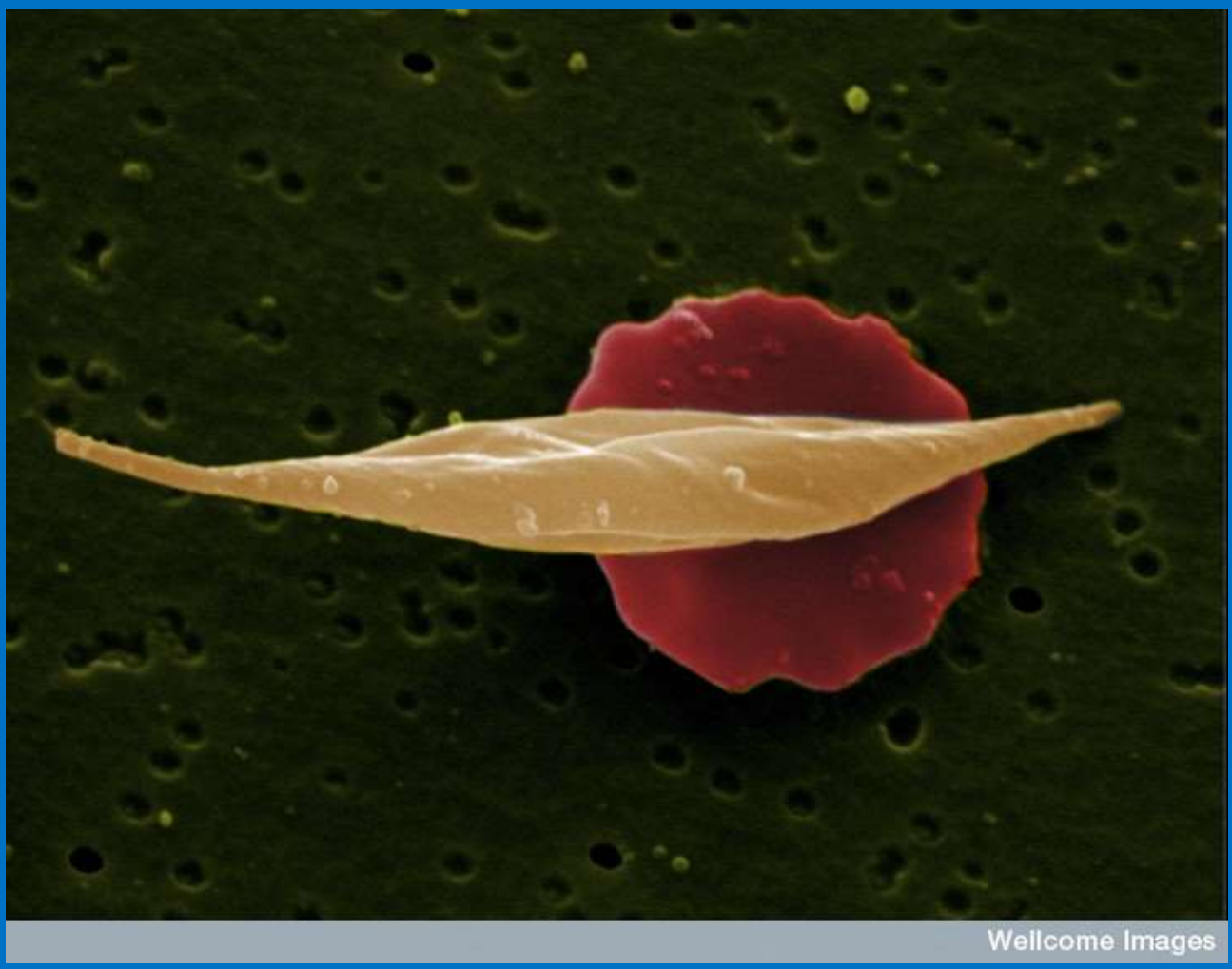
National Comparative Audit
of Blood Transfusion

NHS
Blood and Transplant

National Comparative Audit of Blood Transfusion

2014 Audit of Transfusion in Children and Adults with Sickle Cell Disease



Wellcome Images

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Participation

Hospitals that agreed to be in the pilot

The Ipswich Hospital NHS Trust

The North West London Healthcare NHS Trust

Birmingham Children's Hospital NHS Foundation Trust

King's College Hospital NHS Foundation Trust

Hospitals that took part in the audit

See Appendix 4

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Abbreviations

ACS	Acute chest syndrome
BCSH	British Committee for Standards in Haematology
EI	Electronic Issue
Hb	Haemoglobin
IQR	Interquartile range
LHT	Local Haemoglobinopathy Team
LIMS	Laboratory Information Management System
RCE	Red cell exchange
SCD	Sickle cell disease
SHOT	Serious Hazards of Transfusion
SHT	Specialist Haemoglobinopathy Team
SOP	Standard Operating Procedure
SpiCE	Specialist Services Integrated Clinical Environment
TCD	Transcranial Doppler

Executive Summary

This audit of red cell transfusions in children and adults with sickle cell disease was conducted from September 1st to December 12th 2014 in hospitals throughout the United Kingdom and Ireland. 54% (99/183) of hospitals contributed data. 32% (59/183) of hospitals declined to participate because they said they did not look after patients with sickle cell disease. Provision of care for people with sickle cell disease has not improved since this audit and these audit findings are very relevant to the care of patients today.

Organisational audit

80 hospitals participated in the organisational audit. Within this audit the 80 sites were grouped according to whether they saw 0 to 4 cases during the clinical audit (40 sites – **low transfusion activity**), 5 to 24 cases (22 sites – **medium transfusion activity**) or more than 25 cases (18 sites – **high transfusion activity**).

Network

36% (29/80) of hospitals reported themselves as a Specialist Haemoglobinopathy Team (SHT), 60% (48/80) as a Local Haemoglobinopathy Team (LHT), and 4% (3/80) were unknown. Only 46% (22/48) of LHTs classified themselves as part of a network (**Organisational Standard 1**).

Guidelines

Guidelines on when to perform a red cell exchange (RCE) were available at: 57% (40/70) of sites for adults, and 41% (29/70) of sites for children (**Organisational Standard 2a**). Of those sites that performed RCE, there were no guidelines on how to perform the procedure at: 30% (17/56) of sites for adults, and 24% (9/38) sites for children (**Organisational Standard 2b**).

Staffing

91% (71/78) of sites had a consultant who provided cover for sickle cell disease or had a special interest in sickle cell disease (**Organisational Standard 3**). 69% (50/73) of sites who cared for children had a paediatrician or paediatric haematologist who had a special interest in sickle cell disease (**Organisational Standard 4**). Only 85% (33/39) of sites that had a "low transfusion activity" had a nominated consultant. Only 49% (17/35) of sites that had a "low transfusion activity" and cared for children had a nominated paediatrician. Just under half of hospitals that responded had a clinical nurse specialist caring for adults (34/70, 49%) or children (35/71, 49%). However, for hospitals with high transfusion activity this was much higher (adults 88%; children 81%) (**Organisational Standard 5**).

Red Cell Exchange (RCE)

10% of sites (7/71) did not have 24 hour access to urgent RCE for adults either at their site or via their specialist centre. 16% of sites (11/67) did not have 24 hour access to urgent RCE for children either at their site or via their specialist centre (**Organisational Standard 6**).

Access to elective red cell transfusion available locally

An elective top-up transfusion within working hours could be provided to adults at 93% of sites (66/71), and children at 91% of sites (60/66) (**Organisational Standard 7**).

Clinical audit

84 hospitals submitted 1290 cases to the audit, median 6 (IQR 2 to 15) cases per site, range 1 to 151. 14 additional sites had no eligible cases during the audit period. 75% (971/1290) of all cases came from the 18 sites submitting 25 or more cases, of which 84% (812/971) came from 14 sites located in the London area.

Nearly all transfusions were administered to patients with HbSS (91.2%; 1164/1276). Most patients required blood that was Rh CE negative (60%; 732/1227).

Type of transfusion

There were 4,528 transfusion episodes during the audit period, median 3 (IQR 1 to 5) per patient.

A top-up transfusion was the most common type of transfusion (62%; 2785/4528). Automated RCEs accounted for 31% of transfusions (1405/4528). Manual RCEs were uncommon (6%; 261/4528).

