Piloting a new Patient Reported Experience Measure for Sickle Cell Disease: A report of the findings

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Picker Institute Europe

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- Influence policy and practice so that health and social care systems are always centred around people's needs and preferences.
- Inspire the delivery of the highest quality care, developing tools and services which enable all experiences to be better understood.
- Empower those working in health and social care to improve experiences by effectively measuring, and acting upon, people's feedback.

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Contents

Section one

Introduction

Background

Picker Institute Europe are a healthcare research organisation who recognise the importance of understanding the care experiences of lesser-heard groups and those living with chronic conditions. They recently collaborated with the National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care (CLAHRC) for Northwest London (NWL) on the development of a series of survey tools to collect feedback from patients (all age ranges) with sickle cell disease.

Sickle Cell Disease (SCD) is a genetic blood disorder affecting approximately 15,000 people in England. It occurs more frequently in Black Afro-Caribbean people from parts of tropical and sub-tropical sub-Saharan areas where malaria is or was common. Formerly only a childhood illness due to the life-limiting nature of the disease, as many as 50% of patients now live into their fifth decade thanks to developments such as screening in newborns, increased knowledge of lifestyle factors which can reduce incidences of sickle cell crisis and medications preventing complications.

There is little research in England on the healthcare experiences of sickle cell patients. Although the NHS National Patient Survey Programme regularly gathers the views of patients about a specific healthcare episode, the programme does not focus on the specific needs of people with chronic health conditions (with the exception of the national cancer survey). Though the disease is relatively rare, it is the UK's most prevalent genetic blood disorder. It is characterised by episodes of intense pain, vulnerability to infection and increased risk of stroke; as such, people with SCD are frequently in contact with healthcare services and have specific needs, with a particular requirement for intensive pain relief. Therefore, it is essential to understand and measure the care experiences of SCD patients in order to inform healthcare improvement. Picker Institute Europe were commissioned for this purpose. They formed a stakeholder working group to consult to develop, pilot and validate a new Patient Reported Experience Measure (PREM) for people living with sickle cell disease. Members of the working group included clinicians, researchers, and members of the Sickle Cell Society.

The Questionnaires

A series of PREMs for sickle cell patients were developed based on findings from focus groups with patients and parents, as well as consulting the working group. The surveys were to understand views on:

- access to healthcare services;
- experience of seeing clinicians about SCD – including during planned care episodes (e.g. inpatient admission, outpatient appointments) and during urgent care;
- treatment for their condition and self-management;
- access to relevant information;
- the potential stigma associated with SCD;
- physical and mental well-being, and access to psychological therapies and support;
- transition of care from paediatric to adult services.

The surveys were in the form of a Patient Reported Experience Measure (PREM). PREMs are tools designed to measure the quality of healthcare by assessing the experiences of patients, their relatives and carers. They move away from widely used satisfaction measures, instead asking about specific events and experiences that have occurred during a person's healthcare and treatment, in order to effectively target areas for improvement.

The surveys needed to be appropriate for all patients including both adults and younger patients aged under 16 years (and their parents/carers). Therefore the proposed aims were to develop three separate tools to cover all age ranges:

- A survey for adults with sickle cell disease, aged 16 years and above;
- A survey for children with sickle cell disease, aged 8-15 years;
- A survey for parents of children aged 0-15 years with sickle cell disease.

About this report

Any new questionnaire should be piloted to test that the methodology is effective in obtaining feedback from the target patient population in terms of response rates, timescales required for data collection, and usefulness of the data collected. This information can be used to advise how the survey should be implemented going forward. The results can be used to establish a baseline dataset of healthcare experiences for patients with sickle cell disease, the results of which are outlined in the current report.

The current report focuses only on the methods and results from the survey pilot/data collection phase. Separate reports have been provided for the following:

- the full questionnaire development process including stakeholder consultation and focus group findings;
- survey validation study to assess how well the new surveys function (for example by exploring drop-out rates and trends across responses to different questions).

Methods

Survey Implementation

Due to the relatively high implementation costs that would be associated with mailing out multiple survey versions, in addition to the difficulties with obtaining sickle cell patient lists to mail to, an online survey methodology was agreed amongst the working group to be the most suitable approach to data collection. However, since not everyone has internet access or is computer literate, a hand-out paper survey option was also included. Online surveys are more cost efficient than paper, as they obviate the need for postage costs and data entry. It is also a preferable approach for younger populations. Paper questionnaires however, provide a completion option for those who have no access to the internet and/or a preference for this format.

To obtain a large enough dataset to allow for meaningful analysis, the survey fieldwork remained open until a minimum of 200 completions per version were received.

Picker Institute Europe programmed each of the three surveys into Snap, a survey software package, and thoroughly tested the hyperlinks with the working group. A Quick Response (QR) code was also created, and the survey was hosted online using Snap Webhost for the duration of the fieldwork. Information sheets and posters were created to promote the survey and encourage completion. These contained details of the survey web address and QR code for taking part, along with some background about the survey.

To ensure a successful uptake, two survey co-ordinators (Research Nurses) within Imperial College Healthcare NHS Trust were recruited to help promote the survey across haematology clinics. The research nurses were heavily involved in the day-to-day running of the hand-out survey. Six dedicated sickle cell clinic pilot sites were recruited at which the survey promotion efforts could be concentrated. A planned publicity and communications campaign was also initiated to promote the survey and encourage responses. This included presenting at relevant events and writing about the survey in articles. Full details of the clinics involved, and the communication initiatives that were employed, are provided in the overall survey development report.

Data Analysis

Final data files were exported from Snap to Excel and thoroughly checked before importing to SPSS. All analyses were conducted using SPSS version 22.

Section two

Survey Activity

Response Rates

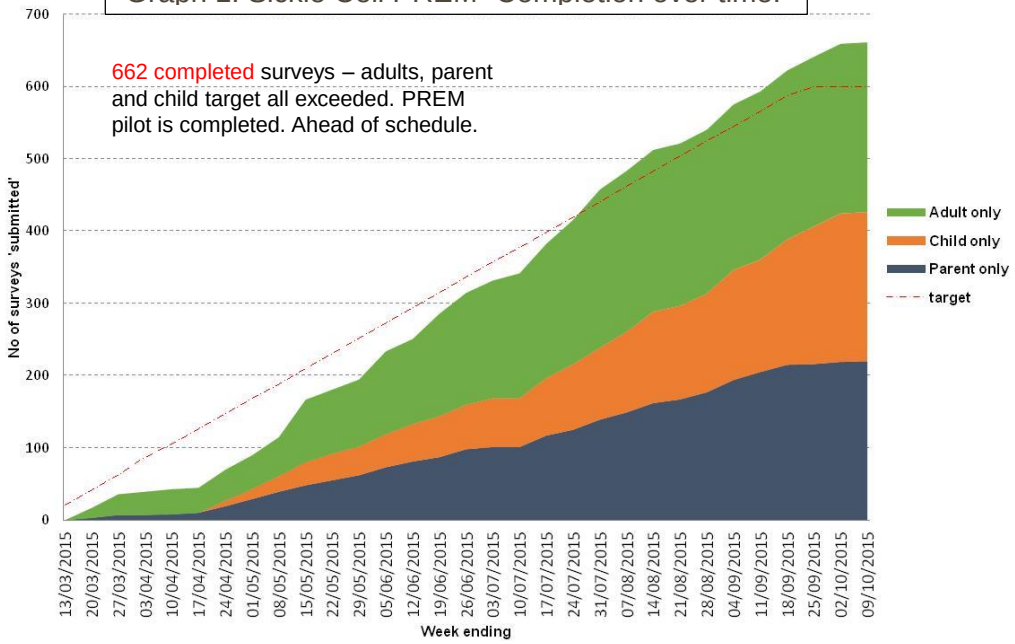
To obtain a large enough dataset to allow for meaningful analysis, the survey remained open until at least 200 completions per survey version were received. The online survey commenced in March 2015 and closed in October 2015. A total of 722 complete responses were received. Please see breakdown for each survey version in the below table.

Table 1: Total number of survey responses by questionnaire version

Survey Version	Total Responses
Adults (16+)	280
Parents of children aged 0-15 years	220
Children (8-15 years)	222
Total	**722**

The graph below indicates the number of responses over time throughout fieldwork, showing the breakdown by survey type, along with the target. This graph was updated and circulated to the working group on a weekly basis throughout fieldwork to monitor survey responses. The count was done on completed surveys as submitted via the online survey link. Upon closing the survey and assessing the partial responses, a number of incomplete surveys were retained, which allowed us to exceed our target of 600 responses overall.

Graph 1: Sickle Cell PREM- Completion over time.



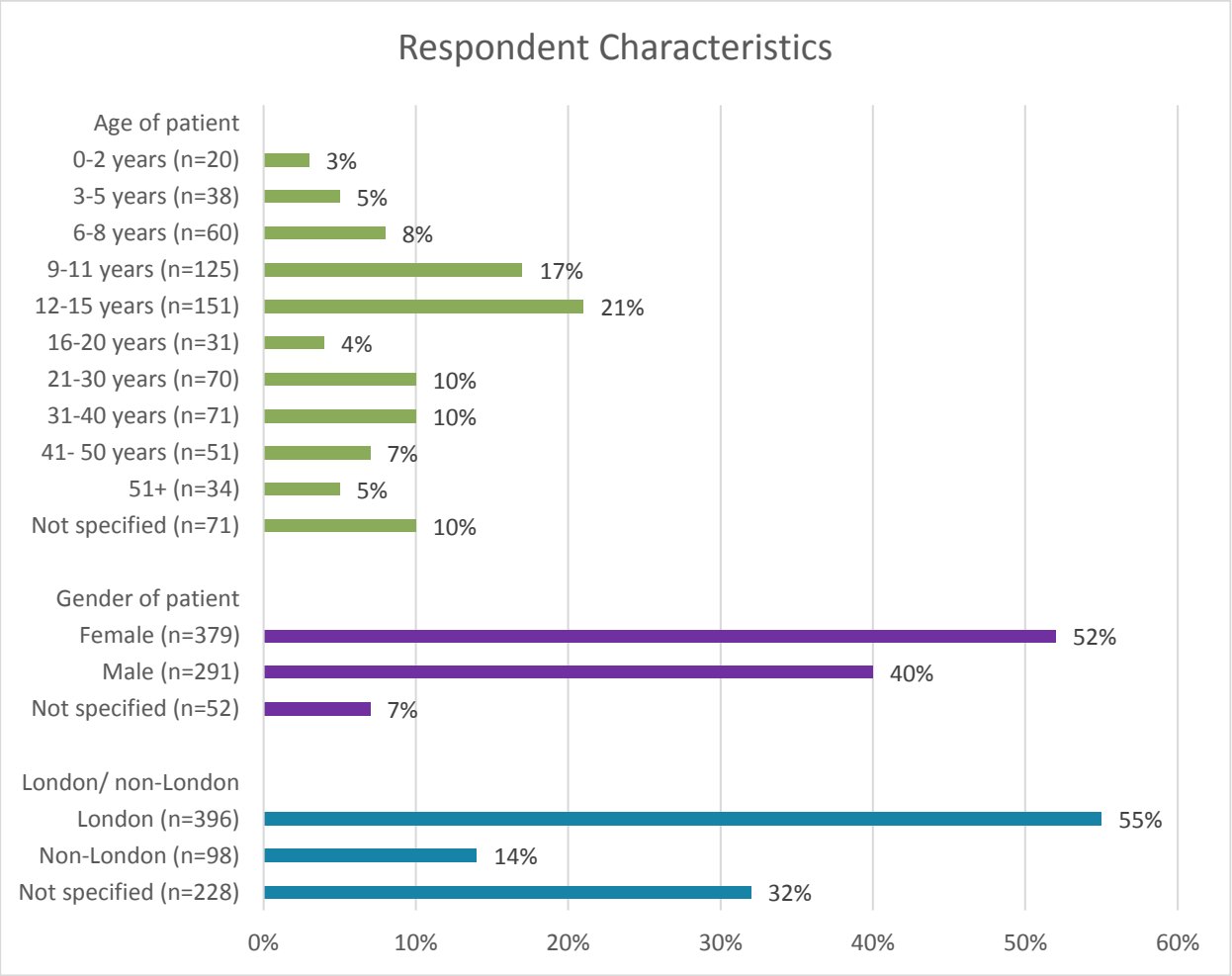
Demographics

The following table displays the characteristics of survey respondents. It shows characteristics of the patient with sickle cell, not the respondent. Therefore, where a parent was asked demographic questions, these were answered about their child rather than themselves.

The graph below shows that slightly more females (52%, n=379) completed surveys than males (40%, n=291).

The most common age ranges that they surveys were completed by (or on behalf of) were 12-15 year olds (21%, n=151) and 9-11 year olds (17%, n=125). Very few parents of children aged 0-2 completed the survey (3%, n=20), equally, very few 16-20 year olds and adults aged 51 years and above completed the survey (4%, n=31, 5%, n=34 respectively).

Graph 2: Respondent Characteristics



Section three

Survey Results

Results

Format of Results

Findings are presented by questionnaire section. Full frequency tables are included at the end of the report in Appendix 1, which display the number of missing responses for each question, along with details of who and how many people answered, and the number and proportion of patients that selected each response option. Quotes are displayed throughout the report in *"purple italics",* taken from the 'Any Other Comments' section of the survey. All freetext comments are sent separately in an excel document.

For comparable questions across the three survey versions (parents, adults and children), data has been combined to show an overall response. However, where possible, noteworthy comparisons have been made across the groups. Individual frequency tables for the separate survey versions (parents, children and adults) are provided as a separate document.

Any differences in responses by age group have also been identified throughout the report, in addition to differences in responses from people living within and outside of London.

Please note that results are only reported where there are 20 or more survey responses (per question). For any sub-group analyses (e.g. by gender or age group), data is not reported on groups lower than 20 since (i) the data can be misleading and unrepresentative from low numbers; and (ii) it risks individual respondents becoming identifiable.

It is important to note that in all tables and graphs, percentages are rounded to the nearest whole number. Totals may not always equal 100% for this reason. Similarly, overall totals may not always represent the total number of survey respondents, as not all respondents provided an answer to all questions. Please refer to the frequency tables in Appendix 1 for full information.

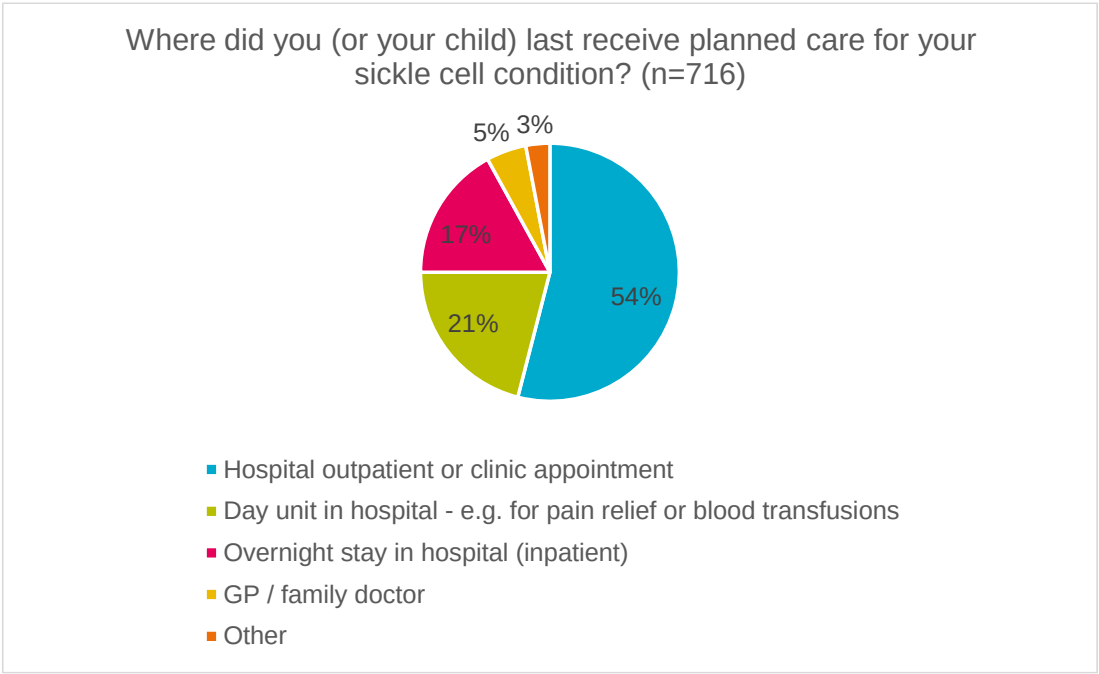
In the interests of accuracy, we use derived questions to produce more meaningful data for questions that are not applicable to all respondents, but are not preceded by a filter question. For example, Question 6 (T) (Did the healthcare staff answer your questions clearly?) is not applicable to all patients, i.e. it does not apply to patients that responded *that they did not have questions to ask.* Additionally, it would not be applicable to those who *had not received planned care in the last six months*. For questions of this nature we have re-calculated the data by excluding those respondents to whom the question does not apply. The new calculation will be illustrated in an additional question (e.g. Q6 (T) +).

Survey findings

Planned Sickle Cell Care (within the last 6 months)

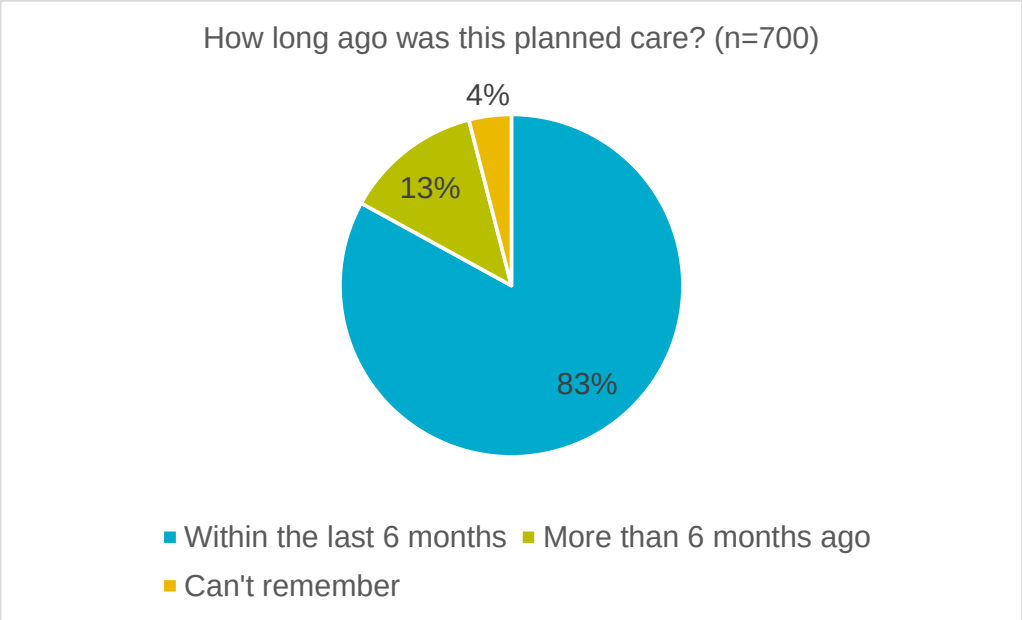
The first question examines where the respondents most recently received planned care for their sickle cell. Graph 3 shows the overall (i.e. parent, child *and* adult data) responses for each appointment type. It is evident that hospital outpatient or clinic appointments are the most common with just over half of the respondents giving this response (54%, n=385).

Graph 3: Q1 (T) Where did you (or your child) last receive planned care for your sickle cell condition?



The majority of respondents (83%, n=582) had received this episode of planned care within the last six months.

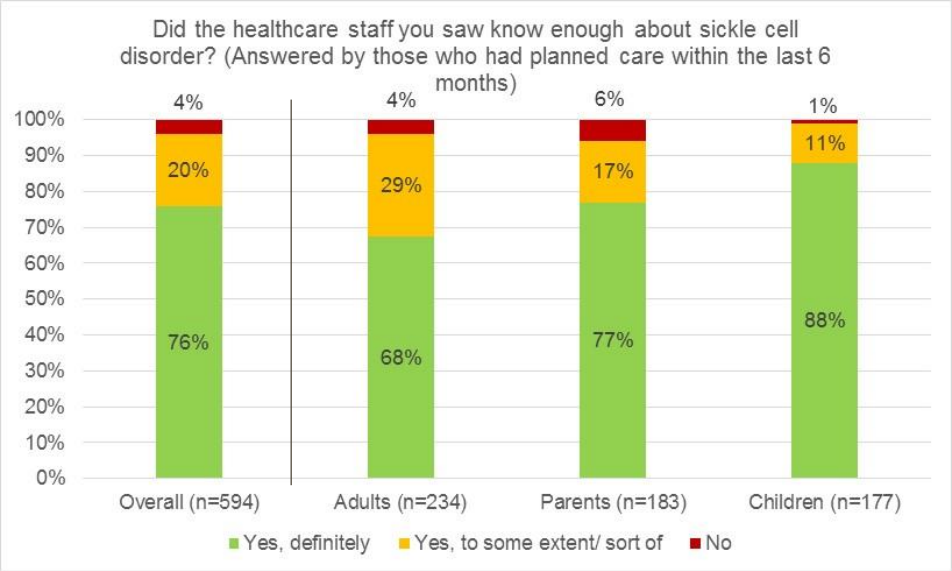
Graph 4: Q2 (T). How long ago was this planned care?



