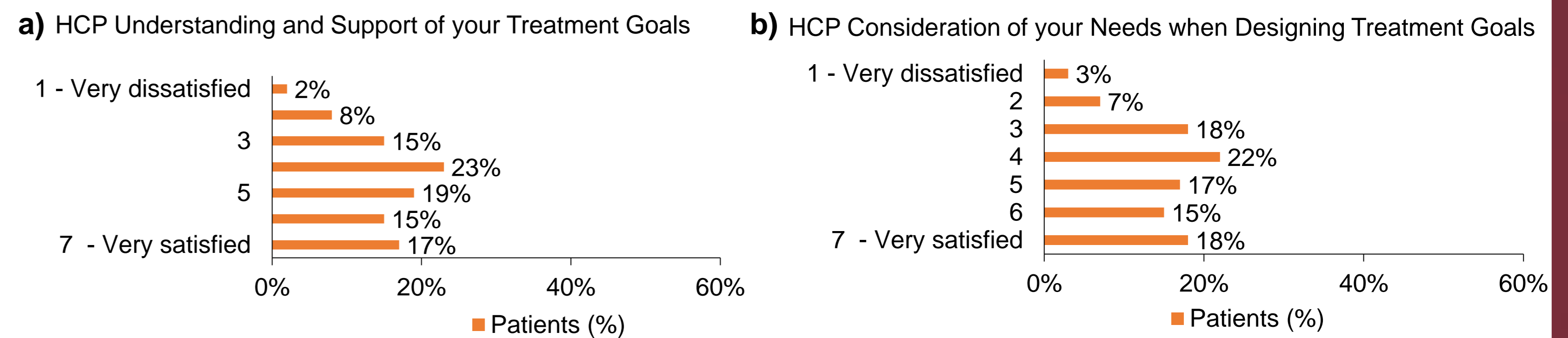
Figure 6. Patients Understand Treatment Goals (n=30, HCP reported)



#### Patient Satisfaction with Main HCP

- 51% of patients were highly satisfied (based on score of 5-7) with their main HCPs' understanding and support of their treatment goals, as shown in **Figure 7**. However, 25% of patients felt dissatisfied (based on score of 1-3).
- 50% of patients were highly satisfied with their consideration of their needs when designing treatment goals, 28% felt dissatisfied.

Figure 7. Patients Satisfaction with Main HCP's Treatment and Management of SCD (n=299)



### CONCLUSIONS

- These results are the first of their kind within the UK and indicate that patients and HCPs align on overall treatment goals in SCD with reference to 'improving quality of life' and 'improvement in overall symptoms'.
- However, differences that exist demonstrate further need for alignment in helping achieve optimal treatment strategies. Notably, patients reported 'improving long term survival' in their top 5 treatment goals, which was not reflected in the HCP response.
- Greater alignment on treatment goals will help patients and HCPs improve overall disease management and enhance patients' quality of life.

### ACKNOWLEDGEMENT

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### REFERENCES

1 Matte A et al. New Therapeutic Options for the Treatment of Sickle Cell Disease. *Mediterr J Hematol Infect Dis* 2019; 11:: 1

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