Adults received 56% of all transfusions (2534/4528). Overall automated RCE was the commonest type of transfusion (50%; 1271/2534), most were performed in high transfusion activity sites. Children received 44% of all transfusions (1990/4528). Top-up transfusion was the commonest type of transfusion (87%; 1736/1990), this was unaffected by the size of the site.

Reason for transfusion

Most transfusion episodes were elective (84%; 3803/4528).

Stroke prevention was the most common reason for transfusion (42%; 1914/4528 of all transfusion episodes). This accounted for 65% (1290/1990) of all transfusions to children and 24% (620/2534) of all transfusions to adults.

Other common reasons for elective transfusions were recurrent vaso-occlusive pain (17%; 636/3803), and “no reason given” (15%; 563/3803).

“Acute or chronic anaemia” was the main reason for urgent transfusions (30%; 215/721), followed by “other” (23%; 166/721) and acute chest syndrome (18%; 127/721).

Laboratory Audit

96% (77/80) of laboratories Rh and Kell matched blood (**Laboratory Standard 1**). Only 71% (904/1282) of patients transfused in the audit had a full red cell phenotype or genotype available at the time of the transfusion (**Laboratory Standard 2**). 96% (77/80) of sites had continuous availability of transfusion services (**Laboratory Standard 3**).

Special requirements

44% (35/80) of hospitals requested blood less than 7 days old for a planned RCE in line with guidelines (**Laboratory Standard 4**). 20% (16/80) of hospitals did not perform a RCE.

26% (21/80) of hospitals requested blood 8 to 14 days old for a top-up transfusion in line with guidelines (**Laboratory Standard 5**). 28% (22/80) of hospitals requested fresher blood than guidelines suggest, which may limit supplies of fresher blood unnecessarily.

5% (4/80) of hospitals routinely ask for CMV-negative blood for people with SCD, which is not required (**Laboratory Standard 6**).

Cross-matching

93% (74/80) of hospitals' laboratory acceptance criteria for a group and save sample if the patient had been transfused less than 28 days previously was a maximum of 72 hours in line with guidelines (**Laboratory Standard 7**). In 3 hospitals, this could be extended under certain circumstances to one week, also in line with BSH guidance for those on regular transfusions.

80% (59/74) of hospitals could provide a cross-match and RCE transfusion on the same day for routine transfusion in adults, and 75% (56/75) for children.

55% (44/80) of hospitals used electronic issue in SCD patients who had no history of alloimmunisation. Only 82% (61/74) of the hospitals in England and North Wales can access NHSBT results for patients electronically using Specialist Services Integrated Clinical Environment system (SpICE), when processing a sample from a patient with sickle cell disease. Of these, just over a third (36%, 22/61) would always do this.

Clinical Scenarios

In Part 2 of the clinical audit, we asked sites to audit in more depth some of their patients who had received a transfusion for one of the following reasons: stroke prevention; pregnancy complication prevention; acute chest syndrome; acute stroke; pregnancy complication; hyperhaemolysis.

Stroke prevention and acute chest syndrome were the two commonest reasons for transfusion. 22 pregnant women received transfusions (28 episodes); 7 patients received transfusions after an acute stroke (9 episodes); and there were no reported cases of hyperhaemolysis.

Stroke Prevention (183 patients, 81 adults, 102 children)

49% (89/183) received transfusions for primary stroke prevention and 51% (94/183) received transfusions for secondary stroke prevention.

Primary stroke prevention was common in children (80%, 82/102), but uncommon in adults (9%, 7/81). Most primary stroke prevention in children was because of abnormal transcranial Doppler results (72/82).

The most common reason for secondary stroke prevention was a previous acute ischaemic stroke (70/94: adults 55/74; children 15/20).

The median age for initiation of a transfusion regimen was 8 years (IQR 5 to 14 years) (reported for 163/183 cases).

The average pre-transfusion HbS% in the audit period (January 1st to June 30th 2014) was 33% (IQR 25 to 41) (reported for 176/183 cases). 79% (137/173) of cases had a target HbS% of 30% during this time. 13% (23/173) of cases had a higher target HbS% (35 to 50%).

62% (50/81) of adults and 6% (6/102) of children received automated RCE. Patients on automated RCE were less likely to be iron overloaded. Overall 66% (121/182) of patients were on treatment for iron overload. However, 15 patients with a ferritin > 1000 µg/l were not on chelation.

Acute chest syndrome (92 patients, 68 adults, 24 children)

Most patients were transfused on the ward (73%; 74/102 transfusion episodes), and the majority were top-up transfusions (88%, 21/24 in children; and 53%, 41/78 in adults). Incentive spirometry was used in only 29% of patients (27/92: 25%, 17/68 adults; 42%, 10/24 children).

Patient View and Recommendations

I am a 39 year old female HbSS patient and am the patient representative on the panel for the National Comparative Audit of Blood Transfusion 2014 audit. I have first-hand experience of acute chest syndrome; stroke prevention, having had a stroke in 1996 at the age of 17; and am currently pregnant. I have been and am still part of the automated exchange programme, which I have been on since 2008 having had 2 years of manual exchanges beforehand. I experienced many crises for which I received emergency care in different parts of the UK between 1992 and 2006. I have not received emergency care since this date.

I have been fortunate enough to be involved in voluntary projects that have allowed me to discuss emergency and other forms of care with SCD patients around the UK. It is with the experience of other patients, as well as my own and those of a sibling who is also HbSS that I comment on the following report. I have also been involved in 2 different projects within the last two years where I have had the opportunity to speak with patients regarding their hospital treatment. The first was a meeting group with patients transitioning from paediatric to adult care. I am also a patient reviewer and was involved in the most recent round of the NHS Haemoglobinopathy Peer Review in 2014.

Organisational resources and Network Arrangements

Emergency Departments (EDs) are often the focus of concern with patients as this is where they will often attend in crisis, when they are at their most vulnerable. The development of a protocol for ED to contact the haematology department of the hospital where the patient has presented at ED is advised so as, to pass on information about their clinical care and history as well and transfusion requirements. This is particularly pertinent in the all too common scenario where patients attend the ED of a hospital that they do not have their sickle care at.

The communication pathways with the specialist centre are also extremely important. This would provide an additional safeguard so that patients receive appropriate treatment in a timely manner that would not further exacerbate the effects of crisis and would allow them access to any specialist treatment they require. It would also be beneficial to include the hospital where the patient is currently receiving their care, both inpatient and outpatient.

The knowledge and awareness of SCD for all levels of staff within EDs in particular should be a mandatory inclusion as it is with other comparable serious and chronic illnesses. The fact that SCD only affects a minority of the population is irrelevant, as the illness still remains the biggest inherited single gene disorder in the U.K. and therefore warrants a higher level of awareness than currently exists. It would appear that making training mandatory will be the only effective way to correct this oversight.

The establishment and continued development of networks seems an essential requirement for the improved care of patients with SCD on a national basis. As suggested in the report, this would require the coordination of local specialist centres and ambulance services in developing protocol of how best to manage such services. It would be extremely beneficially for patients to be taken to the nearest specialist centre with immediate effect when in acute crisis by the ambulance service where the calculated delay will not impair their treatment.

Transfusion Specifics and delivery:

It is concerning that exchange transfusion might be delayed while a bed in ITU/HDU is sought when there is no evidence that such a bed is necessary for transfusion.

Departments need to be made aware that it is perfectly acceptable to conduct transfusions on the ward and this should indeed become procedure, however it is also worth noting that some departments may feel that they have neither the staff training nor the equipment to carry out such a procedure. A dedicated team of staff would be required to run a transfusion service and the liability involved might be the deterrent. This is a problem that could be solved by increasing the number of link nurses and developing stronger networks. The effects for patients in not having such lengthy delays to treatments would be of significant benefit to both patients and treatment facilities in avoiding the added and severe consequences of withholding the procedure.

Despite the need to provide wider access to both manual and automated transfusions and exchanges, it should still be noted that the procedure is an extremely demanding, physically invasive procedure for the patient that requires the development of effective protocols, as well as the acknowledgment that patients often need a period of time for recuperation. The administration of the procedure should not be allocated in a haphazard manner as it becomes more 'routine' in nature, and the patient's welfare should still be considered paramount.