Those respondents that indicated having received planned care within the last six months were then asked subsequent questions about this specific care episode.

Overall, 76% (n=454) agreed that the healthcare staff that they saw for this planned appointment definitely knew enough about sickle cell disorder. However, adults provided poorer feedback than parents or children, with only just over two thirds of adults (68%, n=158) reporting that the healthcare staff knew enough, relative to 77% (n=141) of parent's and 88% (n=155) of children. Children were most confident that staff knew enough about sickle cell. Please see graph 5 below for a breakdown of these results.

Graph 5: Q3 (T). Did the healthcare staff (planned appointments) you saw know enough about sickle cell disorder? Data presented by survey type.

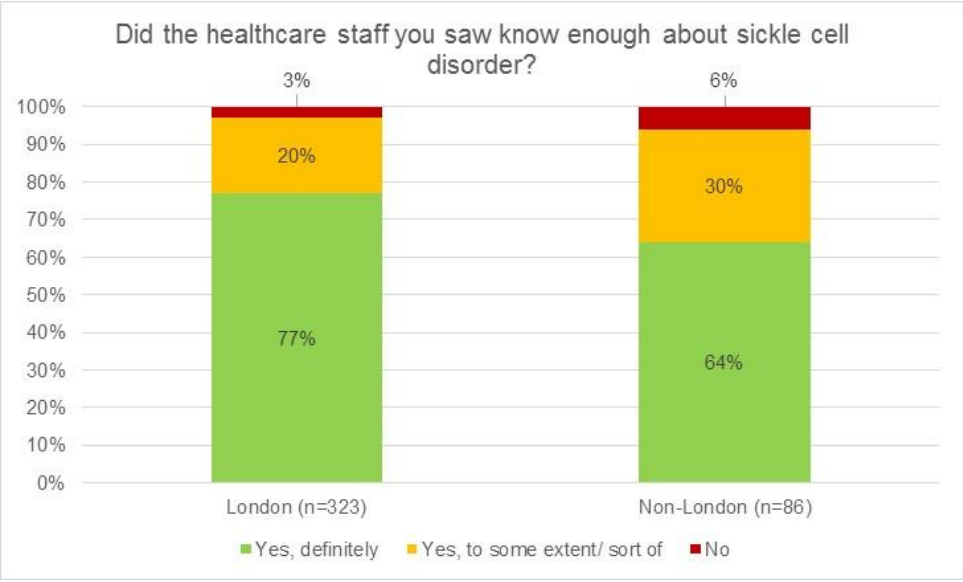


A comment from the free text section of the survey reveals that only more recently have NHS staff been more aware of the condition; a very positive progression.

"NHS staff know more about sickle cell disorder. I am happy! 12 years ago it was very scary when my child was not well. Most health staff never heard of sickle cell disorder or knew very little. Many occasions he was left in A&E screaming in pain…I was sent back home so many times while my son was actually in crisis…"

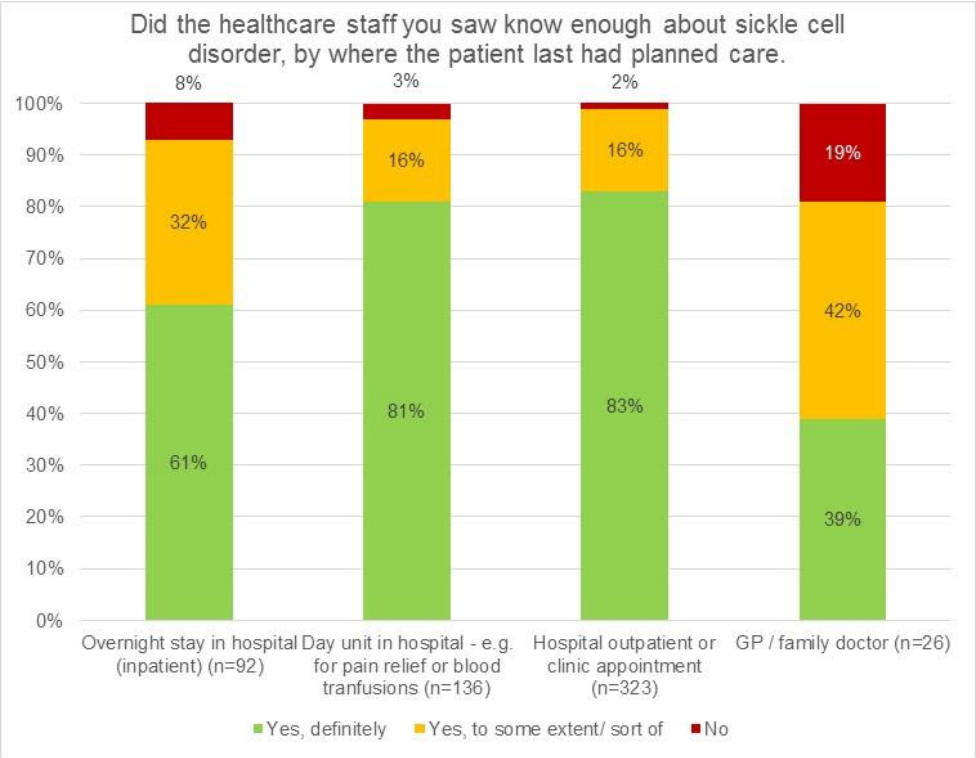
Breakdown by region indicates that those respondents in London are more likely to report that healthcare staff definitely know enough about sickle cell (77%, n=248) than those outside of London (64%, n=55).

Graph 6: Q3 (T). Did the healthcare staff (planned appointments) you saw know enough about sickle cell disorder? Data presented by region.



Patients attending planned care at a hospital outpatient or clinic appointment were most confident about staff knowledge of sickle cell, where 83% (n=267) reported that they definitely knew enough, followed closely by 81% (n=110) for hospital day unit attendees. Graph 7 below also shows that patients seemed to have the least confidence in the knowledge of their GP or family doctor (compared to other staff), where 61% (n=16) felt that the GP did not fully know enough about sickle cell disorder. However, please be cautious of the relatively low number of respondents (n=26) in the GP category.

Graph 7: Cross tabulation of Q3 (T) (Did the healthcare staff you saw know enough about sickle cell disorder) and Q1 (T) (Where did you (or your child) last receive planned care?)



Respondents' comments show the confidence of some patients in the knowledge of specialists and consultants.

"Consultant appointments are very helpful. Feels as if we're in good hands"

"What's particularly good is the opportunity of speaking with the specialist"

However, some respondents indicate that their care varies according to where they go for help.

"The help at [certain hospitals] has been good. I avoid some because of the lack of knowledge and care provided there."

"It would be good to have a bit more support from healthcare team. The hospital is excellent but at GP level it could be much better."

While others have experienced healthcare staff who have little or no knowledge or understanding of the condition.

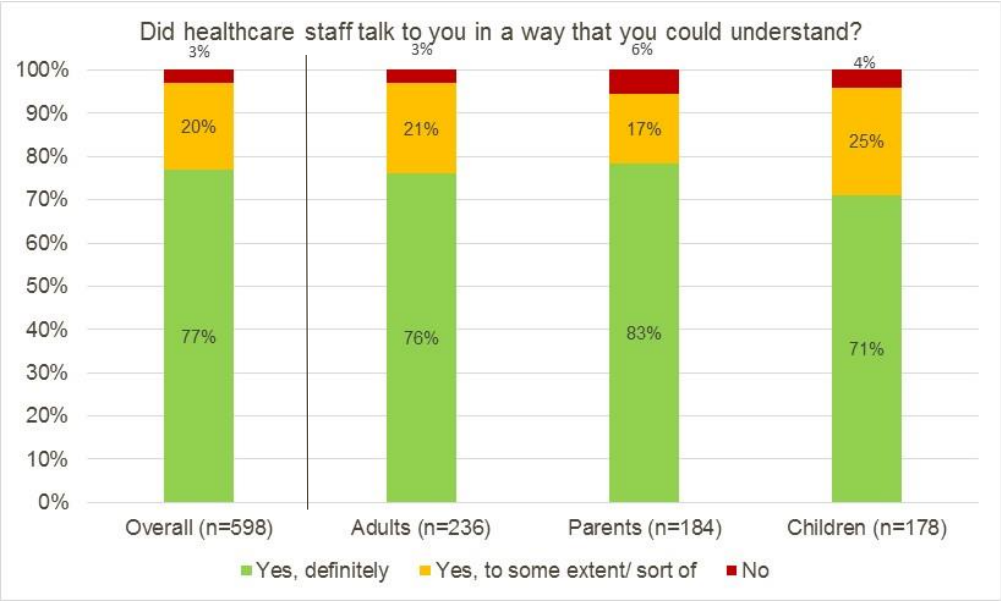
"The doctors at [one] hospital say they don't know how to treat my child, he is the first person they ever came across with the condition… we were sent home on three occasions without giving him any pain relief, they didn't know how to ease some of his symptoms and were asking me what the protocol is in other hospitals we went, shocking!"

"GP's need educating on the urgency of medication, ensuring prescriptions are always ready especially at a time when the child has a virus or cold."

Communication is a central component of person-centred care, therefore several questions asked patients to provide feedback on communication with staff.

The surveys explored the extent to which the healthcare staff spoke to patients in a comprehensive way. This was asked to all groups of respondents, with children being asked whether the healthcare staff spoke to them directly (*rather than a parent/ carer*) in a way that they could understand. Graph 6 below indicates that the overall majority (77%, n=458) believed that the staff were clear when talking to them. The breakdowns by respondent type show that children felt this less so, with fewer definitely agreeing that staff spoke to them in a way they could understand (71%, n=126)

Graph 8: Q4 (T). Did healthcare staff (planned appointments) talk to you in a way that you could understand? Data presented by survey type.



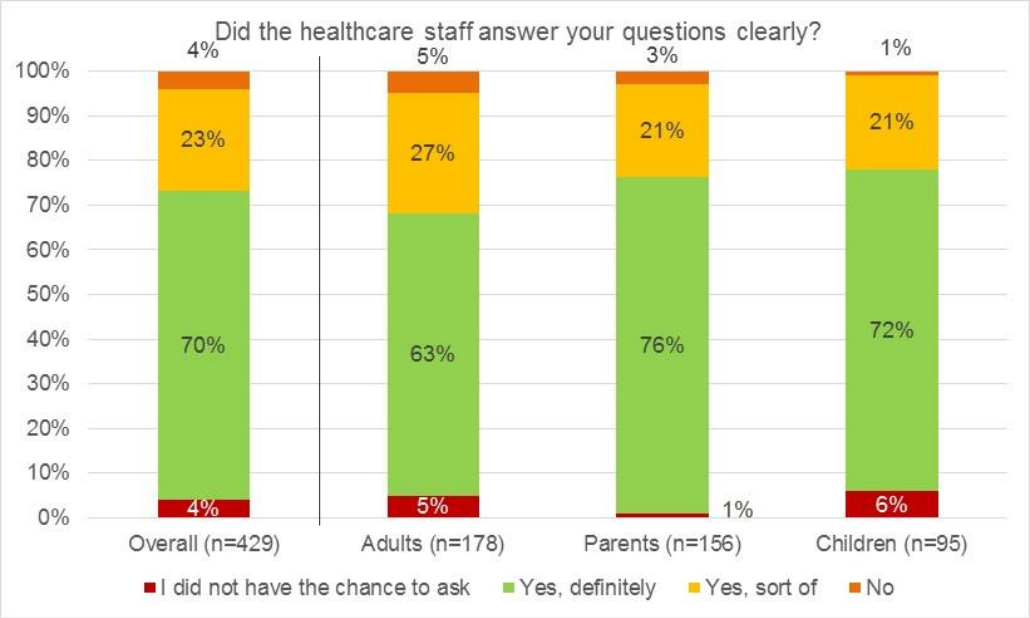
Parents were also asked whether they felt the staff spoke to their child in a way they could understand and 79% (n=131) felt that they definitely did, with a further 17% (n=28) responding that this was true to some extent. Only 4% (n=7) felt that staff did not speak in a way their child could understand. Free text comments reflect these findings.

"Her consultant is respectful and talks to her in a approachable way"

Those who had questions to ask the healthcare staff were asked whether they thought their questions were answered clearly. Around three quarters (76%, n= 118) of parents and (72%, n=68) of children felt that their questions were 'definitely' clearly answered, compared to just under two thirds (63%, n=112) of adults. Graph 9 below shows that 6% (n=6) of children

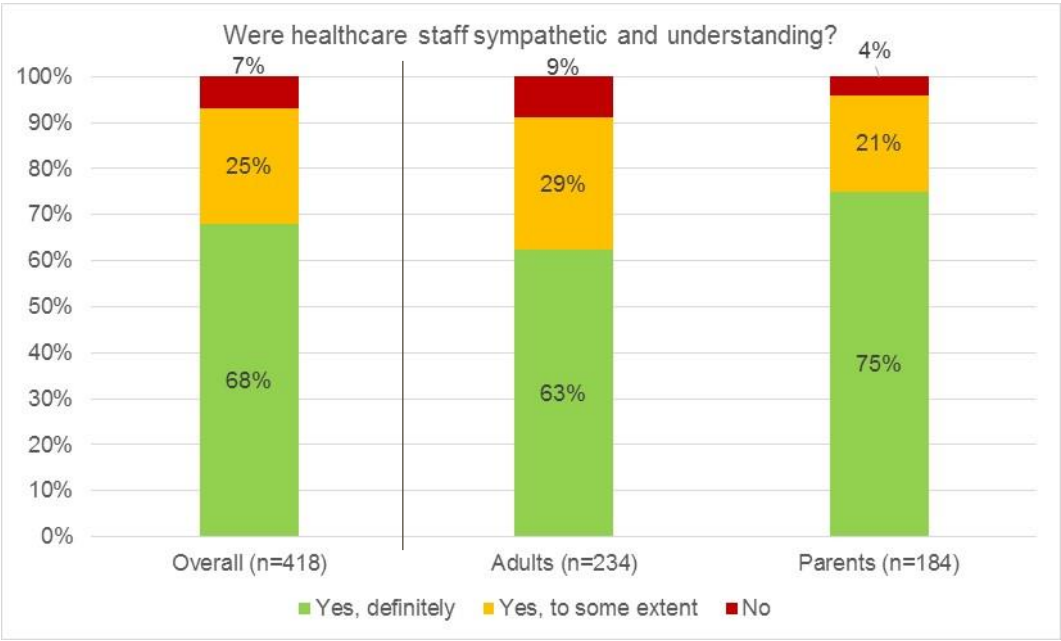
were not given the chance to ask any questions at all, compared to 5% (n=9) of adults and 1% (n=1) of the parent respondent group.

Graph 9: Q6 (T). Did the healthcare staff answer your questions clearly (planned care)? Data presented by survey type.



Whilst overall, 68% of parents and adults felt that the healthcare staff during planned care were definitely sympathetic and understanding, a quarter of parents (25%, n=47) and 38% (n=87) of adults felt that staff were not fully sympathetic and understanding.

Graph 9: Q7 (P&A). Were healthcare staff sympathetic and understanding (planned care)? Data presented by survey type.



Free text comments reflect the respondents' views of the healthcare staff.

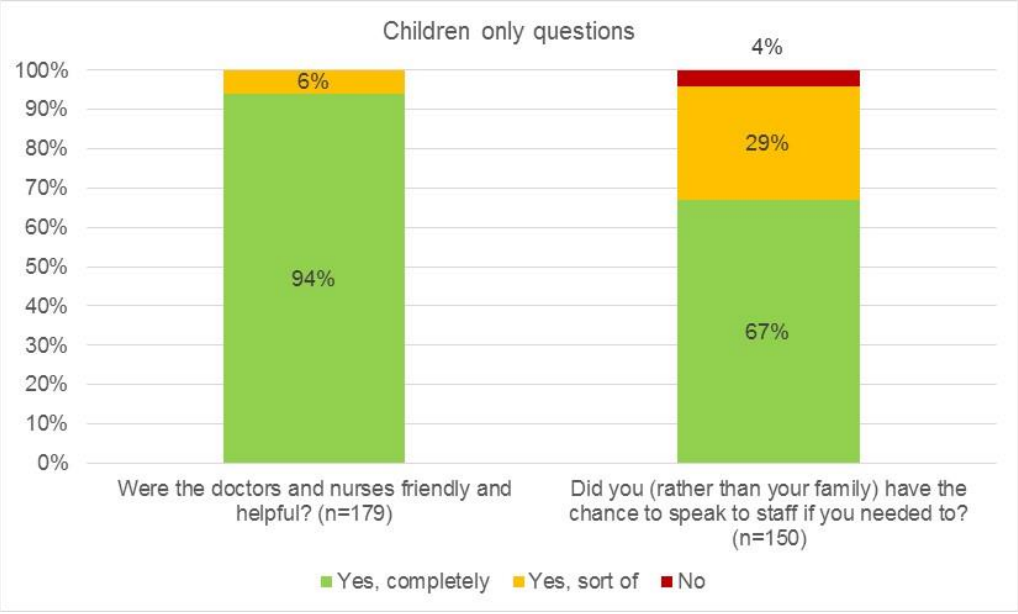
"When we see the specialists, we find they're always very understanding, caring and sympathetic."

"Most of the people we deal we have known since she was days old and have been very professional, empathic and understanding to the whole family"

"The good thing about the care is that you have doctors and nurses in the department try to understand what you're going through...."

A more child-friendly question was asked in the children's survey asking about the friendliness of staff during planned care, and this revealed that 94% (n=168) completely agreed that the doctors and nurses that they saw were friendly and helpful. Children were also asked whether they (rather than their family) had the chance to speak to staff and this revealed that of those who needed this, two thirds (67%, n=101) agreed that they definitely had the chance. A further 29% (n=43) reported that they were 'sort of' able to speak to staff and just 4% (n=6) did not have the opportunity. There was little difference in the results when factoring in age group, which suggests that these results are consistent for children of all ages (8-15 years). The graph below shows the results of these two children's questions.

Graph 10: Q8 (C). Were the doctors and nurses friendly and helpful? With Q9 (C). Did you (rather than your family) have the chance to speak to staff if you needed? – planned care



Free text responses reveal that some younger patients would prefer to be able to speak to or confide in staff without parents present.

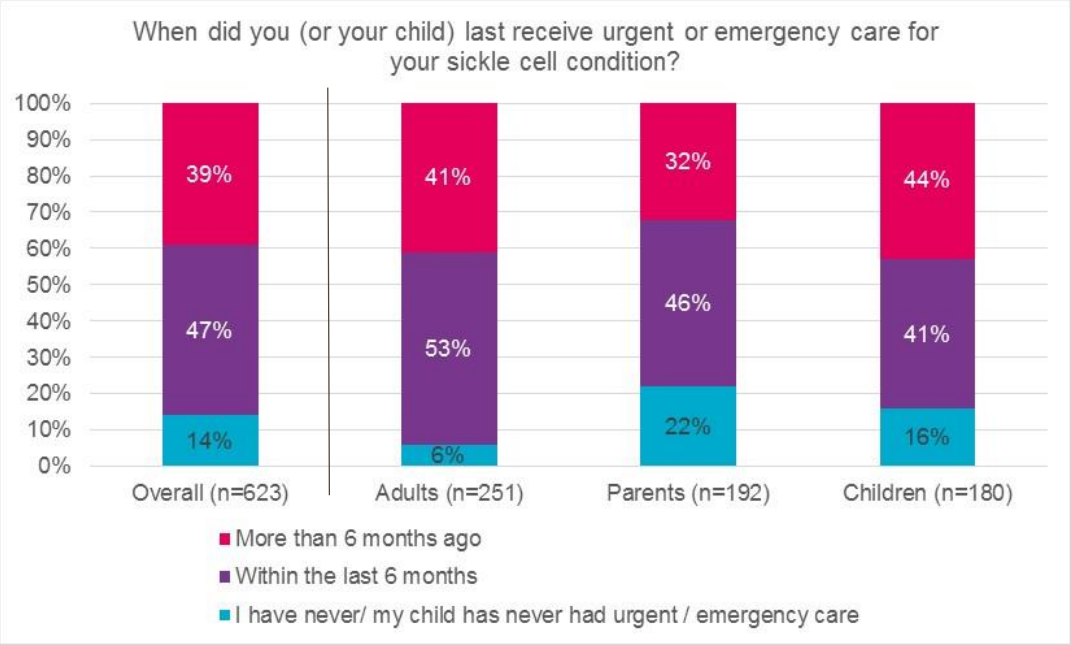
"Being able to talk to the doctors without my parents and being able to tell the doctor personal information that the doctor won't tell my parents."

Children and parents were asked about their choice in parental presence during a recent planned care appointment. For those who this was necessary (child was old enough to make this decision) 90% (n=85) of parents reported that their child had the option to choose whether they (as the parent) attended with them. This question was also asked (slightly differently) to children and 95% (n=124) reported that they were given the option for their parent to be present. There was little difference when looking at this by age of child, which suggests that all age groups are given this option (8-15 years).

Urgent/ Emergency Sickle Cell Care (within the last 6 months)

All respondents were asked to reflect on when they (or their child) last received urgent or emergency care for their sickle cell, in order to explore any differences in care between planned/ emergency services, and to understand the experiences of those who had recently received urgent care. Graph 11 below shows that parents and children both reported a slightly higher instance of never having required urgent care (22%, n=42; and 16%, n=28 respectively) than adults (6%, n=16), with more adults also reporting needing urgent care within the last six months (53%, n= 132) than parents and children (46%, n=89; 41%, n=73 respectively).

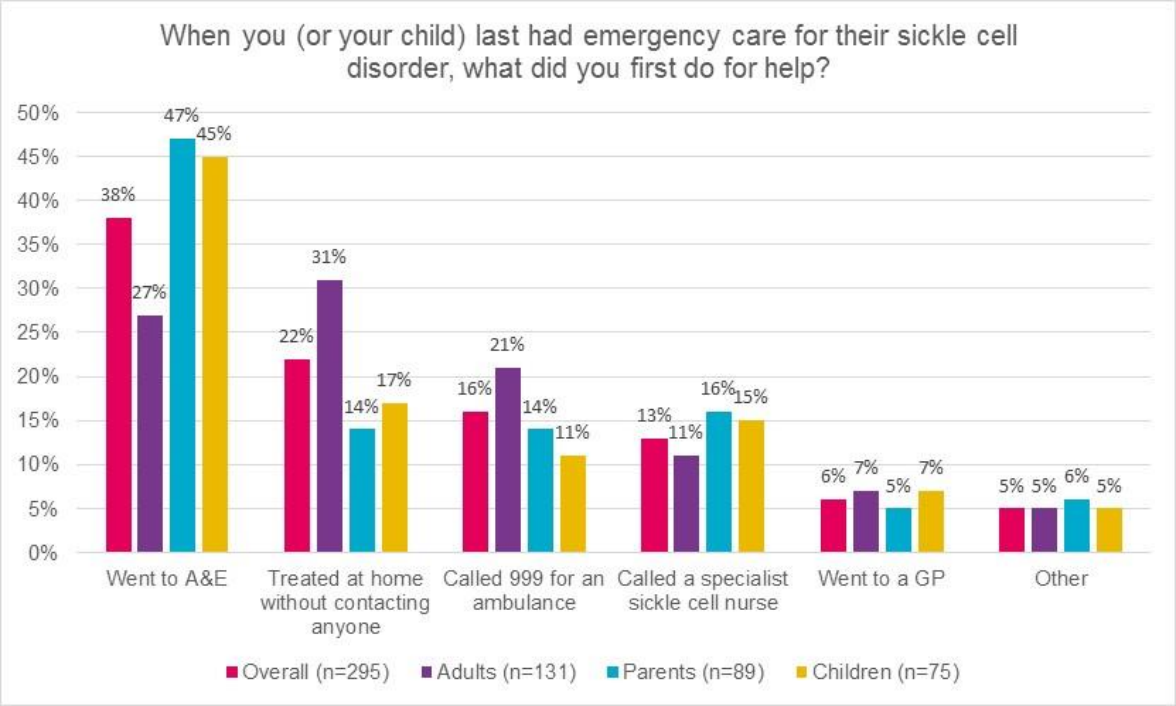
Graph 11: Q12 (T). When did you (or your child) last receive urgent or emergency care for your sickle cell condition?? Data presented by survey type.



When exploring the different routes respondents made when they (or their child) needed urgent care, overall, going to A&E was the most common initial choice (38%, n=111). However adults were less likely to report going to A&E (27%, n=35) than parents/children (47%, n=42/ 45%, n=34) with the most common route for adults to take being to treat at home without contacting anyone (31%, n=40).

Furthermore, adults were more likely to call for an ambulance (21%, n=27) than parent's or children (14%, n=12, 11%, n=8 respectively).

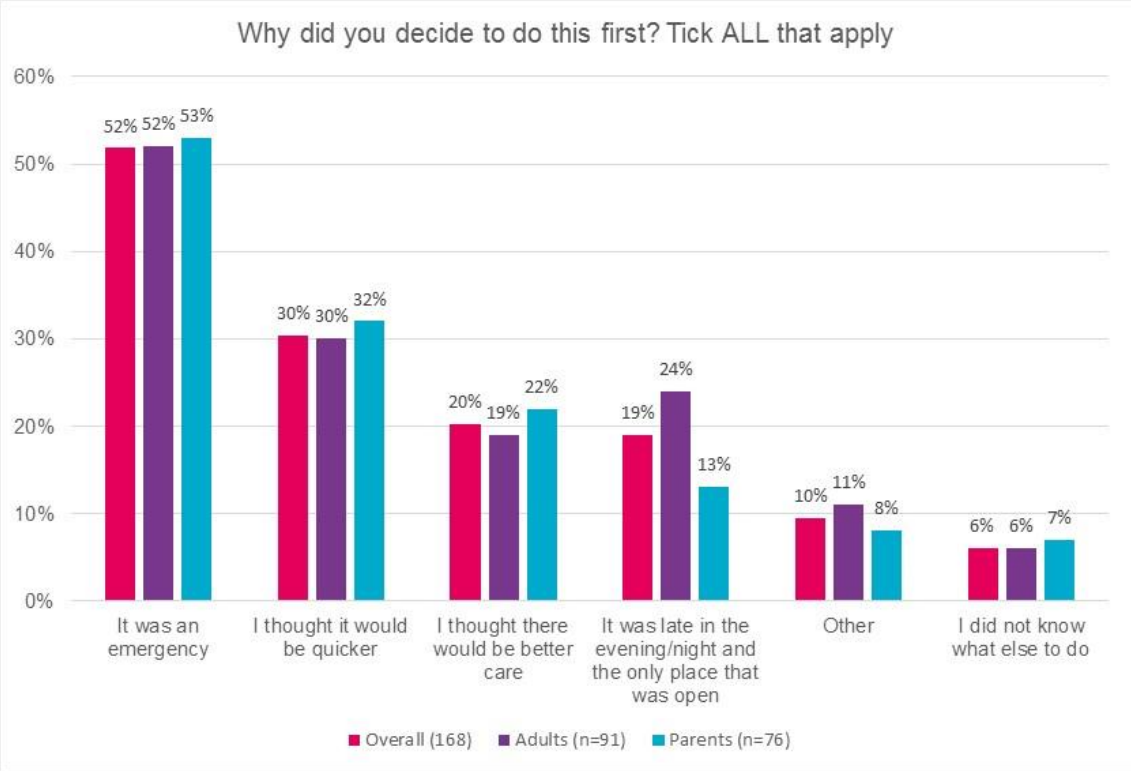
Graph 12: Q13 (T). When you (or your child) last had emergency care for their sickle cell disorder, what did you first do for help? Data presented by survey type & route taken.



Adults and parents of children with sickle cell were then asked the reasoning for the choice in the action they took for urgent/ emergency care. Graph 13 below displays the different reasons these respondents gave for their decisions.

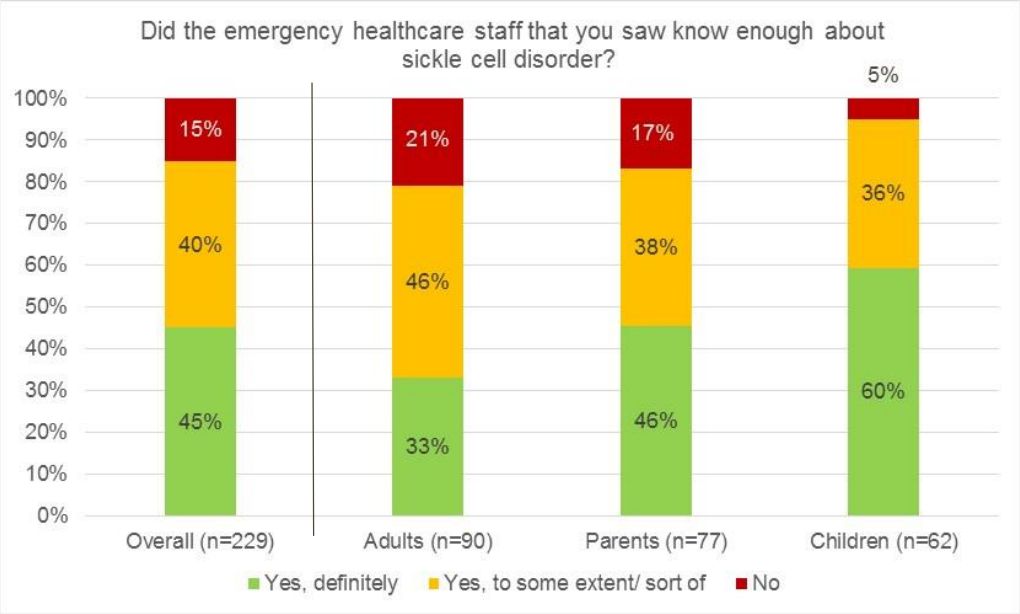
For both adults and parents, the most common reason for choosing the route they did was because they felt it was an emergency (overall; 52%, n= 87). The second response with the highest frequency in parents and adults' choices in urgent care was due to this being a quick option (overall; 30%, n=51). For the third most popular option, parents and adults' selections diverged. For parents, the third most common reason was because they thought it would be the best care for their child (22%, n=17) but for adults, this decision had been made because it was late and the only place open at that time (24%, n=22).

Graph 13: Q14 (P&A). Why did you decide to do this first? Data presented by survey type.



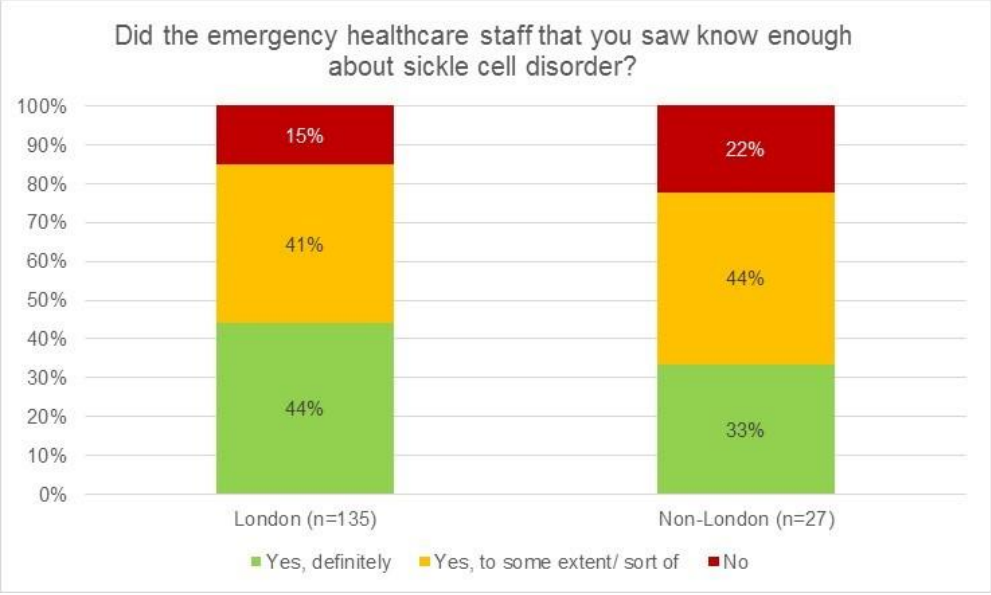
Those who had received urgent care within the last six months were asked a series of questions in order to explore their urgent care experiences. Graph 14 shows that children were most likely to agree that the emergency healthcare staff knew enough about sickle cell disorder (60%, n=37). Adults and parents appeared to have less confidence in the knowledge of the emergency healthcare staff, reporting that 21% (n=19) and 17% (n=13) respectively did not know enough about sickle cell disorder relative to only 5% (n=3) of children.

Graph 14: Q15 (T). Did the emergency healthcare staff that you saw know enough about sickle cell disorder? Data presented by survey type.



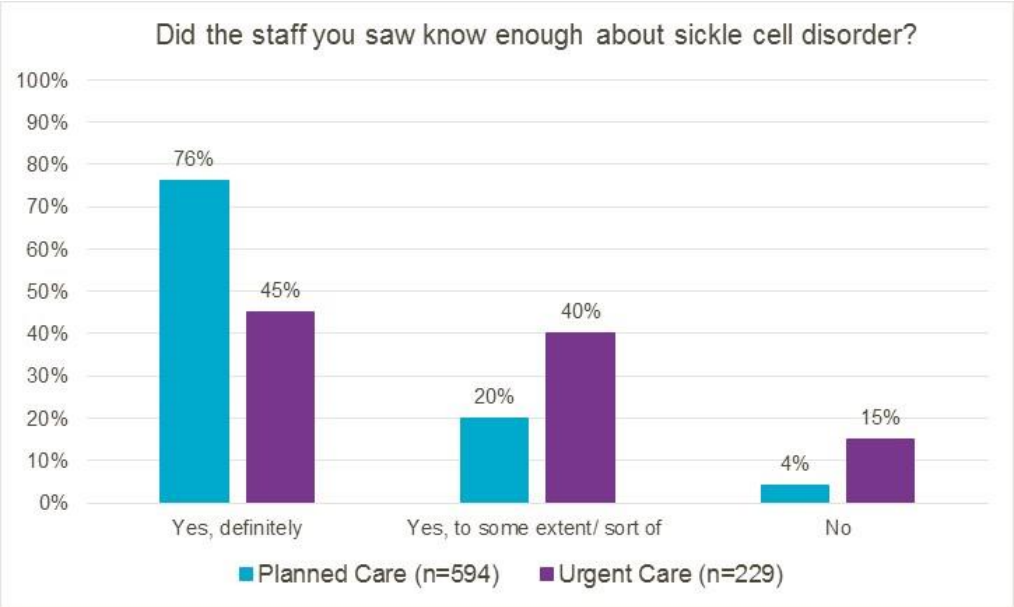
Differences in results by region demonstrated that respondents outside of London were slightly less likely to agree that emergency healthcare staff knew enough about sickle cell disorder (relative to London-based respondents. Please refer to the below graph for full details – but be cautious of the relatively low number of respondents (n=27) in the non-London cohort.

Graph 15: Q15 (T). Did the emergency healthcare staff that you saw know about sickle cell disorder? Data presented by region.



When comparing confidence in knowledge of staff by care settings, respondents were more likely to state that that emergency healthcare staff lacked in-depth knowledge of sickle cell (15%; n=35) relative to planned care staff (4%, n=22).

Graph 16: Comparison of Q3 (T) and Q15 (T). Did the (planned/ emergency) healthcare staff that you saw know enough about sickle cell disorder?



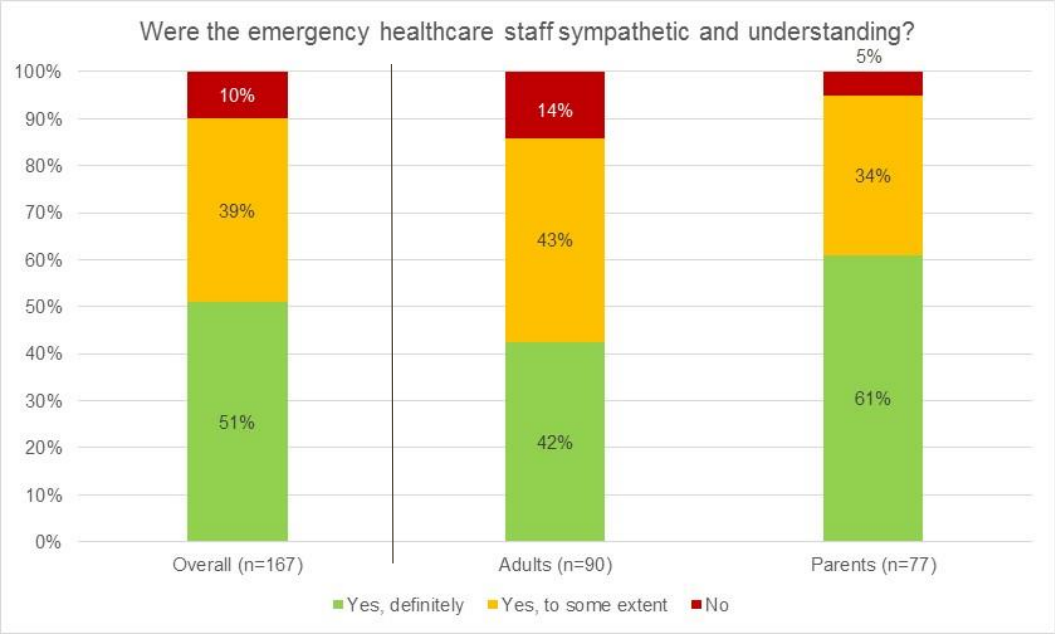
Some free text comments reflect what the data is showing.

"The clinic she attends is very good, it's easy to attend too and the staff know my daughter which makes it easier to cope with. It's more the general health service or accident and emergency they have no idea about sickle cell."

"More information and training for accident and emergency staff is needed."

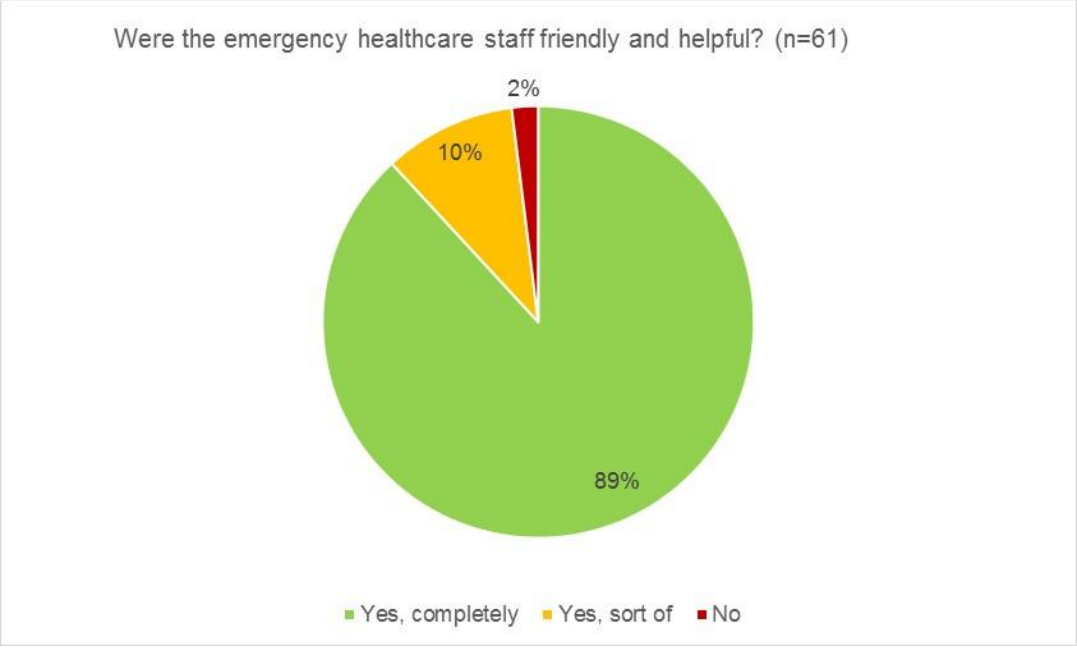
Adults and parents were asked whether they thought the emergency healthcare staff were sympathetic and understanding. Overall, just over half (51%, n=85) stated emergency staff were definitely sympathetic and understanding. However, this was lower for adults (42%, n=38) than for parents (61%, n=47).

Graph 17: Q16 (P&A). Were the emergency healthcare staff sympathetic and understanding? Data presented by survey type.



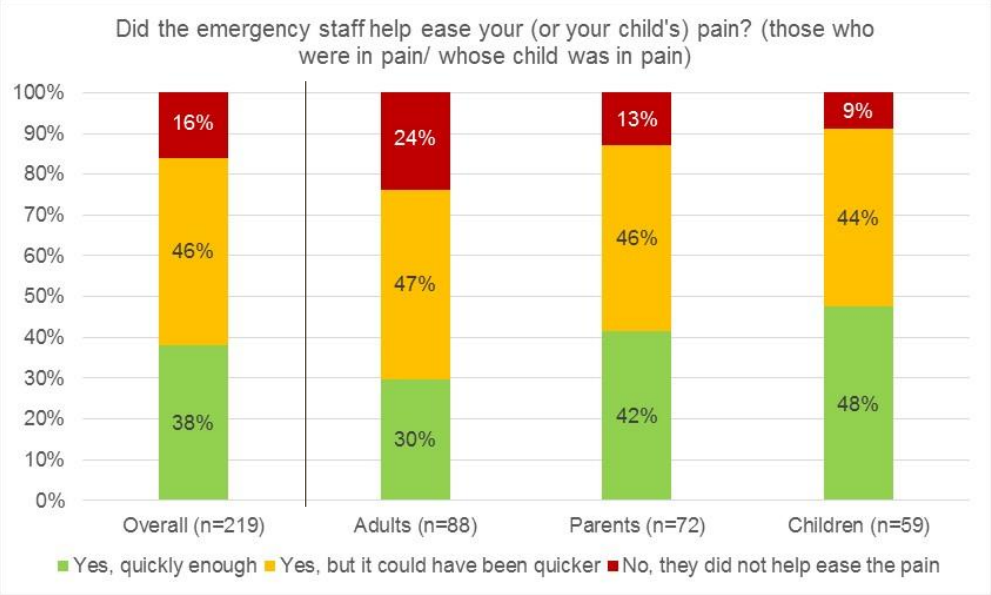
Addressing the children with an easy to understand question, they were asked whether they thought the emergency healthcare staff were friendly and helpful, with almost all respondents agreeing either completely or to some extent (99% n=60).