The conditions of a patient can deteriorate rapidly, and it is the patient in particular who then has to bear the brunt of a longer and more complicated recovery period than is necessary.

Although there is much discussion about provision of services in areas with high transfusion activity vs. low or medium, it is my opinion that patients should not expect a lower quality of care or staff training just because of the size of the local patient cohort. I had a crisis in 2004 and was taken to an ED in the UK that has a BAME population of 1.7%, 0.2% of which are Black African/ Caribbean. (2011 census-UK/NI Statistics and Research Agency). I was quickly cannulated, hydrated and provided with appropriate pain relief and was able to walk away unscathed a few hours later, and I believe the prompt and efficient treatment limited the length and complexity of my crisis.

Laboratory Transfusion Practice

This raises issues surrounding the legal requirements regarding data sharing of patient information.

As stated within the report, in reference to the 'Caldicott Principles', medical information should be shared when in the patients best interests. Transfusion information should be sought each time a patients attends a hospital from the national blood service (using SpICE if available) and other hospitals where they may have been seen. Whilst acknowledging the valid concerns surrounding patient privacy and the implications of data breeches, sharing of pre-existing information regarding a patient's healthcare is important to allow patients to receive the best level of care.

Due to the differences between hospitals in how the cross match procedure is executed, the need for all blood services for SCD patients crescendo as the week continues. With regards to planned transfusions and exchanges, it would be preferable if cross match procedures were available with differing periods of time within phlebotomy departments - from same day to up to 72 after blood is taken. This would allow for a more balanced use of the exchange services throughout the week, helping to minimise the bottleneck effects seen between Wednesdays-Fridays. If bloods could be taken on Friday for use on Monday or bloods taken on a Monday for same day use or 24-72 hours later, this may make better use of the earlier part of the week.

As blood in the UK cannot be used after a period of 48 hours between cross match and exchange if someone has received blood in the last 4 weeks, this would require an exploration of the evidence base to ascertain the safety for such a protocol change. If however, as stated within the report, blood and associated services will require increased use and capacity due to the growth of its use for the treatment of SCD, then this could prove an appropriate area for future consideration and research.

It should be mandatory to specify that a patient has SCD when requesting bloods. Where there is an electronic system with which to order blood, this should be in the mandatory questions, where it is not available, it should be on the pre-printed forms. Either way, the laboratory must know in order to source the correctly phenotyped blood. It would be beneficial if it were specified and then recorded in a hospital database, that the bloods were for use for a patient with SCD, for the purposes of internal audit and future demand planning for services and resources. Indeed such information could support applications for additional resources for the clinical care of patients receiving transfusion e.g. stroke prevention, an older population and pregnancy.

Clinical Scenarios

Stroke prevention was shown to be occurring mostly in younger patients due to the findings of the STOP study. It would be beneficial if SCD was linked more strategically with wider stroke prevention services as this would help to improve the knowledge and outcomes for patients as stroke prevention is now the commonest single reason for regular transfusion in sickle cell disease.

Conclusion

There exists a highly skilled, specialist force within paediatric and haematology departments and laboratories that provide the services for SCD patients. This also includes a range of high level equipment and resources with which to provide increasingly effective treatment. These services, however, are not universal, and nor is access to them. SCD affects a relatively small percentage of the population; however the severity and complexity of the illness does require prompt emergency care and long-term clinical support and intervention. It is imperative that patients are supported to access the care they need, in regards to their own particular requirements. This does not have to involve a physical exodus of patients from one hospital to another. The most realistic way of achieving this outcome should be explored through the development and extension of link hospitals and extended networking in regional areas. The sharing of information, training and formalisation of networks as a primary step could have a very positive impact on patients requiring emergency and long-term care. A top down approach, particularly in areas with little patient activity may support the spread of knowledge and understanding, and the wider use of link nurses who can provide a bridge of knowledge between wards and departments is recommended.

It is of critical importance that SCD clinical care be held to obligatory rather than voluntary standards as is the case with other illnesses. The peer review for example is a fantastic process in theory with clear and relevant standards and hospitals assessed on their ability to meet them. However, participation and therefore any consequent amendments to services are voluntary. This process needs to be made mandatory and have expanded standards vis. a vis. transfusion, to ensure that hospitals can provide the appropriate transfusion care for patients wherever and whenever they attend.

Summary of recommendations

Organisational Resources and Network Arrangements

1. **Commissioners should work with NHS Trusts and Health Boards to ensure the delivery of clinical networks of care for children and adults with sickle cell disease (SCD). There should be clear pathways and management protocols for emergency and elective blood transfusion for all patients in the geographical area including access to automated red cell exchange (RCE), where indicated.**

2. **All hospitals that admit SCD patients should have protocols, training and documentation for staff in transfusion including manual RCE for children and adults.**

3. **NHS Trusts and Health Boards should undertake regular service planning and capacity arrangements to meet the growing requirements for blood transfusion in SCD. This includes the provision of out of hours transfusions for patients on long term transfusion programmes.**

What blood is being transfused, why, how where when and by whom

1. **Blood services need to ensure availability of Ro blood.**

Laboratory transfusion practice

1. **Rh and Kell blood groups should be known prior to transfusion. Red cell geno/phenotypes should be sent to the National Blood Service so that the results will be available throughout the patients' lives wherever they choose to attend for their care.**

2. **Hospitals should ensure that there is clear guidance on how staff inform the transfusion laboratory about patients who have sickle cell disease. This may be through electronic requesting.**

3. **Transfusion laboratories should have a specific SOP on SCD which includes:**
    a. **Identification of a patient who has SCD including in an urgent situation**
    b. **Patient who may have been transfused elsewhere**
    c. **Use of electronic dispatch note (EDN) where available**
    d. **Contacting National Blood Service for any additional support in finding appropriate units for transfusion and using SpiCE or equivalent where available**
    e. **When consideration can be made to override age requirements of donor units**
    f. **When to escalate to the senior medical haematology team for support in such decisions**

4. **Hospitals should allow transfusion information sent to their National Blood Service to be shared with other hospital laboratories.**

5. **Electronic issue (EI) can be considered where there is no history of alloimmunisation.**

Clinical care

1. **Automated RCE should be more widely available to all those on long term transfusion programmes.**

2. **Transfusion decisions regarding acutely unwell patients should be discussed with the senior haematology or paediatric team.**

3. **There is no evidence that an HDU/ITU bed is needed specifically to perform a RCE procedure. Waiting for a bed to become available is likely to delay the procedure. Patients should be admitted to these areas if clinical needs dictate but not solely for the purpose of the RCE procedure.**

Introduction

What is Sickle Cell Disease?

Sickle Cell Disease (SCD) is the commonest inherited single gene disorder in the UK with an estimated prevalence of 14,000 people. The number of people with SCD is increasing with over 250 being born each year (1). While many people with SCD receive coordinated care at Sickle Cell Centres, these are often located in larger towns or cities. Emergency care is often delivered at local hospitals that may or may not have experience in looking after people with SCD. Patients can become rapidly unwell and transfusion may be life-saving.

Patients are surviving longer and living with complications that are often managed with transfusion e.g. stroke in older age and chronic renal failure. A recent Peer Review of Paediatric and Adult Services in Haemoglobin Disorders focussed on the organisation and provision of services (2). This audit examines hospital clinical management of patients with SCD receiving transfusion.

Why is an audit of transfusion in sickle cell disease necessary?

- The evidence for transfusion in these disorders is not robust for many of the accepted clinical indications.
- Current guidelines and standards for both clinical and laboratory transfusion support do not cover the threshold, quantity, timing, modality and mechanism of transfusion.
- The use of transfusion in sickle cell disease is increasing. However, less than 1% of the donor pool is from similar ethnic groups to the patients. It is important to understand how blood is used to ensure appropriate use and provision of blood nationally.
- Considerable resources are required to provide blood in a timely and effective fashion – patients often present out of hours to local hospitals, have poor venous access and will require large volumes of high specification blood.

Aims of the audit

1. Organisational Resources and Network Arrangements: To determine the organisational resources in place for transfusion for patients with SCD whether in local hospitals, accredited haemoglobinopathy centres or specialised haemoglobinopathy centres. To determine what organisational and other resources need to be in place from a blood service perspective to ensure the safe and effective blood supply for this cohort.
2. To find out what blood is being transfused, why, how, where, when and by whom.
3. Laboratory: To examine whether laboratory support and policies meet nationally agreed standards
4. Clinical Scenarios: To examine detailed transfusion timelines for five clinical scenarios

A national comparative audit will establish what current practice is and may provide useful evidence for best transfusion practice in managing patients with SCD.