Graph 18: Q17 (C). Were the emergency healthcare staff friendly and helpful?



Those who experienced pain when accessing urgent care were asked how quickly the emergency staff assisted in easing this pain. Overall, 38% (n=84) felt they were assisted quickly enough. A further 46% (n=100) reported that they were assisted, but that their pain could have been eased more quickly. Sixteen percent (n=35) reported that the emergency staff failed to ease their pain at all. When exploring the differences between respondent types, a higher proportion of adults reported that their pain was not eased at all by staff (24%, n=21) than parents (13%, n=9) and children (9%, n=5).

Graph 19: Q18 (T). Did the emergency staff help ease your (or your child's) pain? Data presented by survey type.



Although emergency care does not seem as efficient or the staff as aware of sickle cell compared to planned care, some comments reveal that the condition and its urgency when in a crisis is understood at some emergency departments that they attend.

"We have a card we should show to A&E. We are priority"

"Having a priority card means he is attended to quick when in A&E"

Although this is unfortunately not always the case.

"It would be better if there was a Fast track service at accident and emergency"

Others can avoid waiting in A&E completely:

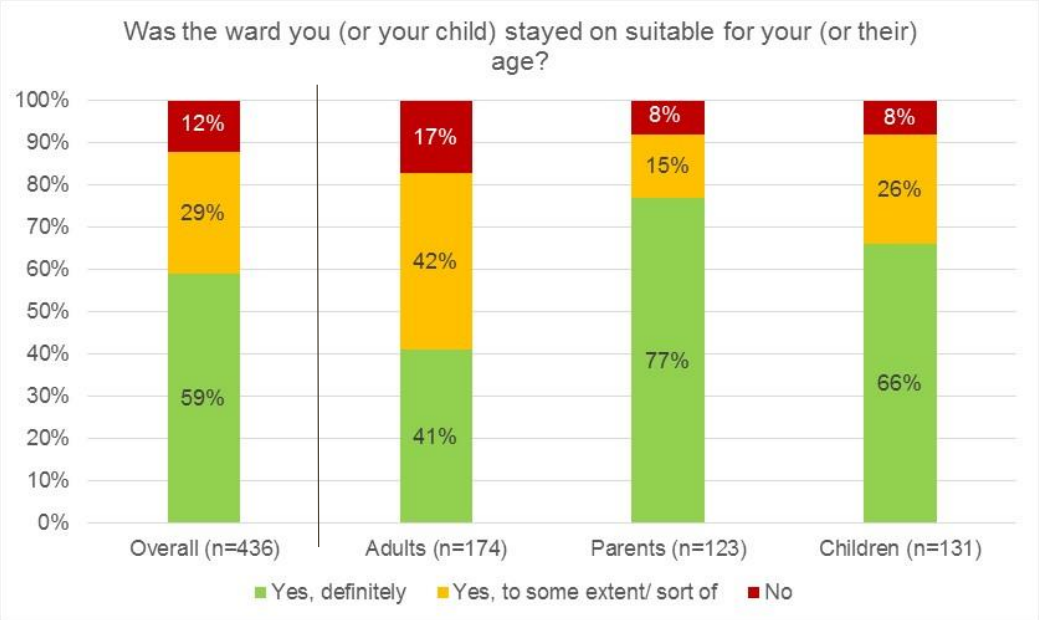
"I can call the hospital if she is unwell and she is admitted straight to the ward instead of waiting in A&E, I find this extremely good."

Hospital Ward Care (within the last 6 months)

Further aspects of the survey explored hospital ward care, with almost two thirds of respondents (62%; n=430) having stayed on a hospital ward within the last year. These respondents were then asked a series of questions about their hospital ward care.

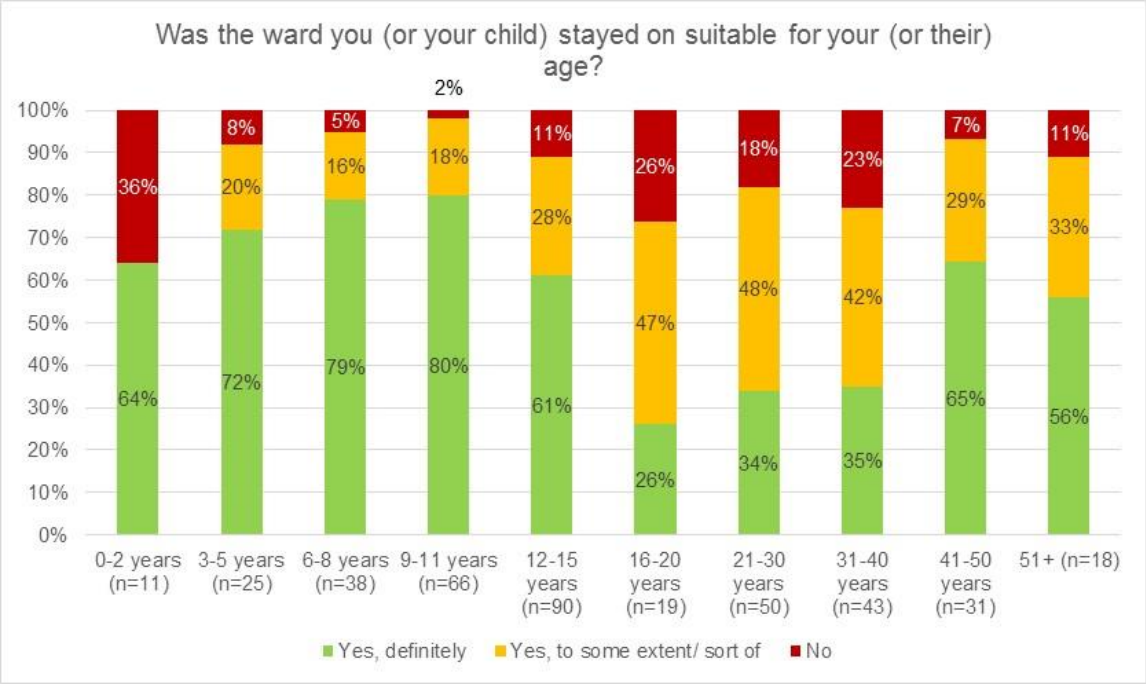
Almost three fifths (59%, n=253) felt that the ward they stayed on was suitable for their (or their child's) age. Respondent breakdown revealed that fewer adults felt this to be true, with just two fifths (41%, n=72) agreeing that the ward they stayed on was definitely appropriate for their age relative to 66% (n=86) of children and 77% (n=95) of parents.

Graph 20: Q20 (T). Was the ward you (or your child) stayed on suitable for your (or their) age? Data presented by survey type



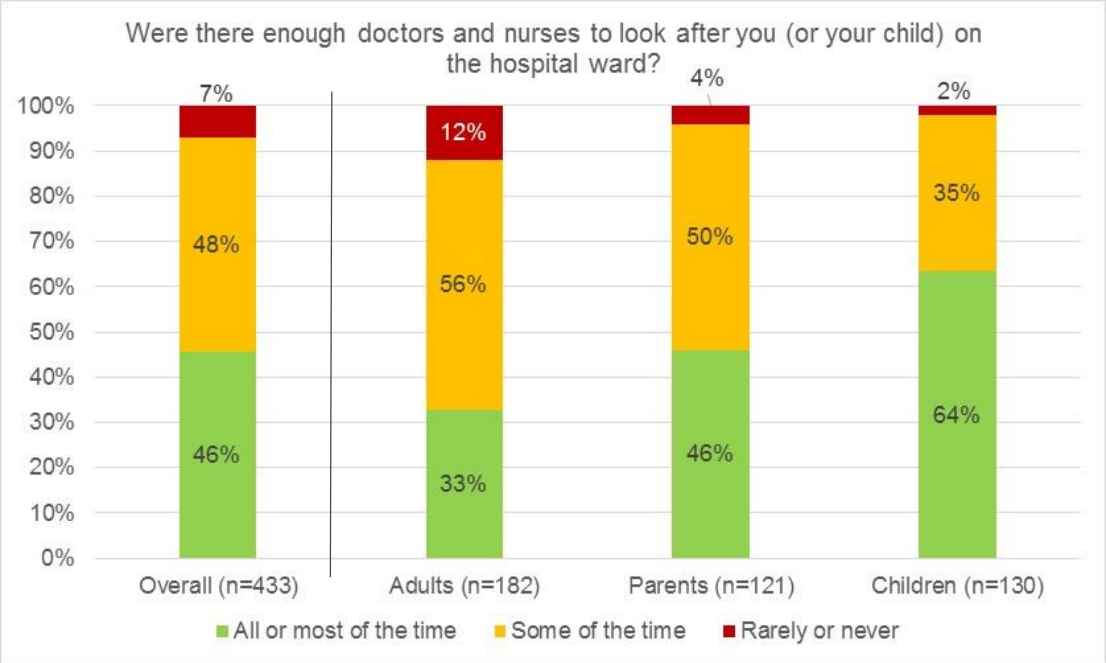
The graph below shows that 16-40 year olds were the least positive about the hospital ward being suitable for their age group, with just 26% (n=5) 16-20 year olds agreeing, 34% (n=17) 21-30 year olds and 35% (n=15) 31-40 year olds – please refer to the below graph for full details.

Graph 21: Q20 (T). Was the ward you (or your child) stayed on suitable for your (or their) age? Data presented by age.



Overall, just 7% (n=28) of respondents reported that there were rarely or never enough doctors and nurses on the ward to care for them in hospital, 46% (n=198) agreed that there were always, or nearly always enough doctors and nurses and a further 48% (n=207) felt that there were sometimes enough ward staff on duty. Interesting differences are revealed when looking into the respondent breakdowns. Where parents are very much in line with the overall data, the adult and children data show a considerable amount of divergence. Sixty four percent (n=83) of children reported that there were enough doctors and nurses to care for them all or almost all of their time on the ward. In comparison, only 33% (n=60) of adults and 46% (n=55) of parents felt the same way.

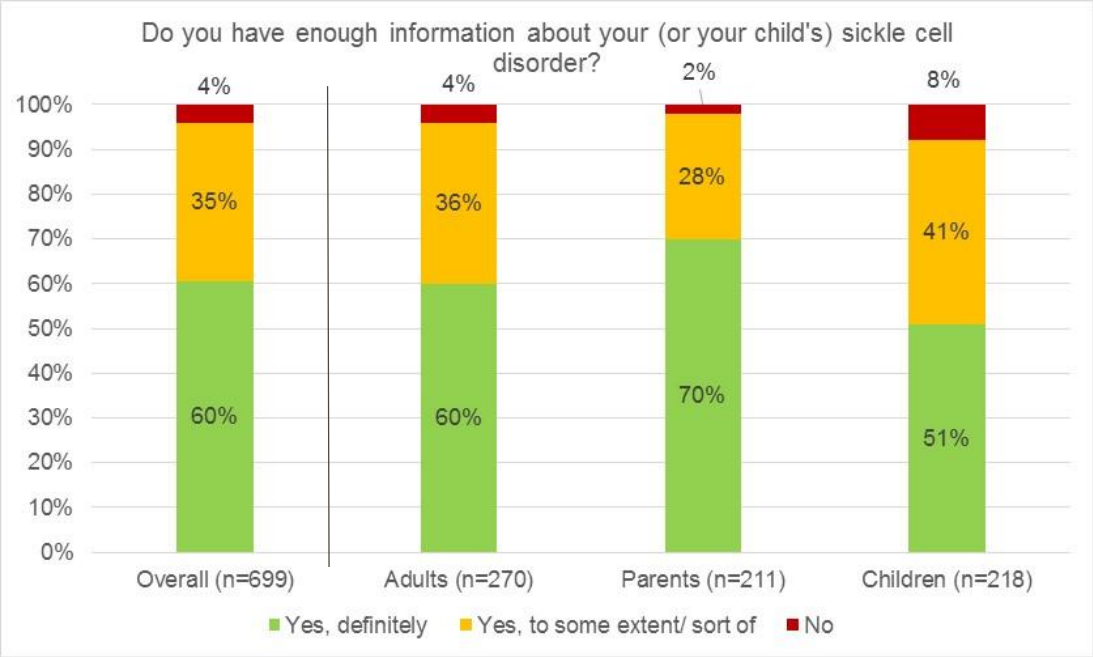
Graph 21: Q21 (T). Were there enough doctors and nurses to look after you (or your child) on the hospital ward? Data presented by survey type.



Information

When respondents were asked about the amount of information they have for their (or their child's) sickle cell condition, 60% (n=421) felt that they definitely had enough, with another 35% (n=247) agreeing to some extent. Whilst adults are consistent with the overall data for this question, parents and children differ slightly. Seventy percent (n=147) of parents agreed that they have enough information about their child's condition, whereas only 51% (n=111) of children were in accord.

Graph 22: Q22 (T). Do you have enough information about your (or your child's) sickle cell disorder? Data presented by survey type.

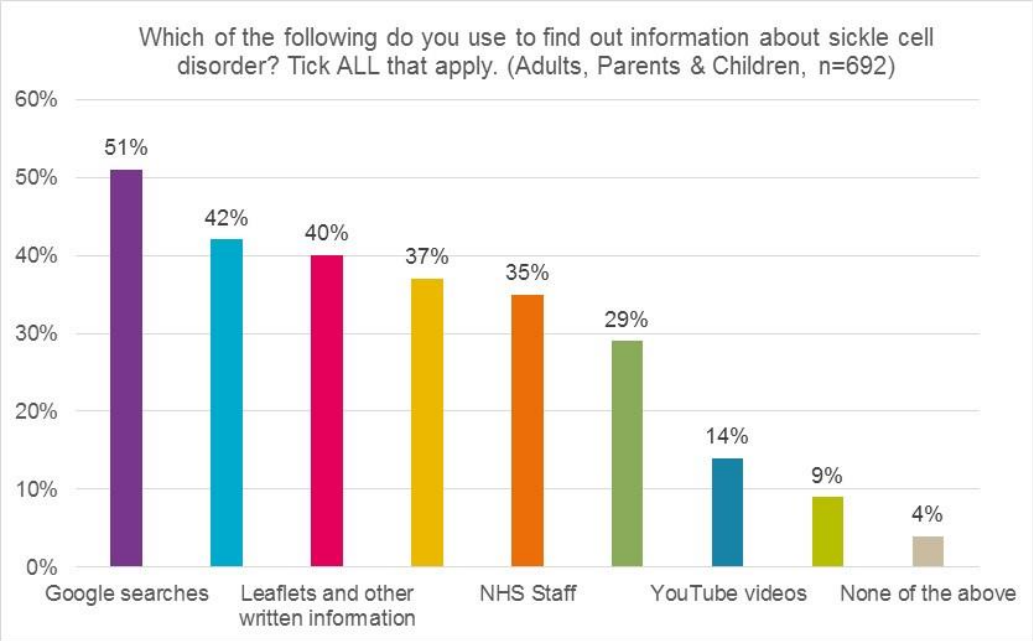


"At every clinic we get information and are allowed to be part of the care which is really good"

"Local Hospital has a lot of information, even a display on wall of kids ward."

The most common methods of gaining more information about sickle cell were Google searches (51%, n=355), using the NHS or sickle cell centre websites (42%, n=288) and by reading leaflets and other written information (40%, n=277).

Graph 23: Q23 (T). Which of the following do you use to find out information about sickle cell disorder?



A breakdown of methods of accessing information about sickle cell by respondent type is displayed in the table below. For adults, the most popular method was Google searches. Although this was also true for parents, they also access information via NHS or sickle cell websites, and leaflets/other written documents. In contrast, children prefer to ask friends, family and NHS staff for relevant information about their condition.

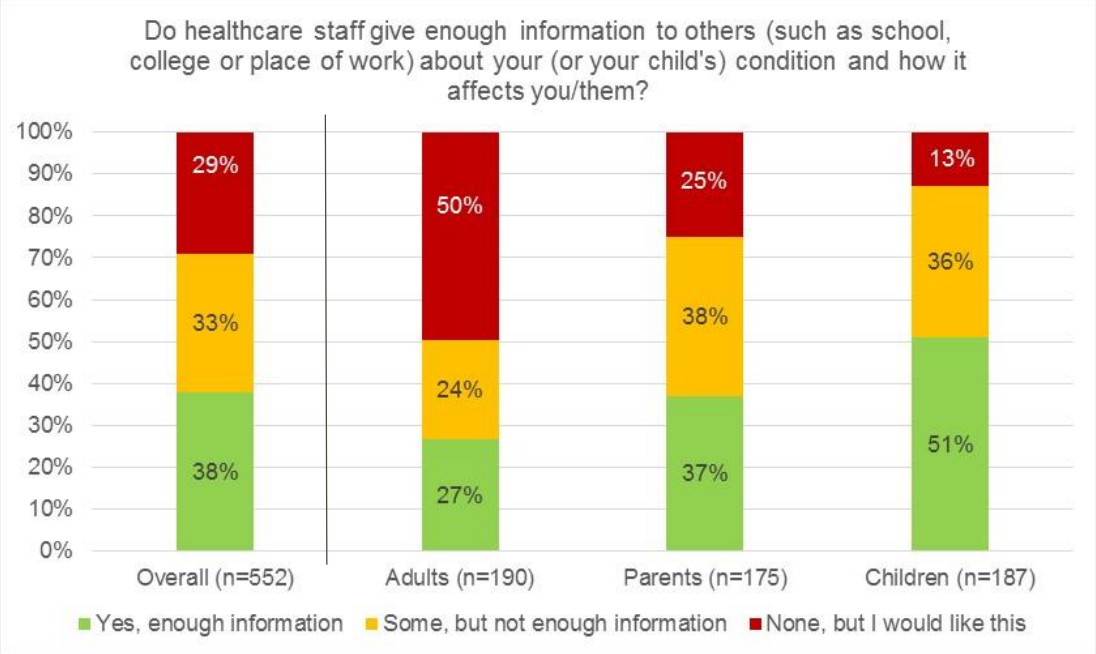
Table 2 Which of the following do you use to find out information about sickle cell disorder?

	Overall (n=692)	Adults (n=269)	Parents (n=207)	Children (n=216)
NHS or sickle cell centre website	42% (n=288)	41% (n=111)	52% (n=107)	32% (n=70)
Sickle Cell Society	37% (n=259)	42% (n=112)	44% (n=90)	26% (n=57)
Leaflets and other written information	40% (n=277)	34% (n=92)	49% (n=102)	38% (n=83)
NHS Staff	35% (n=240)	31% (n=84)	32% (n=66)	42% (n=90)
Google searches	51% (n=355	64% (n=171)	53% (n=110)	34% (n=74)
YouTube videos	14% (n=98)	18% (n=48)	11% (n=23)	13% (n=27)
Ask friends and family	29% (n=200)	25% (n=66)	21% (n=44)	42% (n=90)
Other	9% (n=64)	8% (n=21)	9% (n=18)	12% (n=25)
None of the above	4% (n=28)	5% (n=14)	2% (n=5)	4% (n=9)

Respondents were asked about the extent to which others knew enough about sickle cell disease, since this came across as very important to patients in the focus groups. Overall, just over a third (38%, n=211) agreed that healthcare staff give enough information to others (such as their school or workplace) about their (or their child's) condition and how it affects them, a further 33% (n=180) felt they give others some, but not enough information and 29% (n=161) felt that staff do not give others any information but would like this.

Respondent breakdowns reveal that fewer adults (27%, n=51) than children (51%, n=95) felt that staff give enough information to others. Furthermore, a larger proportion of adults (50%, n=94) than parents (25%, n=43) and children (13%, n=24) reported that staff give no information at all to others, but would like this.

Graph 24: Q24 (T). Do healthcare staff give enough information to others (such as school, college or place of work) about your (or your child's) condition and how it affects you/them? Data presented by survey type.



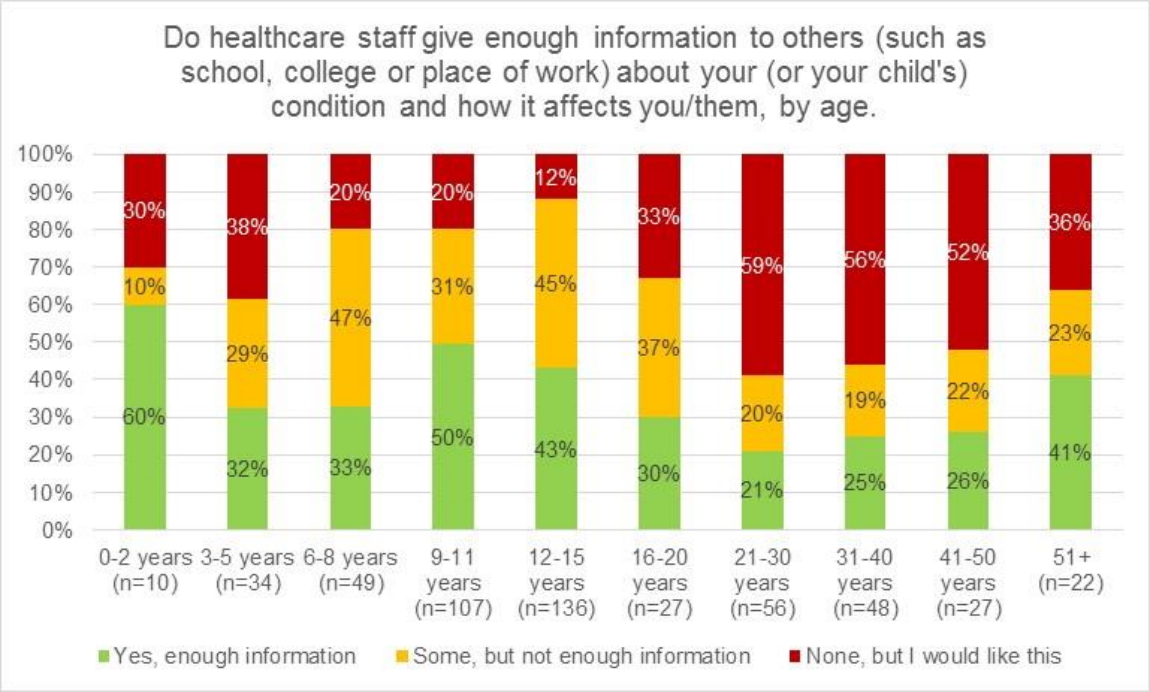
One free text response reveals that they have a keyworker at school, but unfortunately, the results suggest this isn't a common arrangement.

"I can go to my keyworker in school if I feel sick during a lesson instead of going to the school nurses. She hardly knows anything about sickle cell"

"[Could anything be better?] School having more information on sickle cell as they have no info or understand what to do in event of a crisis."

Exploring further by age, the age ranges of patients who reported with the highest frequency that staff give no information to others were those aged 21-30 (59%, n=33), 31-40 (56%, n=27) and 41-50 (52%, n=14) years old.

Graph 25: Q24 (T). Do healthcare staff give enough information to others (such as school, college or place of work) about your (or your child's) condition and how it affects you/them? Data presented by age.



Free text comments also suggest that there could be more information available to others in the community, so that the general public have a better understanding of how to help those living with sickle cell, should a crisis occur.

"I feel that there is not enough information about sickle cell in the community which in dangers those who suffer with the condition. Throughout my son going to school I have constantly had to have meeting with staff to explain his condition and what he needs to reduce the likelihood of him having a crisis."

"There needs to be more awareness in society on a whole about the condition and how to help those who suffer as it can be life threatening."

"[It would be good to have] better communication between boroughs i.e. we live and attend school in a different borough from the hospital we attend for care"

However, some comments show that their child's specialist would actively help to overcome any problems they experience with their child's school.

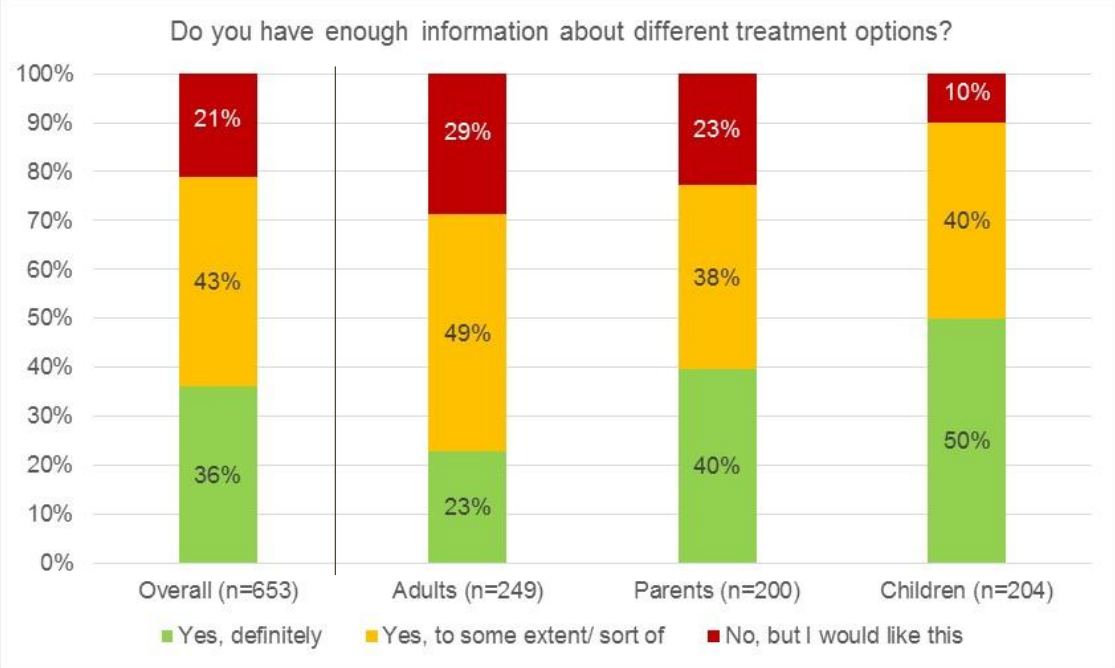
"If I have a problem with the school my child's specialist doctor will be an advocate for me in helping to voice any concerns that I have."

Managing Sickle Cell

Just over a third (36%, n=237) of all respondents definitely agreed that they had enough information about their treatment options, a further 43% (n=279) felt that they to some extent had enough information. One fifth (21%, n=137) do not have enough information about treatment options.

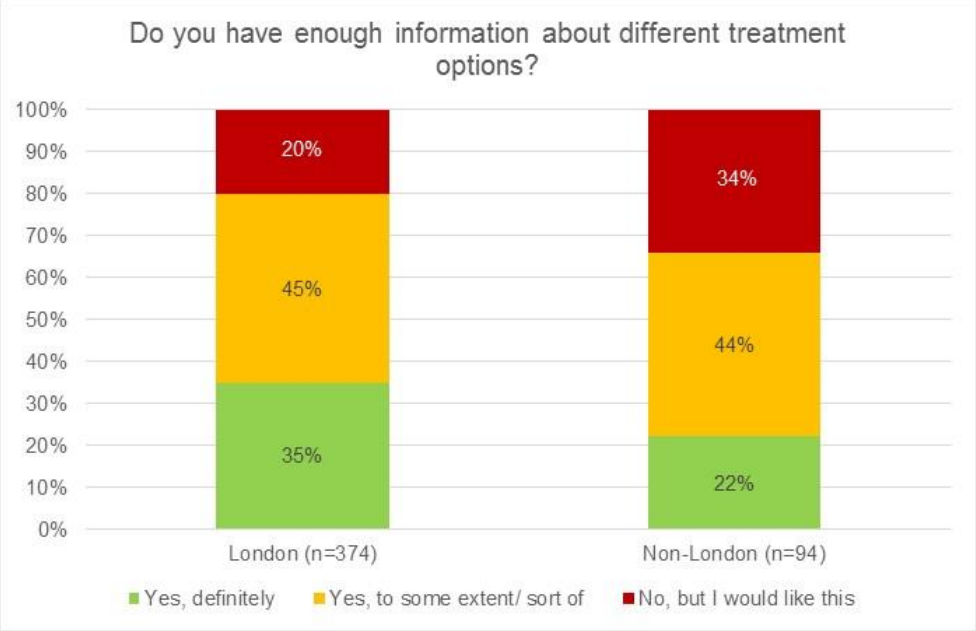
Respondent breakdowns reveal differences between adults, parents and children for those who definitely have enough information. Adults agree the least, with just 23% (n=56) agreeing that they have enough information, in comparison to parents (40%, n=79) and children (50%, n=102).

Graph 26: Q25 (T). Do you have enough information about different treatment options? Data presented by survey type.



Further breakdown by region indicates that a larger proportion of those living outside of London (34%, n= 32) responded that they do not have enough information about treatment options relative to London-based respondents (20%, n=76).

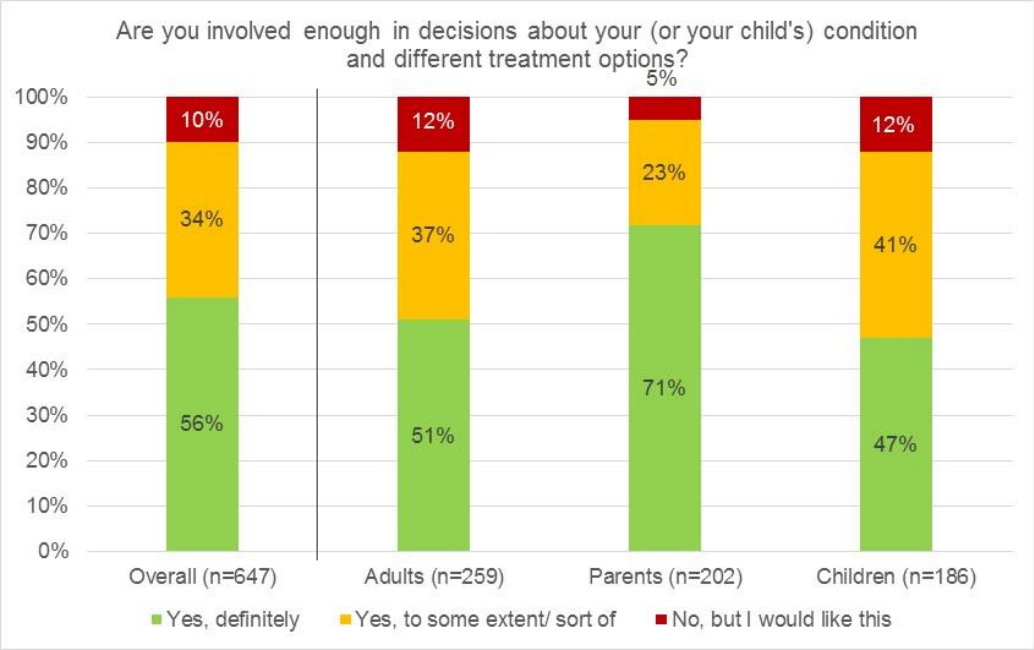
Graph 27: Q25 (T). Do you have enough information about different treatment options? Data presented by region.



Being involved in decisions about care and treatment is an important element of person-centred care. The graph below shows that just over half of all respondents (56%, n=364) definitely feel involved enough in decisions about their (or their child's) condition and their different treatment options, with a further 34% (n=219) answering that they are to some extent involved. Only 10% (n=64) reported that they are not involved enough but would like to be.

In these survey results, parents were more likely to feel involved enough in decisions (71%, n=144) compared with 51% (n=133) of adults and 47% (n=87) of children.

Graph 28: Q26 (T). Are you involved enough in decisions about your (or your child's) condition and different treatment options? Data presented by survey type.

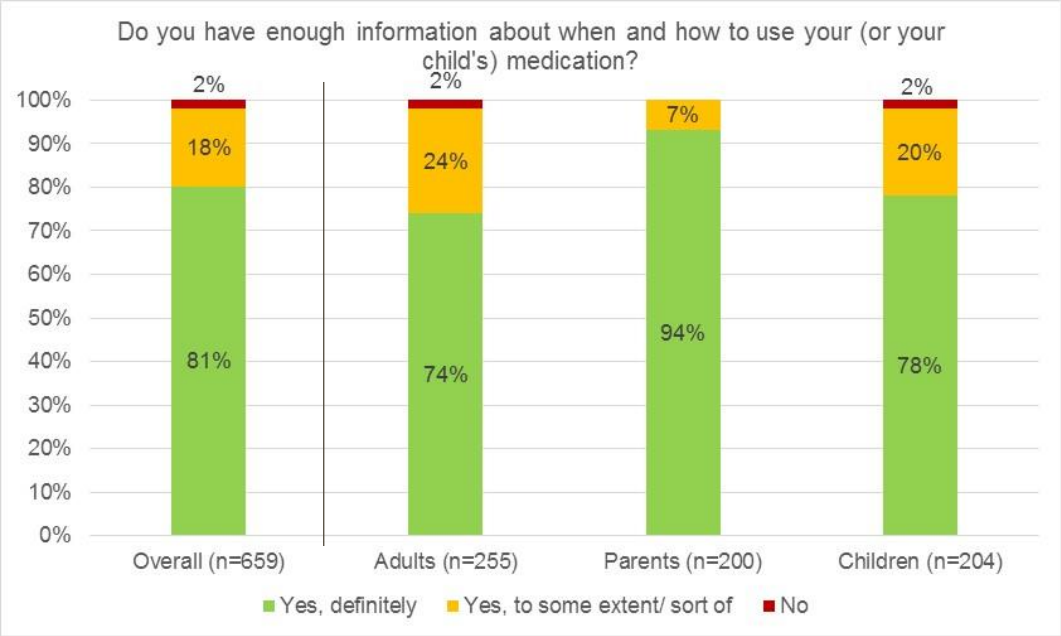


A child respondent shares a desire to be more involved in decisions about their care.

"patients should have more of a say towards their treatment"

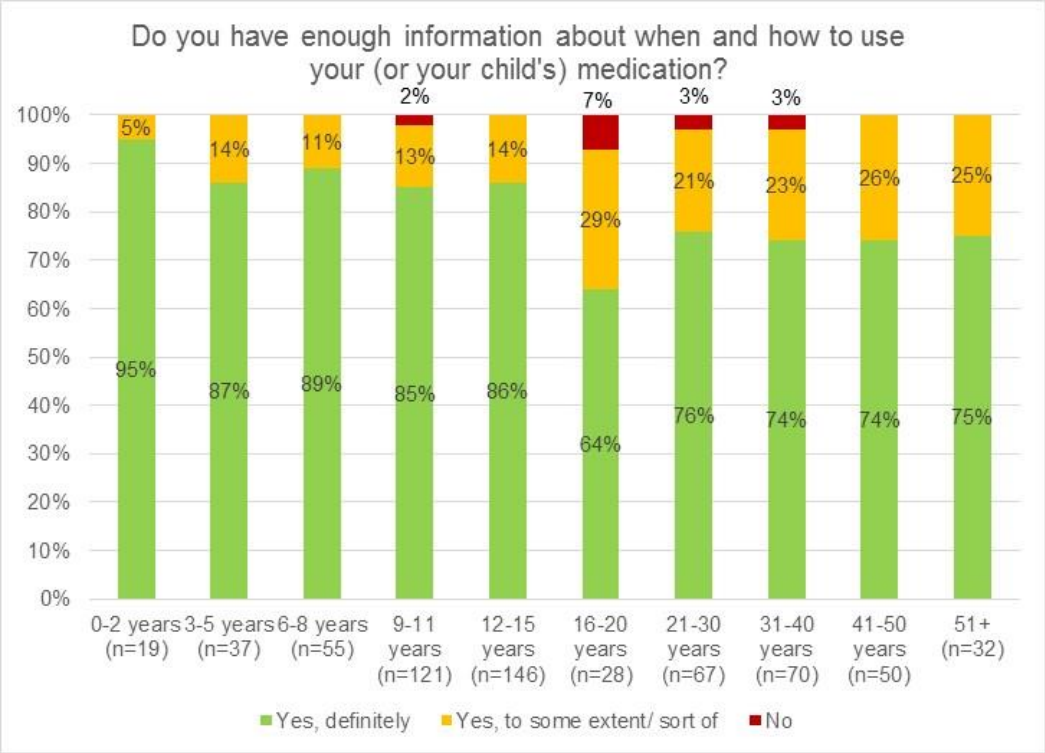
Respondents who use medication were asked whether they have enough information about when and how to use it. The majority were very positive, with 81% (n=534) reporting that they definitely have enough information and a further 18% (n=115) stating 'to some extent'. Just 2% (n=10) did not have enough information. Adult and children data are very much in line with the overall, but parents appear far more positive, with 94% (n=187) definitely having enough information about when and how to use their child's medication.

Graph 29: Q27 (T). Do you have enough information about when and how to use your (or your child's) medication? Data presented by survey type.



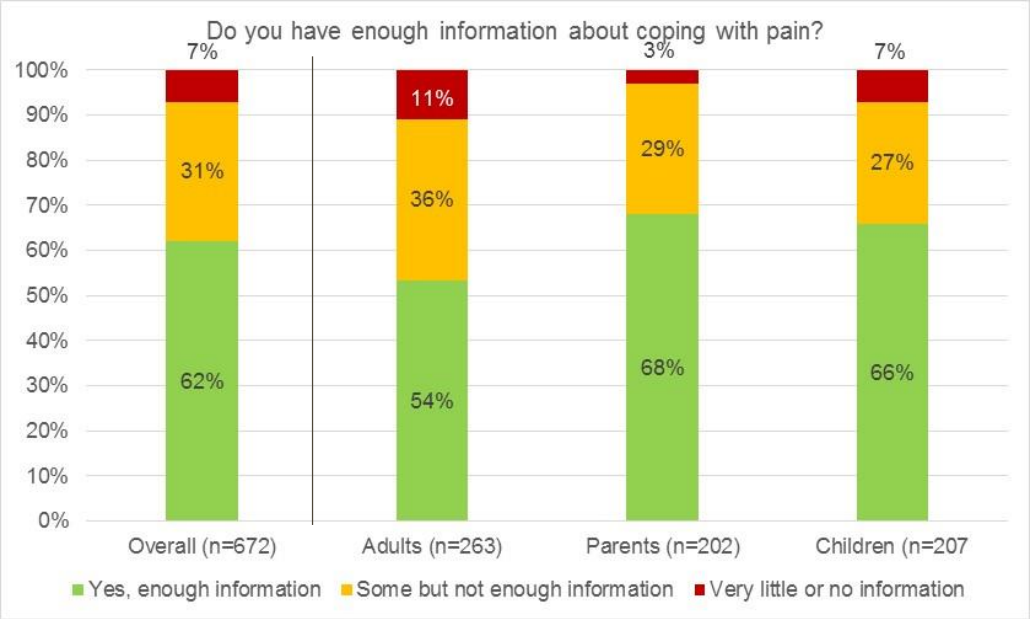
The graph below shows that 16-20 year olds responded more negatively to this question than other age groups, with 64% (n=18) answering that they definitely have enough information about their medication. Under 16 year olds (or their parents) are the most positive. Please see graph 30 for further details.

Graph 30: Q27 (T). Do you have enough information about when and how to use your (or your child's) medication? Data presented by age.



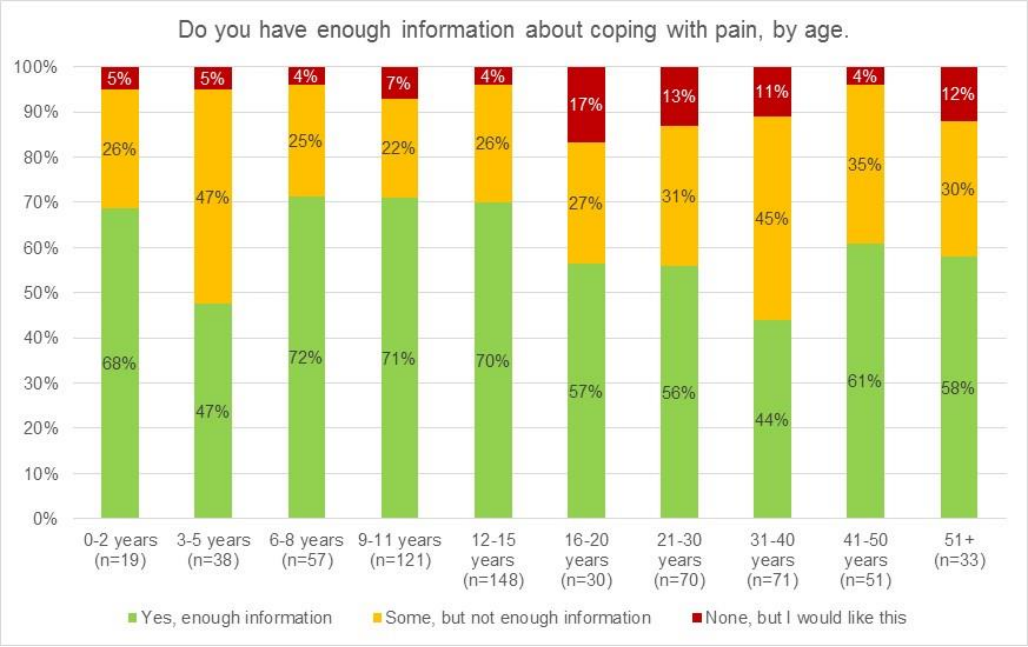
Individuals with sickle cell often experience intense periods of pain. The focus groups revealed that the majority preferred to manage their pain at home and only attend A&E when a crisis occurs and becomes unmanageable, so it is important to provide information about coping with this pain themselves. Respondents were therefore asked whether they have enough information about coping with the pain and this revealed that 62% (n=415) had enough information, 31% (n=208) had some, but not enough and just 7% (n=49) had very little or no information about coping with pain. A slightly higher proportion of adults felt they didn't have enough information about pain self-management relative to children and parents – please refer to the graph below for full details.