Audit Definitions

People with **sickle cell disease** (SCD) are homozygotes (HbSS) or compound heterozygotes (HbSC, HbSBeta thalassaemia, HbSD, HbSO Arab, and others).

Homozygote: A person who has two copies of the same defective gene, one from each parent

Compound heterozygote: A person who has two different copies of a defective gene, one from each parent, that

gives rise to the clinical condition.

Child is a person less than 18 years old at the beginning of the audit period

Adult is a person at least 18 years old at the beginning of the audit period

A site that said they only saw children was defined by the site itself, this could mean up to 18 years or until 16 years, likewise a site which said they only saw adults might see patients from 16 years or from 18 years of age. Note: no hospital that declared itself as adult only saw a child during the audit period. One hospital who declared itself as exclusively paediatric saw one person aged 22 and one aged 18 years old.

A **transfusion episode** was defined as all blood given in any 72-hour period.

UK professional, clinical and laboratory guidelines and standards are in place for transfusion and care of patients with SCD which have been used as sources for the audit standards.

Organisational Resources and Network Arrangements

1. The Specialist Haemoglobinopathy Team (SHT) will coordinate and provide expert care and advice for patients with more complex needs (3).
2. Transfusion guidelines should be in place covering:
    a. Indications for regular transfusion, urgent top up and red cell exchange (RCE) transfusion;
    b. Protocol for carrying out an RCE transfusion (4-7).
3. There is a nominated lead consultant with responsibility for sickle cell patients (adults) (6, 8).
4. There is a nominated lead paediatrician/ paediatric haematologist with responsibility for sickle cell patients (children) (3, 7, 8).
5. There is a nominated lead nurse with responsibility for sickle cell patients (adults, or children, or both) (6, 7).
6. Access to the following specialist staff and services is available: automated or manual RCE transfusion. (6).
    c. 24/7 facility for urgent RCE for acute stroke and acute chest syndrome (ACS) (5).
    d. 24/7 guidance for transfusion from specialist centre (5).
7. Regular administration of transfusion and its monitoring occurs locally where possible (3).

Laboratory Practice

1. Red cells are Rh and Kell-matched (5, 9, 10).
2. Full red cell phenotype is available (4, 5, 9).
3. Continuous availability of transfusion services (4, 5).
4. Age of blood is less than 7 days old for red cell exchange (4).
5. Age of blood is less than 2 weeks old for top-up transfusion (4).
6. Donor cells are not CMV negative for sickle cell disease unless there is another appropriate reason (5, 9, 10).
7. 72 hours from group and save specimen to blood administration if transfused less than 28 days prior (11).

Clinical

1. Routine prophylactic transfusion not indicated in pregnancy (10).
2. Decision to transfuse in pregnancy should be discussed with a senior haematologist (10).

Several guidelines have been published between the audit period and the writing up of the audit. These have not been audited against, per se but are listed below for reference.

- Guidelines on red cell transfusion in sickle cell disease. Part I: principles and laboratory aspects (12).
- Guidelines on red cell transfusion in sickle cell disease. Part II: indications for transfusion (13).
- Quality Standards: Health Services for People with Haemoglobin Disorders v2.3 (2).

Methodology

Organisational audit

An organisational audit questionnaire was sent to each participating site (Appendix 1). The purpose of the questionnaire was to collect information about the nature of the services provided by the hospital and to therefore understand the context in which patient care was delivered.

Clinical audit

The clinical audit was in two parts:

Part 1 Case Capture Form

From September 1st to December 12th 2014 we invited sites to identify patients with SCD (adults and children), who were admitted and transfused between January 1st and June 30th 2014. This included not only known SCD patients who were transfused because of their SCD, but also people with SCD who were transfused for other reasons, for example peri-operatively for hip replacement.

Because it was not known in advance how many people would present and be transfused a minimum sample size was not set. Sites were asked to collect set information on a case capture form for all patients who had received a transfusion within the study period (Appendix 2).

The case capture form provided fixed-answer questions with occasional free text answers. Included within this was rationale for transfusion, which was given a letter code and classified either as a scheduled or an emergency transfusion. Other questions related to blood groups, quantity of blood administered, modality of transfusion, time and date of transfusion and basic patient demographics. Auditors used one form per patient, thus each form could record several transfusion episodes. A linkage record number was used to ensure patient confidentiality. Each case capture form was pre-numbered by the NCA, impressing the importance of using the same audited patient number on the linkage record and case capture form.

Sources of information included the Hospital Information Management department (requesting a list of Adults and Children with code for SCD), or the laboratory information systems (LIMS). Auditors may also have identified these patients from memory or from departmental databases/lists of known patients with SCD and then crossed referenced with LIMS to see if they had been transfused.

Part 2

We asked sites to audit some of their identified patients in more depth with admission for the following reasons:

- Acute chest syndrome,
- Acute stroke (haemorrhagic or thrombotic),
- Hyperhaemolysis
- Pregnancy complication (an acute event in pregnancy) and Pregnancy (regular transfusions in pregnancy)
- Stroke prevention

Individual centres decided whether these conditions were present.

In early January 2015, a list was made of patients to audit in Part 2, together with the appropriate clinical audit tools. These were sent to the participating hospitals to complete the questionnaire. Forms were then returned to the NCA and uploaded on to SNAP (online audit tool) by May 11th 2015. To ensure that sites with large numbers of patients were not overloaded with data requests, requests for data on a maximum of 10 children and/or 10 adults for each indication were made (Appendix 3).

Participation

We invited English NHS Trusts and Northern Irish, Scottish, Welsh and Republic of Ireland hospitals to participate (Appendix 4 for details). Sites registered with the audit: 106/183 sites. Where reasons were given for non-participation most felt the audit was not applicable to them as they very rarely saw eligible cases.

- 84/106 sites submitted data to the clinical audit: 22 did not
    - 14/22 indicated a nil return (i.e. there had been no eligible cases during the audit period)
    - 8/22 where the reason for not submitting data was unclear.

- 80 sites submitted data to the organisational audit.

Section 1– Organisational Resources and Network Arrangements

Results

80 submitted data to the organisational audit. 69 sites saw both adults and children, 5 sites saw adults only, and 6 sites saw children only.

Since some audit questions were directed specifically at adult or children's services we have used denominators of 74 for those relating to adult services, 75 for children's services and 80 for services applying to both.

Type of centre:

- 36% (29/80) of hospitals reported themselves as a Specialist Haemoglobinopathy Team (SHT)
- 60% (48/80) as a Local Haemoglobinopathy Team (LHT).
- 4% (3/80) unknown.

Organisational Standard 1

The Specialist Haemoglobinopathy Team (SHT) will coordinate and provide expert care and advice for patients with more complex needs.

Of the 48 sites that classified themselves as an LHT, only 58% (28/48) named their SHT.

83% (24/29) of SHTs and 46% (22/48) of LHTs classified themselves as part of a network (as defined in the Peer Review Programme) (2, 6, 7).

Within this audit the 80 sites were grouped according to transfusion activity as follows: 0 to 4 cases seen during the clinical audit (40 sites – **low transfusion activity**), 5 to 24 cases (22 sites – **medium transfusion activity**) or more than 25 cases (18 sites – **high transfusion activity**) (Table S1).

Policies and Documentation

Organisational Standard 2

Transfusion guidelines should be in place covering:

a. *Indications for regular transfusion, urgent top up and red cell exchange (RCE) transfusion*
b. *Protocol for carrying out an RCE transfusion*

There was wide variation in availability of guidelines and protocols for transfusion of SCD patients (Table 1a).

Guidelines on when to perform a RCE were available at: 57% (40/70) of sites for adults, and 41% (29/70) of sites for children.

Of those sites that performed RCE, there were no guidelines on how to perform the procedure at: 30% (17/56) of sites for adults, and 24% (9/38) of sites for children.