Graph 31: Q28 (T). Do you have enough information about coping with pain? Data presented by survey type.



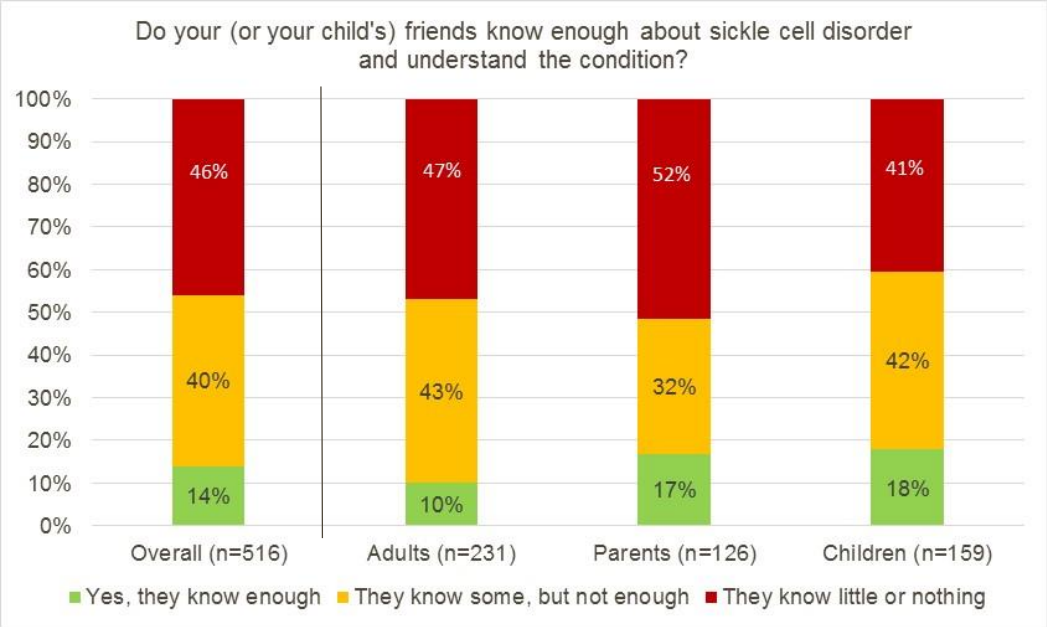
Age breakdown revealed that 16-20 year olds report more often than any other age group, that they have no information about coping with pain (17%, n=5).

Graph 32: Q28 (T). Do you have enough information about coping with pain? Data presented by age.



As well as providing information to others (such as schools, colleges or places of work), it is also important to people living with sickle cell that their friends are educated about the condition, in order for them to have a clear understanding about what it is and how sufferers are affected. This was explored in the survey, and it was demonstrated that a large proportion respondents' friends' do not know enough or understand the condition. Overall, 46% (n=238) reported that their friends knew little or nothing about sickle cell. A further 40% (n=205) stated that they knew some things about sickle cell but still not enough. Only 14% (n=73) reported that their friends knew enough about the condition. This was fairly similar across all respondent types. Please see the graph below for further information.

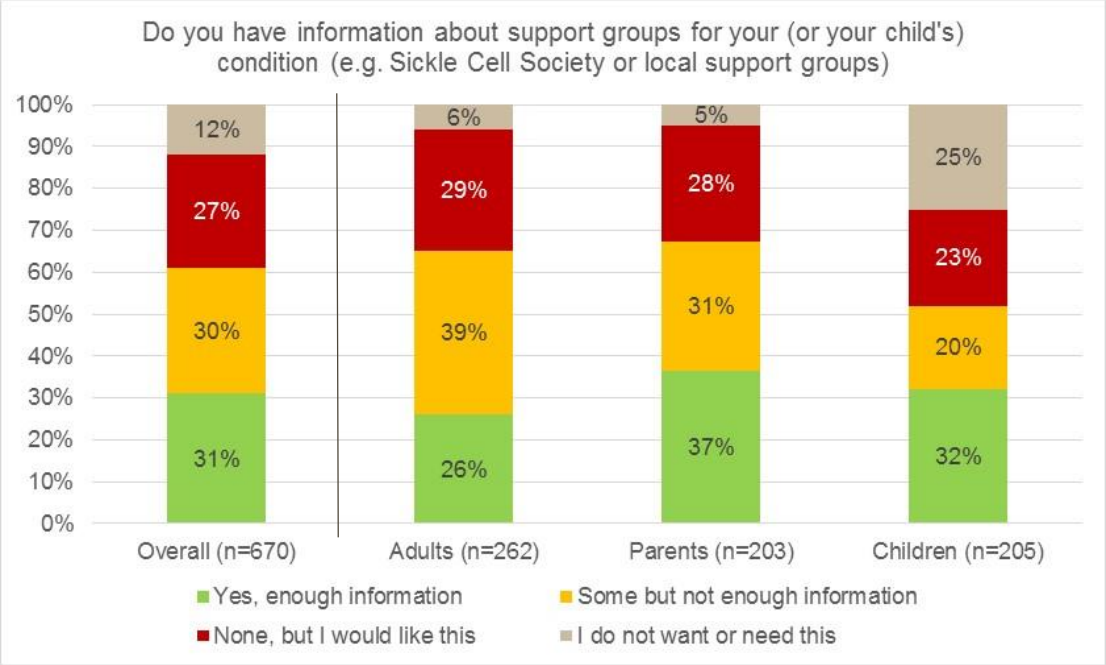
Graph 33: Q29 (T). Do your (or your child's) friends know enough about sickle cell disorder? Data presented by survey type.



Support

Focus groups revealed that access to support groups are helpful to people living with sickle cell, offering opportunities to converse with others in the same situation as themselves. Overall, when respondents were asked whether they had enough information about support groups to attend, 31% (n=207) definitely had enough information. A further 30% (n=204) reported that they have some, but not enough and 27% (n=180) stated that they had no information about support groups, but would like this. Twelve percent (n=79) reported that they do not want or need this. Breakdown by respondent type reveals that children are more likely to report that they do not want or need this information about support groups (25%, n=52) than adults (6%, n=16) and parents (5%, n=11).

Graph 34: Q30 (T). Do you have information about support groups for your (or your child's) condition? Data presented by survey type.

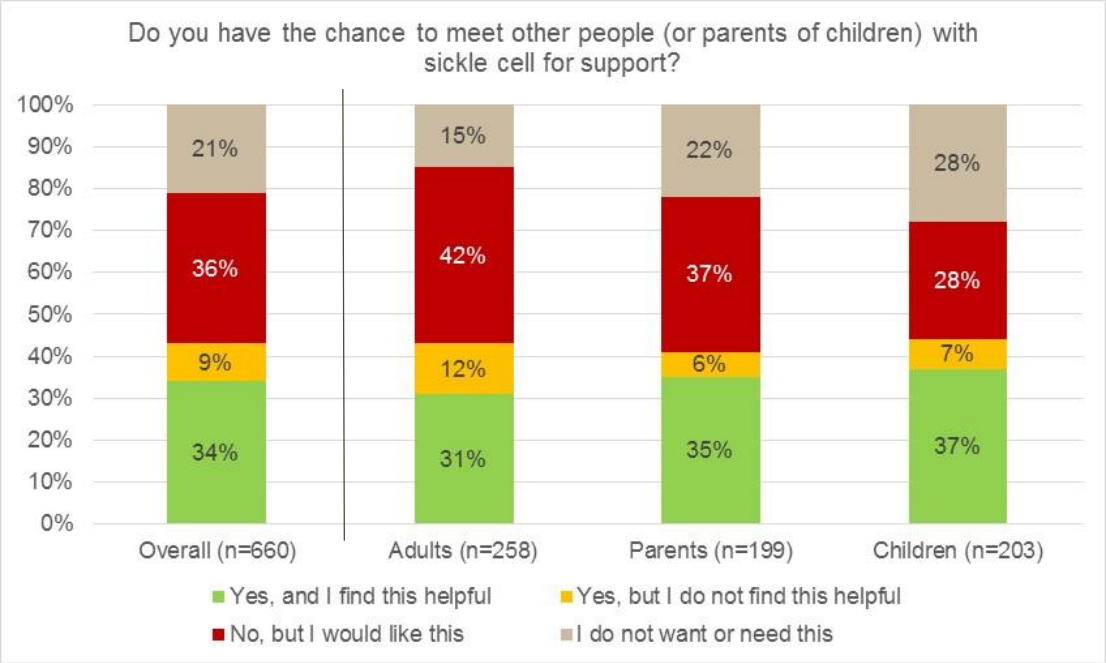


Support groups were mentioned by respondents in the survey, suggesting a need for making these more accessible to those living with sickle cell.

"I need more information- groups"

Similarly, just meeting others with sickle cell for support can also be beneficial to people living with sickle cell. Approximately one third (34%, n=227) of the respondents do have the chance to meet other people (or other parents of children) living with sickle cell and report that this is helpful. Just 9% (n=57) have the chance to meet others with sickle cell, but do not find it helpful. A further 36% (n=238) have not had the opportunity to meet others but would like this and 21% (n=138) do not want or need this. There is very slight variation when looking at the breakdown by respondent type. Please see graph 35 for further information.

Graph 35: Q31 (T). Do you have the chance to meet other people (or parents of children) with sickle cell for support? Data presented by survey type.

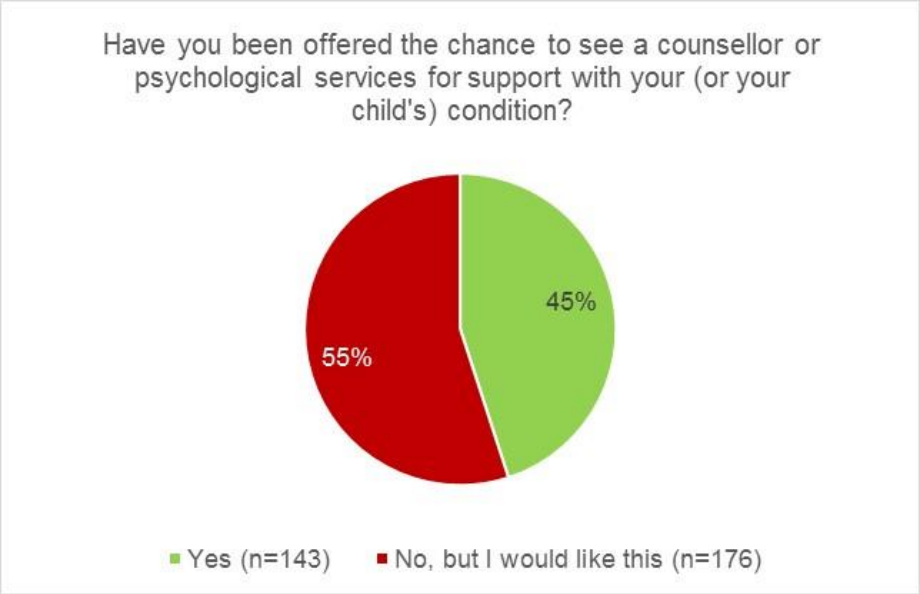


Some parents commented on the lack of support they receive as a carer, which could suggest that this maybe gets overlooked.

"As a carer I don't have a life, all my schedules are influenced by his health. You have to miss your work or your studies to be with him. But we don't receive the financial support to help us deal with the situation."

Adults and parents were also asked whether they have been offered the chance to see a counsellor or psychological services for support with their (or their child's) sickle cell condition. Over half (55%, n=176) had not been offered this service but would like to receive it, whereas 45% (n=143) had been offered this support.

Graph 36: Q32 (P&A). Have you been offered the chance to see a counsellor or psychological services for support with your (or your child's) condition?

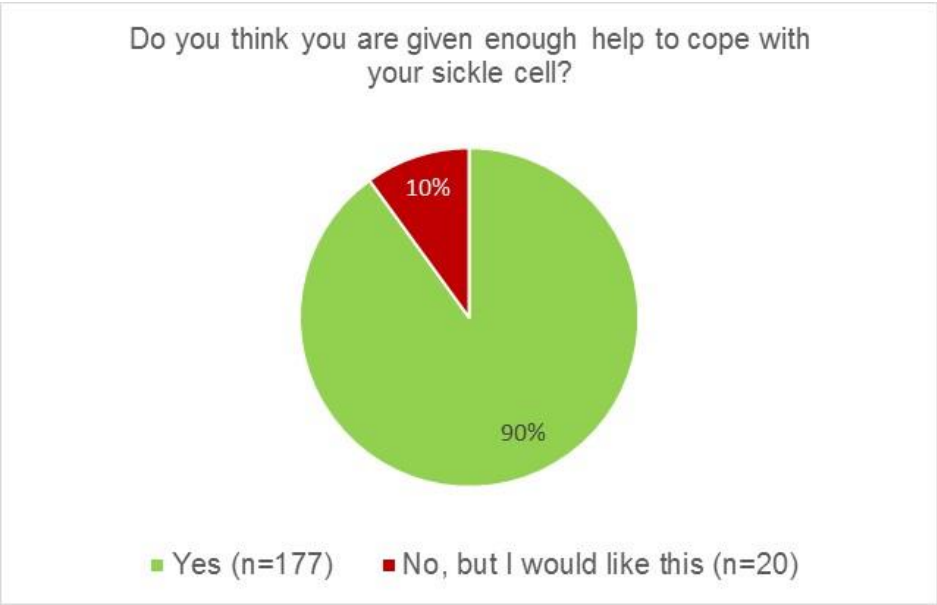


Emotional and physical support needs were also highlighted in the free text comments.

"It would be better if there was support with issues that relate to sickle cell but affect her emotional and physical development"

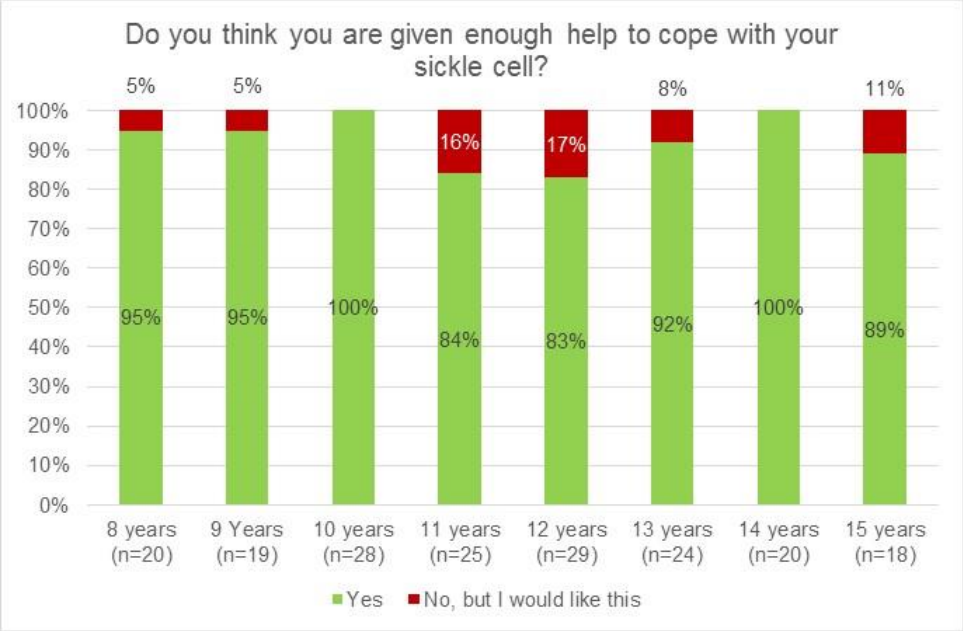
Children were asked whether they thought they were given enough help to cope with their sickle cell. Ninety percent (n=177) agreed that they did and just 10% (n=20) thought the help they are given to cope with their sickle cell is insufficient and would like more support.

Graph 37: Q33 (C). Do you think you are given enough help to cope with your sickle cell?



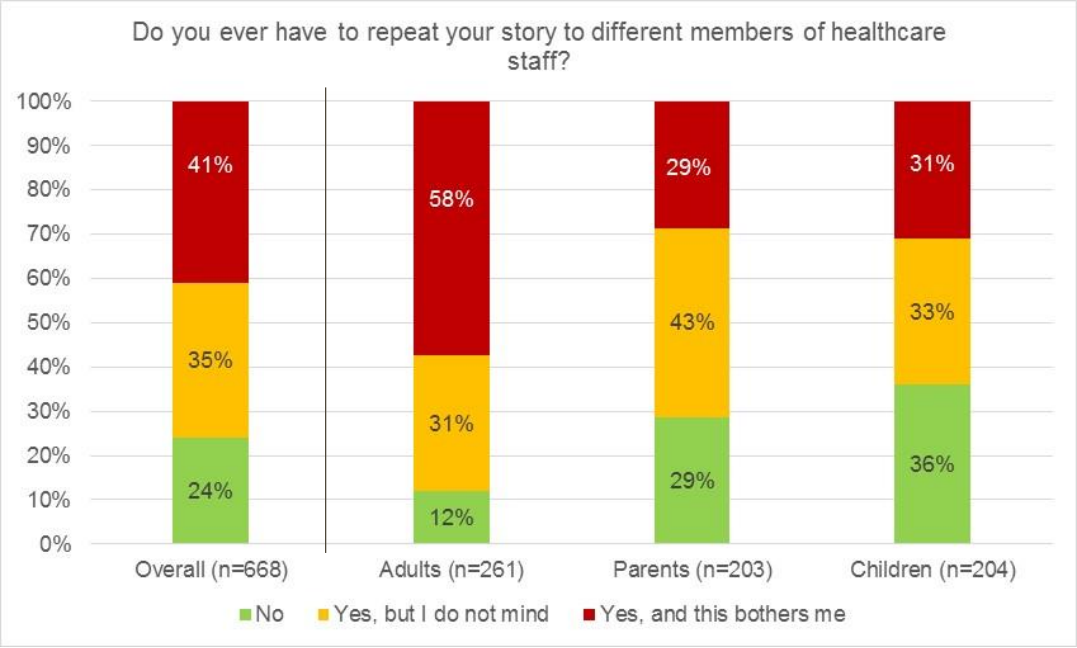
Age breakdowns show that it is fairly even across all ages for those agreeing that they are given enough help to cope with their sickle cell, however, 11 and 12 year olds were more likely than other ages to report that they are not given enough help, but would like this (16%, n=4 and 17%, n=5 respectively).

Graph 38: Q33 (C). Do you think you are given enough help to cope with your sickle cell? Data presented by age.



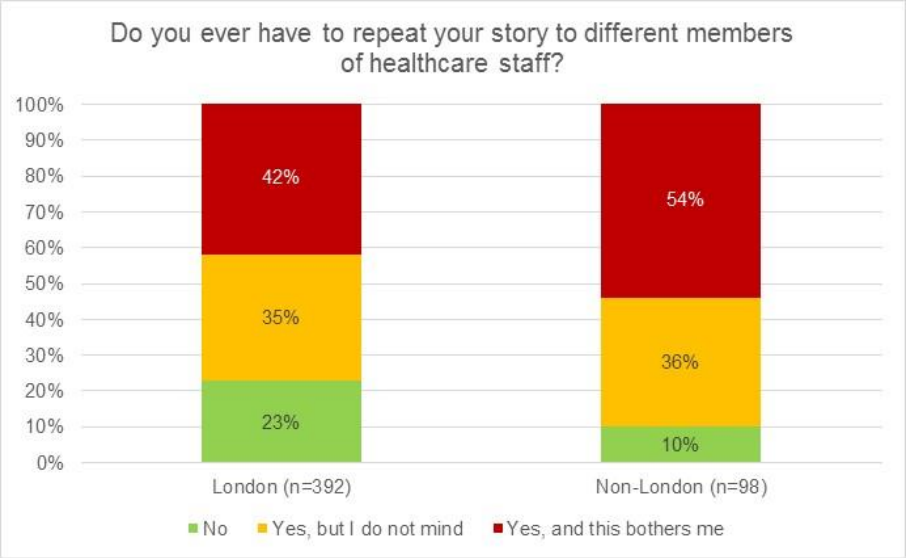
Further discussions in the focus groups revealed that often it is difficult for people living with sickle cell to see the same healthcare professional about their condition. In the survey, just under a quarter (24%, n=162) did not have to repeat their story to multiple staff members, but 76% (n=506) did. Forty one percent (n=271) of the respondents were bothered by having to repeat themselves to different members of healthcare staff. Breakdowns by respondent type are displayed in the graph below and demonstrate that adults were more likely to report being bothered by this (58%, n=150) than parents (29%, n=58) or children (31%, n=63).

Graph 39: Q34 (T). Do you ever have to repeat your story to different members of healthcare staff? Data presented by survey type.



When exploring breakdowns by region, a higher proportion of those living outside of London report having to repeat their story to different members of healthcare staff and that this bothers them (54%, n=53) compared to those living in London (42%, n=165).

Graph 40: Q34 (T). Do you ever have to repeat your story to different members of healthcare staff? Data presented by region.



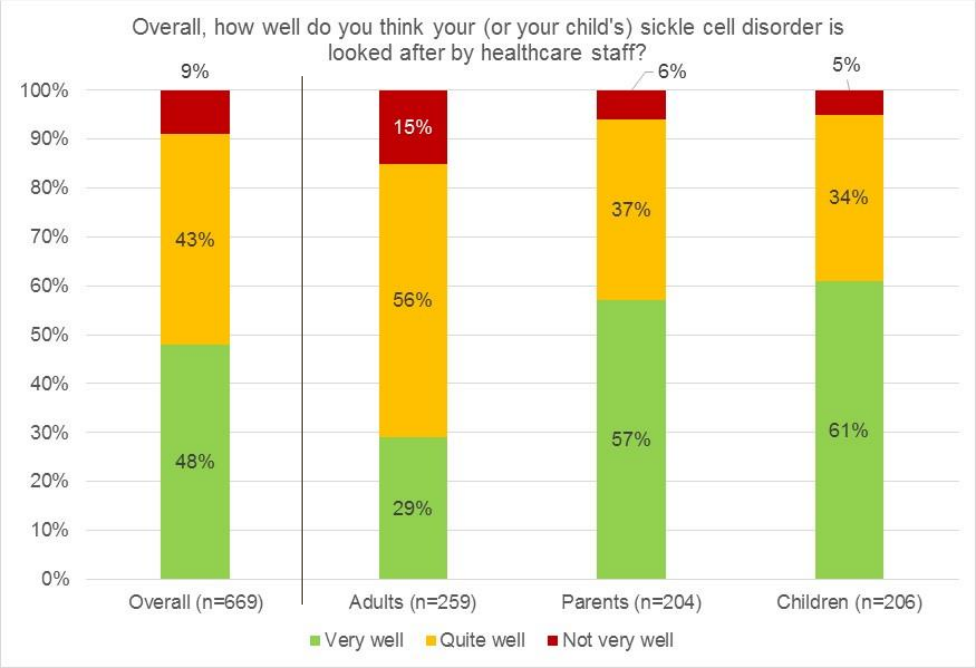
Some comments were made about having consistency with the healthcare staff that they see. This could, in turn, reduce the repetitive explanations and stories that patients have to give each time they attend a healthcare setting for their sickle cell, however it is not always possible, particularly with urgent/non-planned care.

"We need the same consultant every time we attend clinic."

Overall

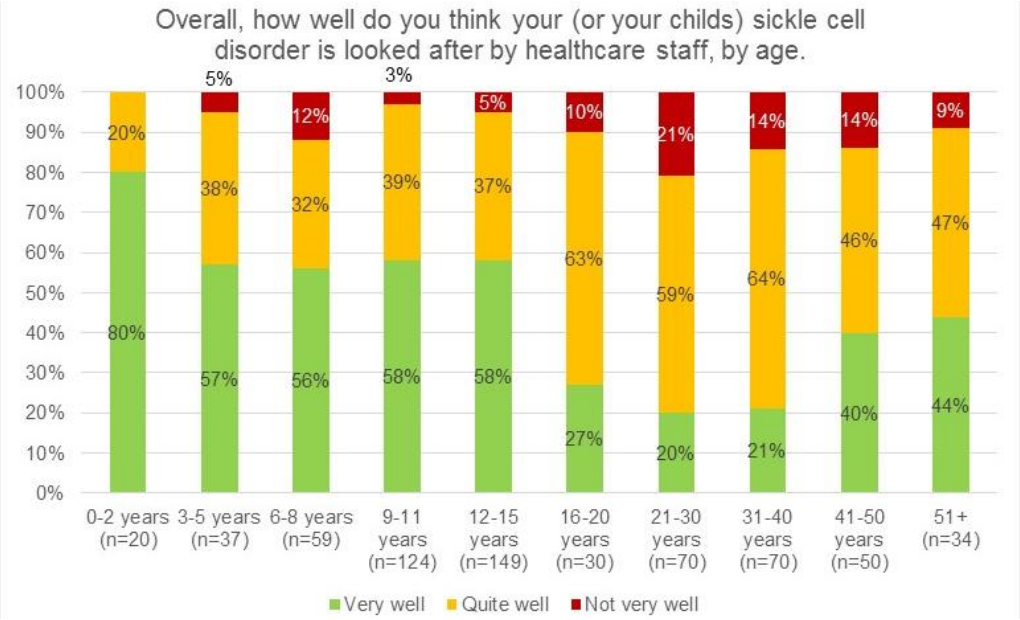
Respondents were asked how they felt their (or their child's) sickle cell condition is looked after by healthcare staff overall. The majority (91%, n=609) indicated that it is looked after very well or quite well. However, 9% (n=60) felt their condition is not looked after very well. The graph below indicates that children and parents were more likely (61%, n=126; 57%, n=117 respectively) than adults (29%, n=76) to agree that their condition is looked after very well. Adults responded most negatively about how their sickle cell is treated by healthcare staff, with 15% (n=38) reporting that this is not done very well.

Graph 41: Q35 (T). Overall, how well do you think your (or your child's) sickle cell disorder is looked after by healthcare staff? Data presented by survey type.



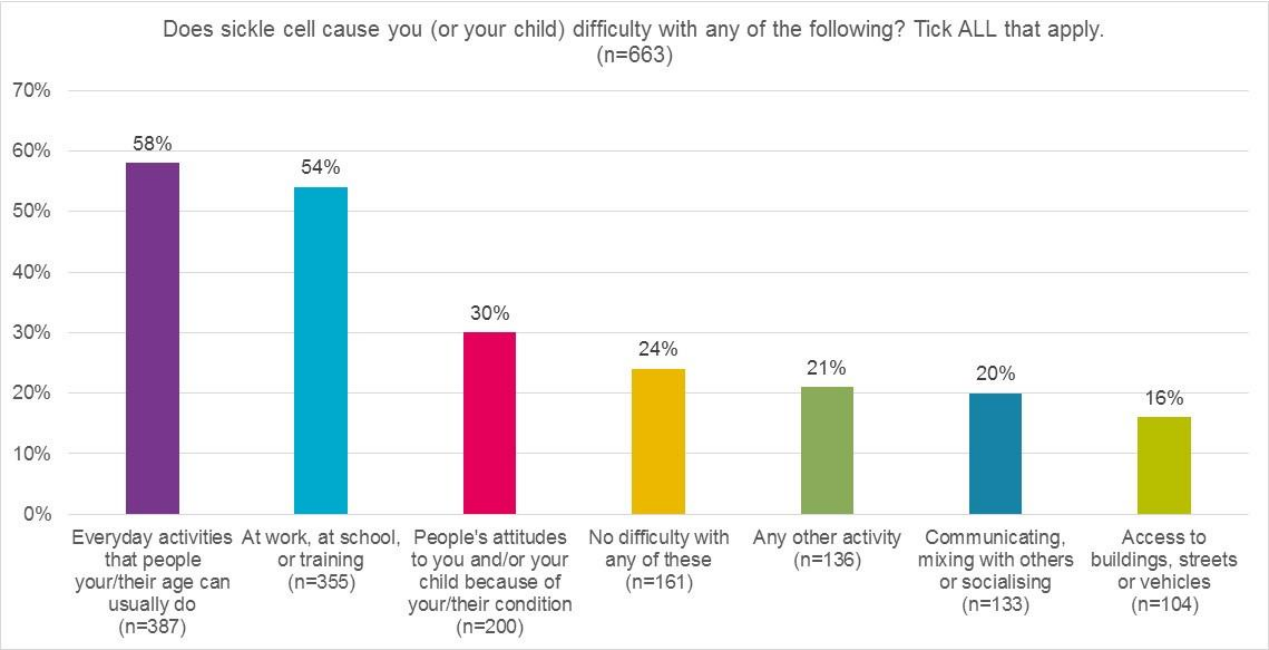
Breakdowns by age reveal some interesting differences. Young adults were most negative about overall sickle cell care, with just one fifth of 21-30 year olds (20%, n=14) and 31-40 years olds (21%, n=15) reporting that their condition was looked after by healthcare staff 'very well'. Slightly more than a quarter (27%, n=8) of 16-20 year olds report the same. Parents of children aged 0-2 years old were most positive, with 80% (n=16) responding 'very well' and a further 20% (n=4) reporting 'quite well'. Please refer to the below graph for full breakdowns.

Graph 42: Q35 (T). Overall, how well do you think your (or your child's) sickle cell disorder is looked after by healthcare staff? Data presented by age.



Living with sickle cell affects many aspects of an individual's daily life. To explore this further, respondents were asked to specify the areas in which they experience difficulties. Respondents were asked to select all options that apply, so the percentages exceed 100%. Over half (58%, n=387) indicated that sickle cell causes them (or their child) difficulties in everyday activities, 54% (n=355) also reported problems with work, school or training. This question also highlights that 30% (n=200) report that other people's attitudes to them (or their child) as a result of their condition causes them difficulties.

Graph 43: Q36 (T). Does sickle cell cause you (or your child) difficulty with any of the following?



Freetext Comments

Further free text comments highlight hopes and wishes for the future regarding sickle cell, the treatment for it and research around it.

"It would be nice if there are more research on sickle cell disorder to enable a cure for it."

"It would be good to have more information about cures being trialled"

"They should make the bone marrow transplant readily available for all children with this condition"

"It would be beneficial to introduce alternative treatment remedies and herbs"

Additionally, supporting the findings of the focus groups, the survey comments revealed that it is important to those living with sickle cell that the wider community gain a greater awareness about the condition. Additionally, further information for young adults and their parents on how to manage their condition themselves as they get older would be beneficial to many.

"More effective information sharing and improvements at community level"

"Information on new treatment and care, and information for parents on how children can be helped as they grow up into adults managing their own treatment"

"More information on what children need to do to help themselves living with this condition, how important it is to eat the right foods etc. How to prevent gall stones etc."

Free text comments also reveal that information and care can be inconsistent between different hospitals, suggesting that some care provider sites are not as informed as others with regards to sickle cell.

"Since my child has changed to a different hospital, the medical explanation and treatments are thoroughly explained and one is informed."

"Better communication and shared knowledge between hospitals and healthcare staff."

"Ever since I moved to the area, I have benefited a lot more and have been able to gain access to better care from people who are more knowledgeable about sickle cell."

Patients were asked to describe in three words how living with sickle cell disorder made them or their child feel. Of the 505 people who answered this question, the most commonly stated words were:

Word	Count
tired	78
sad	72
frustrated	44
different	31
not	31
worried	31
depressed	27
painful	27
stressed	26
anxious	25

The word cloud below, which displays those words most frequently used by respondents as larger than those words less frequently used.

Word cloud 1: Please describe in **three words** how living with sickle cell disorder makes you (and your child) feel. (n=505)

Patients were also asked whether there was anything particularly good about the care they (or their child) received. Of the 409 people who answered this question, the most commonly stated words were:

Word	Count
Care	90
Good	64
Nurses	42
Hospital	41
Staff	39
Doctors	32
Help	29
Always	27
Pain	27
Well	26

The word cloud below, which displays those words most frequently used by respondents as larger than those words less frequently used.

Word cloud 2: Is there anything that is **particularly good** about the care you (your child) receives for your/their sickle cell disorder? (n=409)

Patients were also asked whether there was anything about the care that they (or their child) received that could be better. Of the 396 people who answered this question, the most commonly stated words were:

Word	Count
Care	52
Pain	49
Hospital	49
Time	35
Staff	30
Need	27
Support	27
Information	26
Nurses	23
Better	22

The word cloud below, which displays those words most frequently used by respondents as larger than those words less frequently used.

Word cloud 3: Is there anything about the care you (your child) receives for your/their sickle cell disorder **that could be better**? (n=396)

Conclusion

The pilot demonstrated successful implementation of three new survey tools to measure experiences of sickle cell care across different age groups, and the validation study (supplied as a separate report) demonstrated that each questionnaire functions well as a tool to measure patient experience.

The three surveys indicated that experiences of planned care are generally more positive relative to emergency care episodes. This is in relation to perceptions of how knowledgeable the staff are and the sympathy and understanding that they show. Survey respondents perceived healthcare staff in planned care settings (in particular, hospital outpatient or clinic appointments and day unit hospital admission) to have a much better understanding of sickle cell relative to urgent care staff, which could explain why patients report a better experience in these settings. Adults are less confident in the knowledge of emergency care staff than parents and children, as are Londoners relative to non-London residents.

For the majority of children and parents of children with sickle cell who received urgent care in the last six months, A&E was the route that they first took, whereas the majority of adults treated their pain and discomfort at home without contacting anyone. The most common reasons for choosing these options were 'because it was an emergency' and because they 'thought it would be quicker'. This could also suggest that adults have a better understanding of their condition, than children or parents of children living with sickle cell, therefore are more capable of treating or dealing with the pain themselves. If this is the case, this highlights the importance of providing individuals (in particular parents and children) with enough information about coping with pain, which may improve their ability to self-manage and in turn reduce their attendance at A&E.

Less than half of adults who have stayed on a hospital ward in the last year felt that the ward was age-appropriate. Additionally, just one third felt there were enough nurses and doctors to look after them. Children seem more positive about staffing levels, but just under half of the parents felt there were enough nurses and doctors to care for their child all or most of the time.

Sixteen to twenty year olds were less likely to report having enough information on coping with pain than any other age group. Patients of this age are often transferring out of paediatric care to adult services, and adopting a more independent lifestyle (e.g. leaving school and moving out of home). To reduce the likeliness of them using urgent care services such as A&E, it is particularly important that enough accessible information is provided to teenagers directly, rather than to their parents, to enable the young person to self-manage their condition effectively.

The majority of respondents felt that they had enough information about sickle cell disorder, however, children are less likely to report having enough information about their condition compared to parents and adults. This suggests a need to provide children with more information, and perhaps an assessment of how accessible information is to younger patients, to ensure they have a clear understanding of their condition.

The majority of respondents indicated that healthcare staff could be giving more information to others (schools, colleges and places of work) to promote a better understanding of sickle cell across society. Providing information to or educating schools, colleges and workplaces

on the symptoms of the condition and how these affect people living with sickle cell disease could therefore be quite beneficial to those living with the condition, as well as peers or colleagues. Furthermore many respondents felt that their friends do not know or understand enough about the condition, so could be educated further. Therefore, it could be useful to consider providing information for patients to give to others, ensuring an easy read version is also available to make it accessible to all, so friends, family and colleagues can gain a better understanding of the condition.

Regarding the management of sickle cell, less than half of all respondents definitely had enough information about the different treatment options available to them. This could have an impact on how involved they are in their decisions about their (or their child's) sickle cell treatment options, since further understanding of the options available would ensure that the patient could make a more informed contribution or decision on his or her care. Overall, just over half of all respondents felt that they were definitely involved, but children and adults felt less involved in decisions about their condition and treatment than parents.

Whilst the majority of respondents had enough information about medication, information on pain management demonstrated some room for improvement with only three fifths of respondents having enough information on coping with pain. This is an important issue to address, as coping strategies could lead to fewer A&E admissions. It seems that this would be most beneficial for adults.

The survey results revealed a gap in the amount of support available for sickle cell sufferers, with only around one third of respondents reporting that they have (i) enough information about support groups, and (ii) the opportunity to meet others with sickle cell in a less formal setting. Therefore, support networks for those living with sickle cell could be improved. The majority of adults and parents would like this support, which suggests that it would be a well-received provision for these groups.

Whilst the majority of the children felt they are given enough help to cope with their condition, half of the adult and parent respondents felt that a counsellor or psychological services would be beneficial to them or their child. Regional breakdown also suggests that psychological/counselling services are offered less often to those living outside of London compared to London residents.

Overall, children seem to be more positive about their care and treatment for their sickle cell, while adults are less so. The results also suggest that those living with sickle cell in London are more satisfied than non-London residents with their sickle cell care – this may be a result of more sickle cell specialist care being available in London as a result of the higher sickle cell prevalence.

The development of this tool has enabled a detailed insight into the service users' experience of their sickle cell healthcare, which is extremely valuable in highlighting key areas for improvement.

Problem Scores

Picker Institute Europe calculate problem scores to assist with action planning. Problem scores are summary scores that are calculated for each performance-related question to indicate where there is room for improvement in delivering care to people living with sickle cell disease.

Problem scores are a helpful way of targeting areas in need of attention– this in turn can help bring about real quality improvement for patients. The problem score shows the percentage of patients for each question who, by their response, indicated that a particular aspect of their care could have been improved.

We calculate the problem scores by combining the response categories. For example, for the following question 'Were healthcare staff sympathetic and understanding?' we have combined the responses 'Yes, to some extent' and 'No', to create a single problem score. Asterisks on the frequency tables indicate which response categories have been combined to create the problem score.

EXAMPLE DATA ONLY:

The below example would be interpreted as '19% of respondents did not feel the healthcare staff were fully sympathetic and understanding'.

Q7 (P&A). Were healthcare staff **sympathetic and understanding**?	Frequency	Valid Percent
Yes, definitely	171	80.7
*Yes, to some extent	23	10.8
*No	18	8.5
Total	**212**	**100.0**
Problem Score: 19.3%		

The frequency tables (provided in Appendix 1) indicate how the problem score for each question was calculated. The problem score for each performance-related question is displayed in the below tables.

Problem Scores: Planned Care

	Problem Score (Total)	Problem Score (Adult)	Problem Score (Parent)	Problem Score (Child)
Q3 (T) Healthcare staff did not know enough about sickle cell disorder	24%	32%	23%	12%
Q4 (T) Healthcare staff did not talk to patient in a way they could fully understand	23%	24%	17%	29%
Q5+ (P) Parent felt that healthcare staff did not talk to their child in a way they could fully understand	21%	Parent only question	21%	Parent only question
Q6+ (T) Healthcare staff did not answer questions clearly enough for those who had questions	31%	37%	24%	29%
Q7 (P&A) Healthcare staff were not completely sympathetic and understanding	32%	37%	26%	Parent & adult only question
Q8 (C) Doctors and nurses were not completely friendly and helpful	6%	Child only question	Child only question	6%
Q9+ (C) The child (rather than their family) did not completely have the chance to speak to staff	33%	Child only question	Child only question	33%
Q10+ (P) Child could not choose to have their parent/ carer with them at appointment (for those who were old enough)	10%	Parent only question	10%	Parent only question
Q11+ (C) Child could not choose to have their parent/ carer with them at the appointment and would have liked to	5%	Child only question	Child only question	5%

Problem Scores: Emergency Care

	Problem Score (Total)	Problem Score (Adult)	Problem Score (Parent)	Problem Score (Child)
Q15 (T) Emergency healthcare staff did not know enough about sickle cell disorder	56%	67%	55%	40%
Q16 (P&A) Emergency healthcare staff were not completely sympathetic and understanding	49%	58%	39%	Parent & adult only question
Q17 (C) Emergency healthcare staff were not completely friendly and helpful	11%	Child only question	Child only question	11%
Q18+ (T) Emergency healthcare staff did not help to ease pain quickly enough	62%	71%	58%	53%

Problem Scores: Hospital Ward Care

	Problem Score (Total)	Problem Score (Adult)	Problem Score (Parent)	Problem Score (Child)
Q20 (T) Hospital ward was not completely suitable for patient's age	41%	59%	23%	34%
Q21 (T) There were not always enough doctors and nurses on the hospital ward	54%	67%	55%	36%

Problem Scores: Information

	Problem Score (Total)	Problem Score (Adult)	Problem Score (Parent)	Problem Score (Child)
Q22 (T) Respondent does not have enough information about sickle cell.	40%	40%	30%	49%
Q24+ (T) Healthcare staff do not give enough information to others (such as school, college or place of work) about sickle cell	62%	73%	63%	49%

Managing Sickle Cell

	Problem Score (Total)	Problem Score (Adult)	Problem Score (Parent)	Problem Score (Child)
Q25+ (T) Respondent does not have enough information about different treatment options	64%	78%	61%	50%
Q26+ (T) Respondent is not involved enough in decisions about their (or their child's) condition and treatment	44%	49%	29%	53%
Q27+ (T) Respondent does not have enough information about when and how to use their (or their child's) medication	19%	26%	7%	22%
Q28 (T) Respondent does not have enough information about coping with pain	38%	46%	32%	34%
Q29+ (T) Friends do not know enough about sickle cell disorder or understand the condition	86%	90%	83%	82%

Problem Scores: Support

	Problem Score (Total)	Problem Score (Adult)	Problem Score (Parent)	Problem Score (Child)
Q30+ (T) Respondent does not have enough information about support groups for their (or their child's) condition	65%	72%	62%	58%
Q31+ (T) Respondent does not have the chance to meet other people (or parents of children) with sickle cell for support	57%	63%	55%	48%
Q32+ (P&A) Parent or adult respondents have not been offered the chance to see a counsellor or psychological services	55%	51%	62%	Parent & adult only question
Q33+ (C) Child is not given enough help to cope with their sickle cell	10%	Child only question	Child only question	10%
Q34 (T) Respondent had to repeat their story to different members of healthcare staff	41%	58%	29%	31%
Q35 (T) Overall, respondent does not feel that their (or their child's) sickle cell is looked after 'very well' by healthcare staff	52%	71%	43%	39%