Table 1a: Availability of guidelines and protocols for transfusion of SCD patients

		Guideline regarding indications	Training protocol	Guidelines on how to perform procedure	Prescription/record sheet for the RCE
Automated RCE adults	**Yes**	24% (16/67)	48% (12/25)	68% (17/25)	60% (15/25)
	No	13% (9/67)	48% (12/25)	28% (7/25)	40% (10/25)
	Not Done	63% (42/67)	-	-	-
Manual RCE adults	**Yes**	57% (40/70)	36% (20/56)	70% (39/56)	59% (33/56)
	No	23% (16/70)	57% (32/56)	30% (17/56)	34% (19/56)
	Not Done	20% (14/70)	-	-	-
Automated RCE children	**Yes**	23% (16/70)	45% (10/22)	73% (16/22)	59% (13/22)
	No	9% (6/70)	45% (10/22)	23% (5/22)	36% (8/22)
	Not Done	69% (48/70)	-	-	-
Manual RCE children	**Yes**	41% (29/70)	34% (13/38)	76% (29/38)	63% (24/38)
	No	13% (9/70)	63% (24/38)	24% (9/38)	34% (13/38)
	Not Done	46% (32/70)	-	-	-

Sites that indicated "did not know" or "No answer" were excluded from the national analyses.

Sites that said they did not perform a procedure were excluded from the analyses for "training protocol"; "guidelines on how to perform a procedure" and "prescription/record sheet for the RCE"

Staffing

Organisational standard 3

There is a nominated lead consultant with responsibility for sickle cell patients (adults)

91% (71/78) of sites had a consultant who provided cover for sickle cell disease or had a special interest in sickle cell disease (> 0 WTE (Whole Time equivalent)). Only 85% (33/39) of sites that had a "low transfusion activity" had a nominated consultant with some of their job plan allocated to caring for SCD patients. (Table 1b).

Organisational standard 4

There is a nominated lead paediatrician/ paediatric haematologist with responsibility for sickle cell patients (children)

69% (50/73) of sites had a paediatrician or paediatric haematologist who had a special interest in sickle cell disease (> 0 WTE (Whole Time equivalent)). Only 49% (17/35) of sites that had a "low transfusion activity" had a nominated consultant with some of their job plan allocated to caring for SCD patients (Table 1b).

Organisational standard 5

There is a nominated lead nurse with responsibility for sickle cell patients (adults, or children, or both)

Just under half of hospitals that responded had a clinical nurse specialist caring for adults (34/70, 49%) or children (35/71, 49%). However, for hospitals with high transfusion activity this was much higher (adults 88%; children 81%) (Table 1b).

Table 1b Staffing Levels

Nature of post	Number of sites	Low (< 5 cases)	Medium (5 to 24 cases)	High (≥ 25 cases)
Any consultant haematologist	**91% (71/78)**	**85% (33/39)**	**95% (20/21)**	**100% (18/18)**
Consultant haematologist(s) with a special interest	62% (46/74)	34% (13/38)	90% (18/20)	94% (15/16)
Consultant haematologist(s) without a special interest	81% (61/75)	76% (29/38)	90% (18/20)	82% (14/17)
Any paediatric consultant	**69% (50/73)**	**49% (17/35)**	**95% (18/19)**	**94% (15/16)**
Consultant Paediatric haematologist(s) with a special interest in SCD	31% (21/68)	15% (5/34)	35% (6/17)	59% (10/17)
Consultant Paediatrician(s) with a special interest in SCD.	50% (35/70)	33% (12/36)	74% (14/19)	60% (9/15)
Clinical Nurse Specialist(s) for adults with SCD	**49% (34/70)**	**19% (7/36)**	**72% (13/18)**	**88% (14/16)**
Clinical Nurse Specialist(s) for children with SCD	**49% (35/71)**	**24% (9/37)**	**72% (13/18)**	**81% (13/16)**
Link ward nurse(s) for haemoglobinopathies (adult)**	22% (14/65)	6% (2/33)	24% (4/17)	53% (8/15)
Link ward nurse(s) for haemoglobinopathies (paediatric) **	17% (11/65)	14% (5/35)	13% (2/16)	29% (4/14)

denominator is those sites that responded

***RCN definition: shares information – provides formal 2-way communication between specialist teams and nurses in the clinical area*

Admitting patterns

A quarter (26%, 18/70) of hospitals said that their adult SCD patients were not initially admitted under the care of the haematology team for emergency admissions, and only a third (34%, 24/70) were admitted routinely under the haematology team. At those hospitals where patients were not routinely admitted under haematology, one fifth (20%, 9/46) never came under the care of the haematology team, the remainder were routinely or sometimes transferred to haematology. The timing of transfer of patients from acute medical teams to haematology depended on the site: a third (37%, 13/35) were transferred the next working day (Monday-Friday) whereas half (54%, 19/35) were transferred the next day, even if it was a weekend.

Type of transfusion and availability

Organisation Standard 6

Access to the following specialist staff and services is available: automated or manual RCE transfusion.

a. *24/7 facility for urgent RCE for acute stroke and acute chest syndrome (ACS)*
b. *24/7 guidance for transfusion from specialist centre*

10% of sites (7/71) did not have 24-hour access to urgent RCE for adults either at their site or via their specialist centre (Table 1c).

16% of sites (11/67) did not have 24-hour access to urgent RCE for children either at their site or via their specialist centre (Table 1c).

Table 1c: Urgent RCE availability

Urgent RCE (Automated or manual)	24 hours a day facility (on site; specialist centre; or combination)	Availability	Weekdays 9am -5pm	Weekends Sat 9am–Sun 5pm	Nights 17:01-08.59
Adults	**90% (64/71)**	**On site**	76% (54/71)	73% (52/71)	70% (50/71)
		Specialist centre	17% (12/71)	18% (13/71)	20% (14/71)
		No	7% (5/71)	8% (6/71)	10% (7/71)
Children	**84% (56/67)**	**On site**	45% (30/67)	45% (30/67)	45% (30/67)
		Specialist centre	42% (28/67)	39% (26/67)	39% (26/67)
		No	13% (9/67)	16% (11/67)	16% (11/67)
denominator is those sites that responded					

Organisation Standard 7

Regular administration of transfusion and its monitoring occurs locally where possible

An elective top-up transfusion within working hours could be provided to adults at 93% of sites (66/71), and children at 91% of sites (60/66) (Tables 1d & 1e).

Type of transfusion and availability (Adults)

Table 1d Numbers of hospitals that can deliver the different transfusion services for adults (74 sites)

Transfusion type	Availability	Adults In hours	Adults weekends	Adults night
Automated RCE Urgent	**On site**	29% (20/69)	17% (12/69)	16% (11/69)
	Specialist centre*	67% (33/49)	56% (32/57)	53% (31/58)
Automated RCE Elective	**On site**	25% (17/68)	6% (4/68)	3% (2/68)
	Specialist centre*	71% (36/51)	50% (32/64)	47% (31/66)
Manual RCE Urgent	**On site**	70% (50/71)	69% (49/71)	68% (48/71)
	Specialist centre*	57% (12/21)	55% (12/22)	52% (12/23)
Manual RCE Elective	**On site**	46% (33/71)	20% (14/70)	17% (12/70)
	Specialist centre*	37% (14/38)	23% (13/56)	22% (13/58)
Top up transfusion Urgent	**On site**	96% (68/71)	96% (68/71)	93% (66/71)
	Specialist centre*	33% (1/3)	33% (1/3)	20% (1/5)
Top up transfusion Elective	**On site**	93% (66/71)	63% (44/70)	49% (34/70)
	Specialist centre*	20% (1/5)	4% (1/26)	3% (1/36)

Denominator is those sites that responded to each transfusion type question
* Sites were asked what they did if they did not offer a service (i.e. whether they contacted their specialist centre, including organising a retrieval service, or did not offer the service)

Automated Red Cell Exchange (RCE) for adults

29% of hospitals delivered automated urgent RCE to adults; this was less common out of hours even for urgent cases (Table 1d). The majority (53 to 67%) of hospitals not administering automated RCE would seek urgent RCE elsewhere (Table 1d). (Additional data according to transfusion activity Table S2).

Manual Red Cell Exchange (RCE) for adults

70% (50/71) of hospitals said they could deliver an urgent manual RCE for an adult within working hours. Of 21 hospitals not administering manual RCE for adults and giving data about alternative arrangements, 57% (12/21) would contact their specialist centre (Table 1d).