Appendix one

Frequency tables

Planned Care

Q1 (T). Where did you (or your child) last receive planned care for your sickle cell condition? (Answered by all)

		Frequency	Valid Percent
	Overnight stay in hospital (inpatient)	123	17.2
	Day unit in hospital - e.g. for pain relief or blood transfusions	148	20.7
	Hospital outpatient or clinic appointment	385	53.8
	GP / family doctor	38	5.3
	Other	22	3.1
	Total	**716**	**100.0**
Missing	System	6	
Total		722	

Q2 (T). How long ago was this planned care? (Answered by all)

		Frequency	Valid Percent
	Within the last 6 months	582	83.1
	More than 6 months ago	89	12.7
	Can't remember	29	4.1
	Total	**700**	**100.0**
Missing	*System*	22	
Total		722	

Q3 (T). Did the healthcare staff you saw know enough about sickle cell disorder? (Answered by those who had planned care within the last 6 months)

		Frequency	Valid Percent
	Yes, definitely	454	76.4
	*Yes, to some extent/ sort of	118	19.9
	*No	22	3.7
	Total	***594***	***100.0***
Missing	*System*	10	
Total		604	

**Problem score: 23.6%*

Q4 (T). Did healthcare staff talk to you in a way that you could understand? (Answered by those who had planned care within the last 6 months)

		Frequency	Valid Percent
	Yes, definitely	458	76.6
	*Yes, to some extent/ sort of	120	20.1
	*No	20	3.3
	Total	***598***	***100.0***
Missing	*System*	6	
Total		604	

**Problem score: 23.4%*

Q5 (P). Did healthcare staff talk to your child in a way that they could understand? (Answered by all parents)

		Frequency	Valid Percent
	Yes, definitely	131	71.2
	Yes, to some extent	28	15.2
	No	7	3.8
	This was not necessary / they were too young	18	9.8
	Total	***184***	***100.0***
Missing	*System*	3	
Total		187	

Q5 (P)+. Did healthcare staff talk to your child in a way that they could understand? (for those who this was necessary/ child was old enough to understand)

		Frequency	Valid Percent
	Yes, definitely	131	78.9
	*Yes, to some extent	28	16.9
	*No	7	4.2
	Total	***166***	***100.0***
Missing	*System*	3	
Total		169	

**Problem score: 21.1%*

Q6 (T). Did the healthcare staff answer your questions clearly? (Answered by those who had planned care within the last 6 months)

		Frequency	Valid Percent
	I did not have any questions	165	27.8
	I did not have the chance to ask	16	2.7
	Yes, definitely	298	50.2
	Yes, to some extent/ sort of	100	16.8
	No	15	2.5
	Total	***594***	***100.0***
Missing	*System*	10	
Total		604	

Q6 (T)+. Did the healthcare staff answer your questions clearly? (those who had questions to ask) (Answered by those who had planned care within the last 6 months)

		Frequency	Valid Percent
	*I did not have the chance to ask	16	3.7
	Yes, definitely	298	69.5
	*Yes, sort of	100	23.3
	*No	15	3.5
	Total	***429***	***100.0***
Missing	*System*	10	
Total		439	

**Problem score: 30.5%*

Q7 (P&A). Were healthcare staff sympathetic and understanding (Answered by adults and parents of children who had planned care within the last 6 months)

		Frequency	Valid Percent
	Yes, definitely	284	67.9
	*Yes, to some extent	106	25.4
	*No	28	6.7
	Total	***418***	***100.0***
Missing	*System*	5	
Total		423	

**Problem score: 32.1%*

Q8 (C). Were the doctors and nurses friendly and helpful? (Answered by all children who had received planned care within the last 6 months)

		Frequency	Valid Percent
	Yes, completely	168	93.9
	*Yes, sort of	11	6.1
	*No	0	0.0
	Total	***179***	***100.0***
Missing	*System*	2	
Total		181	

**Problem score: 6.1%*

Q9 (C). Did you (rather than your family) have the chance to speak to staff if you needed to? (Answered by all children who had received planned care within the last 6 months)

		Frequency	Valid Percent
	Yes, completely	101	56.4
	Yes, sort of	43	24.0
	No	6	3.4
	I did not need to	29	16.2
	Total	***179***	***100.0***
Missing	*System*	2	
Total		181	

Q9 (C)+. Did you (rather than your family) have the chance to speak to staff if you needed to? (Answered by children who needed to speak to staff)

		Frequency	Valid Percent
	Yes, completely	101	67.3
	*Yes, sort of	43	28.7
	*No	6	4.0
	Total	***150***	***100.0***
Missing	*System*	2	
Total		152	

**Problem score: 32.7%*

Q10 (P). Could your child choose whether to have you (the parent/carer) with them at this appointment? (Answered by all parents who had received planned care for their child within the last 6 months)

		Frequency	Valid Percent
	Yes	85	47.2
	No	9	5.0
	This was not needed / my child is too young	86	47.8
	Total	***180***	***100.0***
Missing	*System*	7	
Total		187	

Q10 (P)+. Could your child choose whether to have you (the parent/carer) with them at this appointment? (Answered by parents who needed this)

		Frequency	Valid Percent
	Yes	85	90.4
	*No	9	9.6
	Total	***94***	***100.0***
Missing	*System*	7	
Total		101	

**Problem score: 9.6%*

Q11 (C). Could you choose to have your parent or carer with you at this appointment? (Answered by all children who had received planned care within the last 6 months)

		Frequency	Valid Percent
	Yes	124	70.1
	No, but I did not mind	47	26.6
	No, but I would have liked this	6	3.4
	Total	***177***	***100.0***
Missing	*System*	4	
Total		181	

Q11 (C)+. Could you choose to have your parent or carer with you at this appointment? (Answered by children who wanted their parent/ carer at the appointment)

		Frequency	Valid Percent
	Yes	124	95.4
	*No, but I would have liked this	6	4.6
	Total	***130***	***100.0***
Missing	*System*	4	
Total		134	

**Problem score: 4.6%*

Emergency Care

Q12 (T). When did you (or your child) last receive urgent or emergency care for your sickle cell condition? (Answered by all)

		Frequency	Valid Percent
	I have never/ my child has never had urgent / emergency care	86	12.1
	Within the last 6 months	294	41.4
	More than 6 months ago	243	34.2
	Can't remember	88	12.4
	Total	***711***	***100.0***
Missing	*System*	11	
Total		722	

Q13 (T). When you (or your child) last had emergency care for their sickle cell disorder, what did you first do for help? (Answered by those who received urgent or emergency care within the last 6 months)

		Frequency	Valid Percent
	Called a specialist sickle cell nurse	39	13.2
	Treated at home without contacting anyone	65	22.0
	Went to a GP	18	6.1
	Went to A&E	111	37.6
	Called 999 for an ambulance	47	15.9
	Other	15	5.1
	Total	***295***	***100.0***
Missing	*System*	10	
Total		305	

Q14 (P&A). Why did you decide to do this first? Tick ALL that apply. (Answered by adults and parents of children who received urgent or emergency care within the last 6 months)

		Frequency	Valid Percent
	I thought it would be quicker	51	30.4
	It was late in the evening/night and the only place that was open	32	19.0
	It was an emergency	87	51.8
	I thought there would be better care	34	20.2
	I did not know what else to do	10	6.0
	Other	16	9.5
Total number of responses		**230**	
Total number of respondents		**168**	
Missing	*System*	9	
Total		177	

Q15 (T). Did the emergency healthcare staff that you saw know enough about sickle cell disorder? (Answered by those who received urgent or emergency care within the last 6 months)

		Frequency	Valid Percent
	Yes, definitely	102	44.5
	*Yes, to some extent/ sort of	92	40.2
	*No	35	15.3
	Total	***229***	***100.0***
Missing	*System*	76	
Total		305	

**Problem score: 55.5%*

Q16 (P&A). Were the emergency healthcare staff sympathetic and understanding? (Answered by adults and parents of children who received urgent or emergency care within the last 6 months)

		Frequency	Valid Percent
	Yes, definitely	85	50.9
	*Yes, to some extent	65	38.9
	*No	17	10.2
	Total	***167***	***100.0***
Missing	*System*	62	
Total		229	

**Problem score: 49.1%*

Q17 (C). Were the emergency healthcare staff friendly and helpful? (Answered by children who received urgent or emergency care within the last 6 months)

		Frequency	Valid Percent
	Yes, completely	54	88.5
	*Yes, sort of	6	9.8
	*No	1	1.6
	Total	***61***	***100.0***
Missing	*System*	15	
Total		76	

**Problem score: 11.4%*

Q18 (T). Did the emergency staff help ease your (or your child's) pain? (Answered by those who received urgent or emergency care within the last 6 months)

		Frequency	Valid Percent
	Yes, quickly enough	84	37.5
	Yes, but it could have been quicker	100	44.6
	No, they did not help ease the pain	35	15.6
	I was not in any pain/ my child was not in any pain	5	2.2
	Total	***224***	***100.0***
Missing	*System*	81	
Total		305	

Q18 (T)+. Did the emergency staff help easy your (or your child's) pain? (those who were in pain/ whose child was in pain) (Answered by those who received urgent or emergency care within the last 6 months)

		Frequency	Valid Percent
	Yes, quickly enough	84	38.4
	*Yes, but it could have been quicker	100	45.7
	*No, they did not help ease the pain	35	16.0
	Total	***219***	***100.0***
Missing	*System*	81	
Total		300	

**Problem score: 61.7%*

Hospital Ward Care

Q19 (T). Within the last year have you (or your child) stayed on a hospital ward either overnight or on a day unit? (e.g. to receive treatment) (Answered by all)

		Frequency	Valid Percent
	Yes, within the last year	430	62.4
	No, not within the last year	259	37.6
	Total	***689***	***100.0***
Missing	*System*	33	
Total		722	

Q20 (T). Was the ward you (or your child) stayed on suitable for your (or their) age? (Answered by those who stayed on a ward within the last year)

		Frequency	Valid Percent
	Yes, definitely	253	58.0
	Yes, to some extent/ sort of	125	28.7
	No	50	11.5
	I had my own room (adult only)	8	1.8
	Total	***436***	***100.0***
Missing	*System*	27	
Total		463	

Q20 (T)+. Was the ward you (or your child) stayed on suitable for your (or their) age? (Answered by those who stayed on a ward within the last year)

		Frequency	Valid Percent
	Yes, definitely	253	59.1
	*Yes, to some extent/ sort of	125	29.2
	*No	50	11.7
	Total	***428***	***100.0***
Missing	*System*	27	
Total		455	

**Problem score: 40.9%*

Q21 (T). Were there enough doctors and nurses to look after you (or your child) on the hospital ward? (Answered by those who stayed on a ward within the last year)

		Frequency	Valid Percent
	All or most of the time	198	45.7
	*Some of the time	207	47.8
	*Rarely or never	28	6.5
	Total	***433***	***100.0***
Missing	*System*	30	
Total		463	

**Problem score: 54.3%*

Information

Q22 (T). Do you have enough information about your (or your child's) sickle cell disorder? (Answered by all)

		Frequency	Valid Percent
	Yes, definitely	421	60.2
	*Yes, to some extent/ sort of	247	35.3
	*No	31	4.4
	Total	***699***	***100.0***
Missing	*System*	23	
Total		722	

**Problem score: 39.7%*

Q23 (T). Which of the following do you use to find out information about sickle cell disorder? Tick ALL that apply. (Answered by all)

		Frequency	Valid Percent
	NHS or sickle cell centre website	288	41.6
	Sickle Cell Society	259	37.4
	Leaflets and other written information	277	40.0
	NHS Staff	240	34.7
	Google searches	355	51.3
	YouTube videos	98	14.2
	Ask friends and family	200	28.9
	Other	64	9.2
	None of the above	28	4.0
Total number of responses		***1809***	
Total number of respondents		**692**	
Missing	*System*	30	
Total		722	

Q24 (T). Do healthcare staff give enough information to others (such as school, college or place of work) about your (or your child's) condition and how it affects you/them? (Answered by all)

		Frequency	Valid Percent
	Yes, enough information	211	30.8
	Some but not enough information	180	26.3
	None, but I would like this	161	23.5
	This is not needed	46	6.7
	I do not/ my child does not work/study	27	3.9
	Don't know / not sure	60	8.8
	Total	***685***	***100.0***
Missing	*System*	37	
Total		722	

Q24 (T)+.Do healthcare staff give enough information to others (such as school, college or place of work) about your (or your child's) condition and how it affects you/them? (those who go to school/ work and need this)

		Frequency	Valid Percent
	Yes, enough information	211	38.2
	*Some, but not enough information	180	32.6
	*None, but I would like this	161	29.2
	Total	***552***	***100.0***
Missing	*System*	37	
Total		589	

**Problem score: 61.8%*

Managing Sickle Cell

Q25 (T). Do you have enough information about different treatment options? (Answered by all)

		Frequency	Valid Percent
	Yes, definitely	237	34.4
	Yes, to some extent/ sort of	279	40.6
	No, but I would like this	137	19.9
	This is not needed	35	5.1
	Total	***688***	***100.0***
Missing	*System*	34	
Total		722	

Q25 (T)+. Do you have enough information about different treatment options? (those who need this)

		Frequency	Valid Percent
	Yes, definitely	237	36.3
	*Yes, to some extent/ sort of	279	42.7
	*No, but I would like this	137	21.0
	Total	***653***	***100.0***
Missing	*System*	34	
Total		687	

**Problem score: 63.7%*

Q26 (T). Are you involved enough in decisions about your (or your child's) condition and different treatment options? (Answered by all)

		Frequency	Valid Percent
	Yes, definitely	364	54.2
	Yes, to some extent/ sort of	219	32.6
	No, but I would like this	64	9.5
	I do not want or need to be	24	3.6
	Total	***671***	***100.0***
Missing	*System*	51	
Total		722	

Q26 (T)+. Are you involved enough in decisions about your (or your child's) condition and different treatment options? (those who want or need to be)

		Frequency	Valid Percent
	Yes, definitely	364	56.3
	*Yes, to some extent/ sort of	219	33.8
	*No, but I would like this	64	9.9
	Total	***647***	***100.0***
Missing	*System*	51	
Total		698	

**Problem score: 43.7%*

Q27 (T). Do you have enough information about when and how to use your (or your child's) medication? (Answered by all)

		Frequency	Valid Percent
	Yes, definitely	534	79.3
	Yes, to some extent/ sort of	115	17.1
	No	10	1.5
	I do not/ my child does not use medication	14	2.1
	Total	***673***	***100.0***
Missing	*System*	49	
Total		722	

Q27 (T)+. Do you have enough information about when and how to use your (or your child's) medication? (those who use or have children that use medication)

		Frequency	Valid Percent
	Yes, definitely	534	81.0
	*Yes, to some extent/ sort of	115	17.5
	*No	10	1.5
	Total	***659***	***100.0***
Missing	*System*	49	
Total		708	

**Problem score: 19.0%*

Q28 (T). Do you have enough information about coping with pain? (Answered by all)

		Frequency	Valid Percent
	Yes, enough information	415	61.8
	*Some but not enough information	208	31.0
	*Very little or no information	49	7.3
	Total	***672***	***100.0***
Missing	*System*	50	
Total		722	

**Problem score: 38.3%*

Q29 (T). Do your (or your child's) friends know enough about sickle cell disorder and understand the condition? (Answered by all)

		Frequency	Valid Percent
	Yes, they know enough	73	10.8
	They know some, but not enough	205	30.5
	They know little or nothing	238	35.4
	It is not needed	93	13.8
	Don't know	64	9.5
	Total	***673***	***100.0***
Missing	*System*	49	
Total		722	

Q29 (T)+. Do your (or your child's) friends know enough about sickle cell disorder and understand the condition? (those who need this)

		Frequency	Valid Percent
	Yes, they know enough	73	14.1
	*They know some, but not enough	205	39.7
	*They know little or nothing	238	46.1
	Total	***516***	***100.0***
Missing	*System*	49	
Total		565	

**Problem score: 85.8%*

Q30 (T). Do you have information about support groups for your (or your child's) condition (e.g. Sickle Cell Society or local support groups) (Answered by all)

		Frequency	Valid Percent
	Yes, enough information	207	30.9
	Some but not enough information	204	30.4
	None, but I would like this	180	26.9
	I do not want or need this	79	11.8
	Total	***670***	***100.0***
Missing	*System*	52	
Total		722	

Q30 (T)+. Do you have information about support groups for your (or your child's) condition (e.g. Sickle Cell Society or local support groups) (those who want or need this)

		Frequency	Valid Percent
	Yes, enough information	207	35.0
	*Some but not enough information	204	34.5
	*None, but I would like this	180	30.5
	Total	***591***	***100.0***
Missing	*System*	52	
Total		643	

**Problem score: 65.0%*

Q31 (T). Do you have the chance to meet other people (or parents of children) with sickle cell for support? (Answered by all)

		Frequency	Valid Percent
	Yes, and I find this helpful	227	34.4
	Yes, but I do not find this helpful	57	8.6
	No, but I would like this	238	36.1
	I do not want or need this	138	20.9
	Total	***660***	***100.0***
Missing	*System*	62	
Total		722	

Q31 (T)+. Do you have the chance to meet other people (or parents of children) with sickle cell for support? (those who want or need this)

		Frequency	Valid Percent
	Yes, and I find this helpful	227	43.5
	*Yes, but I do not find this helpful	57	10.9
	*No, but I would like this	238	45.6
	Total	***522***	***100.0***
Missing	*System*	62	
Total		584	

**Problem score: 56.5%*

Q32 (P&A). Have you been offered the chance to see a counsellor or psychological services for support with your (or your child's) condition? (Answered by adults and parents)

		Frequency	Valid Percent
	Yes	143	31.3
	No, but I would like this	176	38.5
	No, but I do not need this	138	30.2
	Total	***457***	***100.0***
Missing	*System*	43	
Total		500	

Q32 (P&A)+. Have you been offered the chance to see a counsellor or psychological services for support with your (or your child's) condition? (Answered by adults and parents of children who need this)

		Frequency	Valid Percent
	Yes	143	44.8
	*No, but I would like this	176	55.2
	Total	***319***	***100.0***
Missing	*System*	43	
Total		362	

**Problem score: 55.2%*

Q33 (C). Do you think you are given enough help to cope with your sickle cell? (Answered by all children)

		Frequency	Valid Percent
	Yes	177	86.3
	No, but I would like this	20	9.8
	No, but I do not need this	8	3.9
	Total	***205***	***100.0***
Missing	*System*	17	
Total		222	

Q33 (C)+. Do you think you are given enough help to cope with your sickle cell? (those who need help)

		Frequency	Valid Percent
	Yes	177	89.8
	*No, but I would like this	20	10.2
	Total	***197***	***100.0***
Missing	*System*	17	
Total		214	

**Problem score: 10.2%*

Q34 (T). Do you ever have to repeat your story to different members of healthcare staff? (Answered by all)

		Frequency	Valid Percent
	*Yes, and this bothers me	271	40.6
	Yes, but I do not mind	235	35.2
	No	162	24.3
	Total	***668***	***100.0***
Missing	*System*	54	
Total		722	

**Problem score: 40.6%*

Q35 (T). Overall, how well do you think your (or your child's) sickle cell disorder is looked after by healthcare staff? (Answered by all)

		Frequency	Valid Percent
	Very well	319	47.7
	*Quite well	290	43.3
	*Not very well	60	9.0
	Total	***669***	***100.0***
Missing	*System*	53	
Total		722	

**Problem score: 52.3%*

Q36 (T). Does sickle cell cause you (or your child) difficulty with any of the following? Tick ALL that apply. (Answered by all)			
		Frequency	Valid Percent
	Everyday activities that people their age can usually do	387	58.4
	At work, at school, or training	355	53.5
	Access to buildings, streets or vehicles	104	15.7
	People's attitudes to you and/or your child because of your/their condition	200	30.2
	Communicating, mixing with others or socialising	133	20.1
	Any other activity	136	20.5
	No difficulty with any of these	161	24.3
Total number of responses		**2139**	
Total number of respondents		**663**	
Missing	*System*	59	
Total		722	

Demographics

Q37 (T) Age Group of patient (Answered by all)			
		Frequency	Valid Percent
	0-2 years	20	3.1
	3-5 years	38	5.8
	6-8 years	60	9.2
	9-11 years	125	19.2
	12-15 years	151	23.2
	16-20 years	31	4.8
	21-30 years	70	10.8
	31-40 years	71	10.9
	41-50 years	51	7.8
	51+	34	5.2
	Total	***651***	***100.0***
Missing	*System*	71	
Total		722	

Q38 (T). Gender of patient (Answered by all)			
		Frequency	Valid Percent
	Male	291	43.4
	Female	379	56.6
	Total	***670***	***100.0***
Missing	*System*	52	
Total		722	

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