Top-up transfusion for adults

Most hospitals (93 to 96%) could deliver an urgent top-up transfusion to an adult at any time of day or night (Table 4). However, 7% (5/71) were unable to give an urgent top-up transfusion to an adult during the night and 4% (3/71) could not do this at weekends. Elective transfusions could be delivered to an adult with SCD in working hours but this fell to 49% (34/70) during the night and 63% (44/70) at weekends. Only one of four hospitals who did not administer top-up transfusions and provided information would ring their specialist centre.

Type of transfusion and availability (Children)

Table 1e Numbers of hospitals that can deliver the different transfusion services for children (75 sites)

Transfusion type	Availability	Children In hours	Children weekends	Children night
Automated RCE Urgent	**On site**	17% (11/65)	14% (9/65)	14% (9/65)
	Specialist centre*	61% (33/54)	55% (31/56)	54% (30/56)
Automated RCE Elective	**On site**	19% (12/64)	5% (3/64)	5% (3/64)
	Specialist centre*	59% (32/54)	51% (31/61)	49% (30/61)
Manual RCE Urgent	**On site**	44% (28/64)	44% (28/64)	44% (28/64)
	Specialist centre*	67% (24/36)	64% (23/36)	69% (24/36)
Manual RCE Elective	**On site**	33% (21/64)	14% (9/64)	13% (8/64)
	Specialist centre*	56% (24/43)	42% (23/55)	41% (23/56)
Top up transfusion Urgent	**On site**	96% (63/66)	94% (62/66)	91% (60/66)
	Specialist centre*	33% (1/3)	50% (2/4)	33% (2/6)
Top up transfusion Elective	**On site**	91% (60/66)	67% (44/66)	48% (32/66)
	Specialist centre*	50% (3/6)	9% (3/22)	12% (4/34)
Denominator is those sites that responded to the question * Sites were asked what they did if they did not offer a service (i.e. whether they contacted their specialist centre, including organising a retrieval service, or did not offer the service)				

Automated Red Cell Exchange (RCE) for children

19% (12/64) of hospitals who looked after children could deliver an automated elective RCE to children (Table 1e). Out of hours, availability dropped to 5% (3/64) for elective and 14% (9/65) for urgent procedures. The majority (54 to 61%) of hospitals not administering automated RCE would seek urgent RCE elsewhere (Table 1e). (Additional data according to transfusion activity Table S2)

Manual Red Cell Exchange (RCE) for children

Urgent manual RCE could be provided by 44% (28/64) of hospitals looking after children with SCD (Table 1e). The majority (64 to 69%) of hospitals who did not perform manual RCE would seek urgent RCE elsewhere (Table 1e).

Top-up transfusion for children

Most hospitals (92 to 96%) could deliver an urgent top-up transfusion to a child at any time of day or night (Table 1e). However, 9% (6/66) were unable to give an urgent top-up transfusion to a child during the night and 6% (4/66) could not do this at weekends. Elective transfusions could be delivered to a child with SCD in working hours but this fell to 48% (32/66) during the night and 67% (44/66) at weekends. Half of hospitals (3/6) who did not administer elective top-up transfusions and provided information would ring their specialist centre.

Discussion

Participation

Overall participation in this audit was good. Most hospitals (69/80) saw both adults and children.

Types of Service and Networking

NHS England has specified that care will be delivered by a specialist haemoglobinopathy centre (SHC) acting in a hub and spoke model with linked haemoglobinopathy centres (LHC) to support and coordinate a network of care for all patients in the geographical region (3).

In this audit, hospitals reported themselves as an SHT or an LHT.

86% (25/29) of all sites that classified themselves as an SHT had a medium or high transfusion activity (Table S1). 73% (35/48) of sites that classified themselves as an LHT had a low transfusion activity (Table S1). 54% of LHTs did not consider themselves to be part of a network.

All hospitals may encounter patients with SCD particularly in an emergency or through patient relocation e.g. for further education. Thus whilst they do not need to have a dedicated team of sickle cell specialists, arrangements should be in place to manage these patients safely, even if they present infrequently. Without a network it is not clear how local teams will find assistance from those with specialist experience. Furthermore there is unlikely to be any provision for education and training in blood transfusion in SCD across the geographical area.

Policies and Documentation

The availability of protocols and guidelines was generally poor.
Guidelines on when to perform a RCE were not available at: 43% of sites caring for adults, and 59% of sites caring for children (Table 1a).

Of those sites that performed RCE (automated or manual), there were no guidelines on how to perform the procedure at: 30% of sites caring for adults, and 24% of sites caring for children (Table 1a).

National standards require all hospitals to have guidelines on indications for top-up and exchange red cell transfusion and protocols for administration. These guidelines and protocols should be agreed and shared across the network. While it may not be appropriate to have an automated RCE training protocol or a guideline if this is not available on site, all hospitals should be capable of performing a top-up transfusion or manual RCE for the critically ill patients where it is potentially life-saving. This lack of guidelines and provision for emergency blood transfusion is of concern as delayed transfusion can have serious or even fatal consequences for the patient with SCD.

Staffing

Most adults with SCD (91%) have access to consultant haematologist support and, particularly in the larger centres, consultants with a specialist experience in SCD are usually available (Table 1b). Fewer children with SCD (69%) have access to consultant paediatricians or consultant paediatric haematologists with a special interest in SCD (Table 1b).

Nursing support for these patients was variable with clinical nurse specialists for either adults or children in only half the hospitals; link nurses, especially in paediatric wards were rare. This is in discordance with the guidance of the RCN nursing competencies (14). In the hospitals with larger cohorts nursing support was better at 88% and 81% for adults and children respectively.

Although this audit reviewed consultant medical staffing, it did not ask how much of the consultants' job-plan time was allocated specifically to SCD nor did it address junior doctors and out of hours access. There are no clear guidelines on "adequate" staffing numbers for any given SCD population so it is difficult to comment on the findings. Medical and nursing staffing standards are in place for the peer review programme (2, 6, 7) and workforce issues were also addressed in a recent survey, which had not been published at the time of this audit (15). Inadequate medical and nursing support will impact on training of non-specialist staff both within the centres and across the network.

Adult patients were commonly (26% of sites) not admitted under haematology teams, and at half of these sites never came under haematology care. Since these will mostly be urgent admissions of patients who are at risk of acute complications (which may require blood transfusion) there is need for trained nurses and general physicians. Clear protocols and pathways of care across the network would assist this.

Type of Transfusion

10% of sites (7/71) did not have 24 hour access to urgent RCE (automated or manual) for adults either at their site or via their specialist centre (Table S3). 16% of sites (11/67) did not have 24 hour access to urgent RCE for children either at their site or via their specialist centre (Table S3). Some form of RCE must be available for all acutely unwell patients.

Automated RCE is a relatively complicated procedure which needs appropriately trained nursing staff as well as access to cell separators and consumables. Most hospitals in this audit (71% of sites caring for adults and 83% of sites caring for children) were unable to provide automated urgent RCE on site, but the majority (53 to 67%) were able to access it via their specialist centre (Tables 1d & 1e).

Those on long-term transfusion programmes should be considered for automated RCE, as it extends the period between transfusions, is associated with less alloimmunisation,(16) and leads to less iron loading. (17) There are additional considerations for children, but a NICE Health technology assessment suggests that automated RCE for SCD should be considered in children as well as adults (18). The advantages of automated RCE over manual RCE in an emergency are different, these include more accuracy and speed at achieving desired haematological indices, with a finer control of fluid balance.

Provision of Blood and NHSBT resources

Red cell demand for patients with SCD will continue to rise as numbers of children needing transfusion for stroke prevention increase and older patients are surviving longer and developing chronic complications for which transfusion may be needed. This will require additional service provision in terms of facilities, staffing and training.

Recommendations

1. **Commissioners should work with NHS Trusts and Health Boards to ensure the delivery of clinical networks of care for children and adults with sickle cell disease (SCD). There should be clear pathways and management protocols for emergency and elective blood transfusion for all patients in the geographical area including access to automated red cell exchange (RCE), where indicated.**

2. **All hospitals that admit SCD patients should have protocols, training and documentation for staff in transfusion including manual RCE for children and adults.**

3. **NHS Trusts and Health Boards should undertake regular service planning and capacity arrangements to meet the growing requirements for blood transfusion in SCD. This includes the provision of out of hours' transfusions for patients on long term transfusion programmes.**

Section 2: Transfusion specifics and delivery - What blood is being transfused, why, how, where, when, and by whom

Results

Eighty-four sites submitted 1290 cases to the case-capture audit, median 6 (IQR 2 to 15) cases per site, range 1 to 151.

- 41 sites submitted 1 to 4 cases (total 84 cases),
- 25 sites submitted 5 to 24 cases (total 235 cases) and
- 18 sites submitted 25 or more cases (total 971 cases)

The majority, 75% (971/1290) of all cases came from the 18 sites submitting 25 or more cases, of which 84% (812/971) came from 14 sites located in the London area.

Who is being transfused

The sample comprised 635 males and 655 females. The median (IQR) age of males was 24 years (12 to 38), and 37% (238/635) were under 18 years; the median (IQR) age of females was 26 years (14 to 40) and 30% (198/654) were under 18 years.

The majority of transfusions were administered to HbSS patients

- HbSS 91.2%, (1164/1276)
- HbSC 5.2% (66/1276)
- HbS/β thalassaemia 2.4% (31/1276)
- All other sickle genotypes 1.2% (15/1276)

2% of patients (27/1267) had a previous history of hyperhaemolysis.

What blood is being transfused

Most patients required blood that was Kell negative (99%; 1221/1236) and Rh CE negative (60%; 732/1227).

Type of Transfusion

A transfusion episode was defined as a period of up to 72 hours during which patients received a red cell transfusion for the same indication using the same modality. The total number of transfusion episodes during the audit period submitted was 4,528, with a median number of 3 (IQR 1 to 5) per patient. The transfusion modalities differed according to size of site and age (Figure 1).

Top-up transfusion was the most common type of transfusion (62%; 2785/4528). Automated RCEs accounted for 31% of transfusions (1405/4528). Manual RCEs were uncommon (6%; 261/4528).

Adults received 56% of all transfusions (2534/4528). Overall automated RCE was the commonest type of transfusion (50%; 1271/2534), most were performed in high transfusion activity sites. In low (77%; 62/81) and medium (62%; 224/363) transfusion activity sites top-up transfusion was the commonest type of transfusion

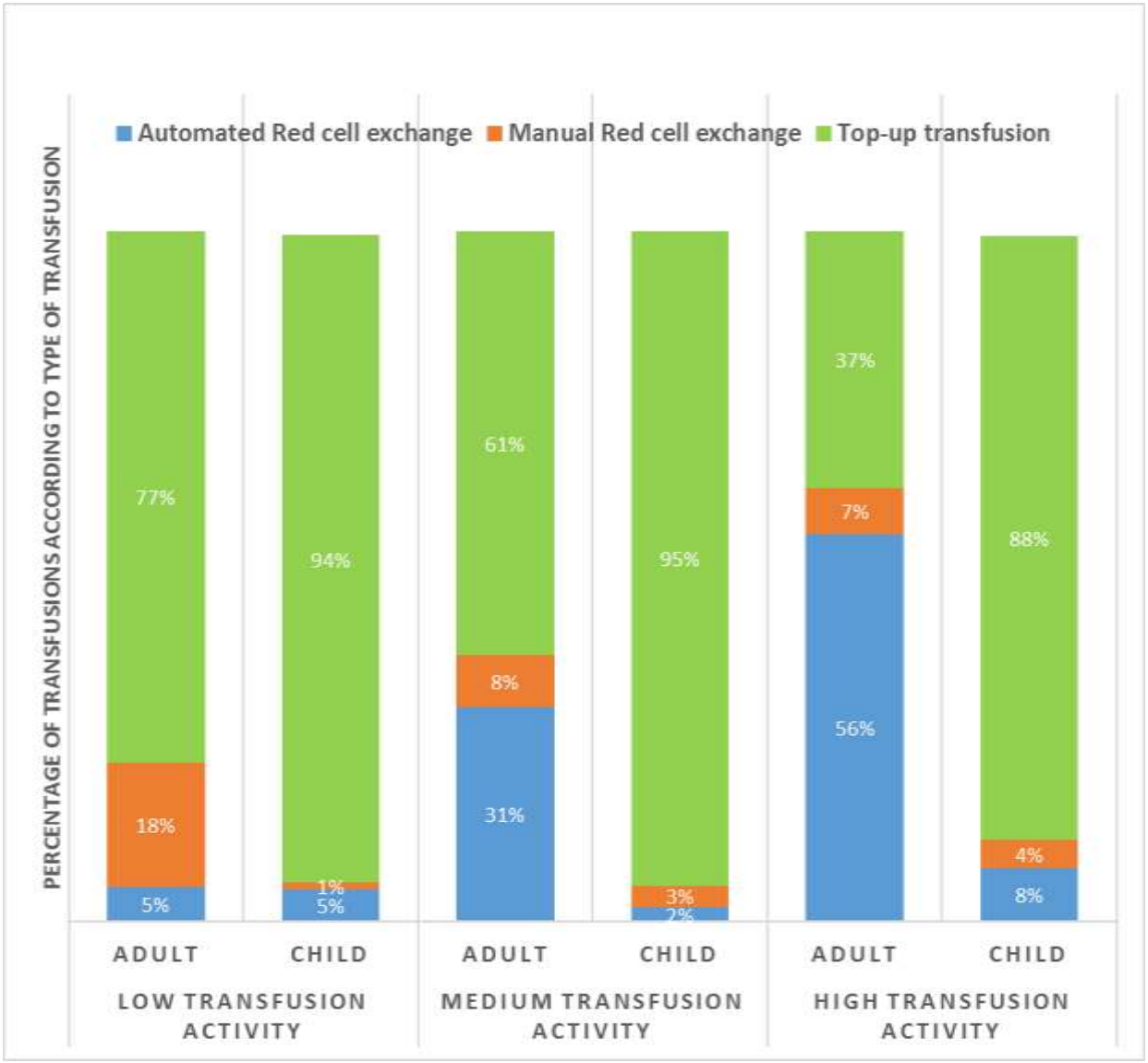
Manual RCEs overall were uncommon accounting for 7% (181/2534) of all transfusion episodes (Table

S4).

Children received 44% of all transfusions (1990/4528). Top-up transfusion was the commonest type of transfusion (87%; 1736/1990), this was unaffected by the size of the site. Only small proportions of children received RCEs at all, either manual (4%; 80/1990) or automated (7%; 130/1990). The lower the transfusion activity of the site, the less likely a child was to receive an automated RCE transfusion (Table S4).

Figure 1 Transfusion episodes by transfusion activity, type of transfusion, and age

(See Table S3 for additional data)



Urgency of Transfusion

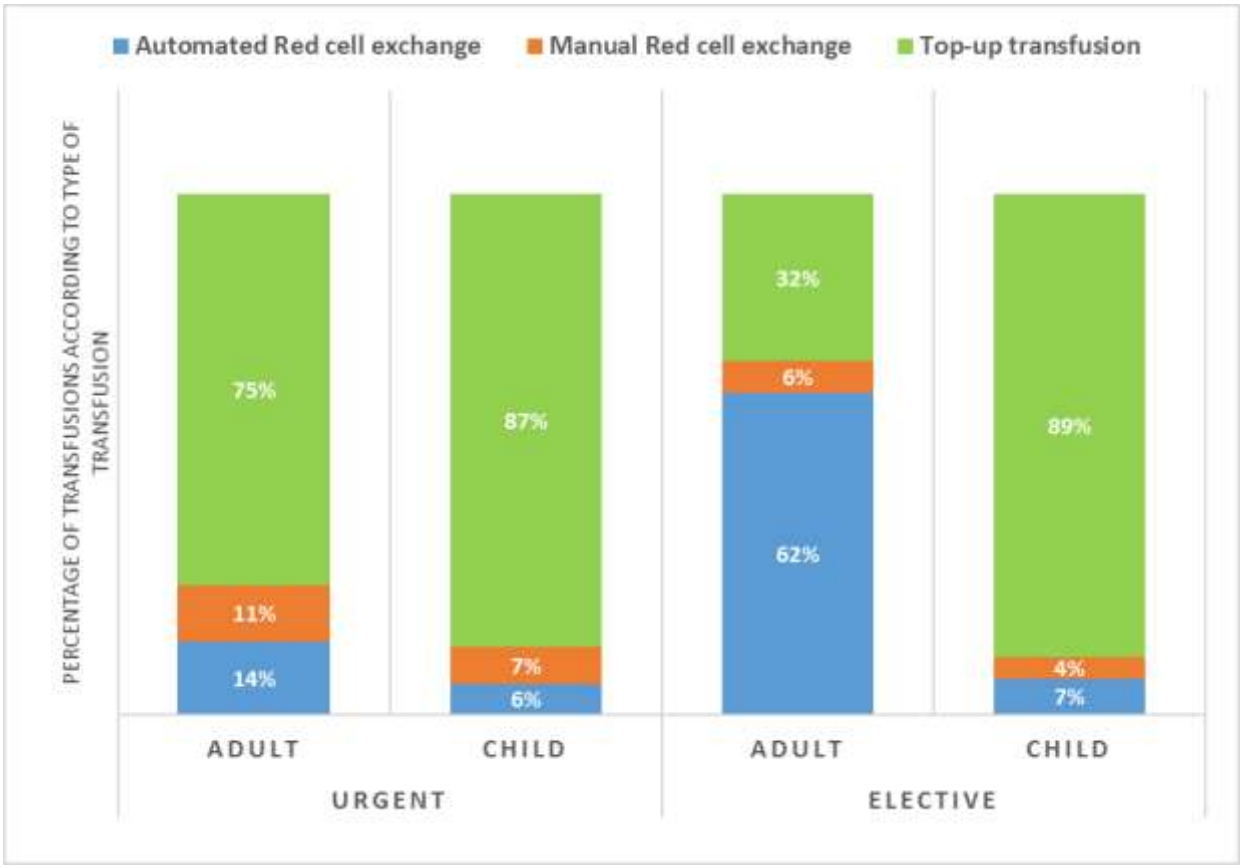
Most transfusion episodes were elective (84%; 3803/4528). The smaller the centre the more likely a patient was to receive an urgent transfusion:

- 39% (81/210) of episodes at sites with a low transfusion activity;
- 25% (172/692) of those with a medium transfusion activity;
- 13% (468/3626) of those with a high transfusion activity.

This pattern was seen for both children and adults. Automated RCEs were more likely to be used in elective rather than urgent cases (Table S3).

Urgent transfusions constituted a higher proportion of total transfusions in adults (22%; 566/2534) than children (8%; 155/1990) (Figure 2). For children the type of transfusion did not differ significantly between urgent (84% top-up; 130/155) and elective (88% top-up; 1605/1834) transfusion episodes. However, for adults there was an inversion of this pattern: 74% of emergency transfusions were top-ups while only 32% of routine transfusions were top-ups, reflecting the greater use of elective RCE transfusions in adults (Table S3).

Figure 2 Percentage of transfusions by urgency and type of transfusion



Indication for transfusion

Stroke prevention was the most common reason for transfusion. It accounted for 42% (1914/4528) of all transfusion episodes:

- children: 65% (1290/1990) of all transfusions.
- adults: 24% (620/2534) of all transfusions.

Stroke prevention was the main reason for elective transfusions (50%; 1914/3803), followed by prevention of recurrent vaso-occlusive pain (17%; 636/3803), and "no reason given" (15%; 563/3803) (Figure 3 & Tables S4-6).

"Acute or chronic anaemia" was the main reason for urgent transfusions (30%; 215/721), followed by "other" (23%; 166/721) and acute chest syndrome (18%; 127/721) (Figure 4 & Table S4-6).

When are transfusions given?

Transfusions were mostly administered in the second half of the working week:

- 67% (3035/4516) of transfusions were given Wednesday to Friday
- 92% (4158/4516) of transfusions were given during Monday to Friday.

Only 1% (19/1405) of automated RCE occurred during the weekend, whereas 20% (143/716) of urgent transfusions occurred at the weekend (Table S7).

Who delivers transfusions in SCD and where?

NB: This information was derived from the organisational audit rather than the clinical audit

Automated red cell exchange (RCE) services

Automated RCE procedures were most commonly performed by specially trained apheresis nurses.

In adults:

76% (13/17) of sites for elective weekday RCE

80% (16/20) of sites for urgent weekday RCE

100% of sites that provided an out-of-hours service (Table S8).

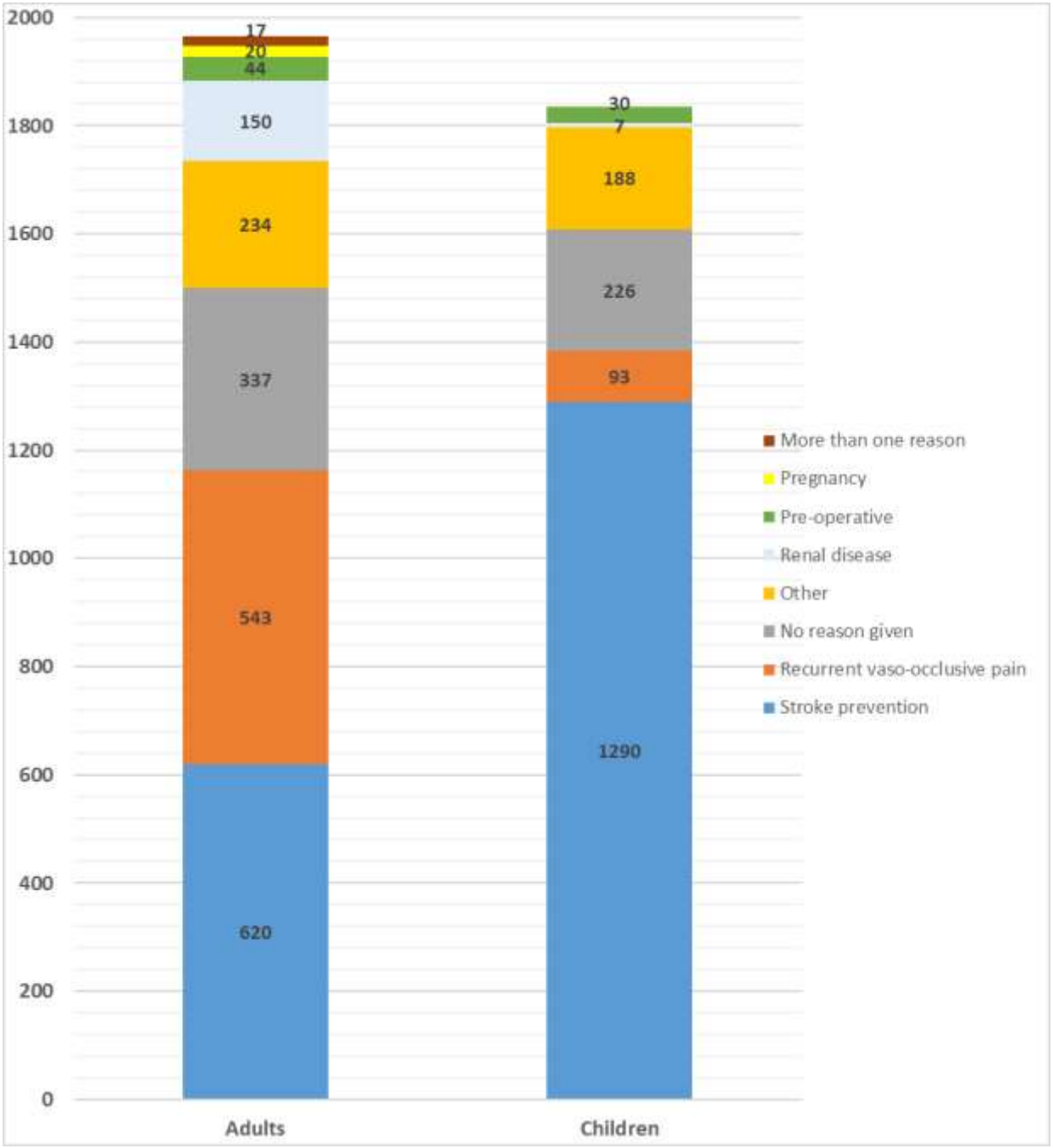
In children:

75% (9/12) of sites for elective weekday RCE

82% (9/11) of sites for urgent weekday RCE

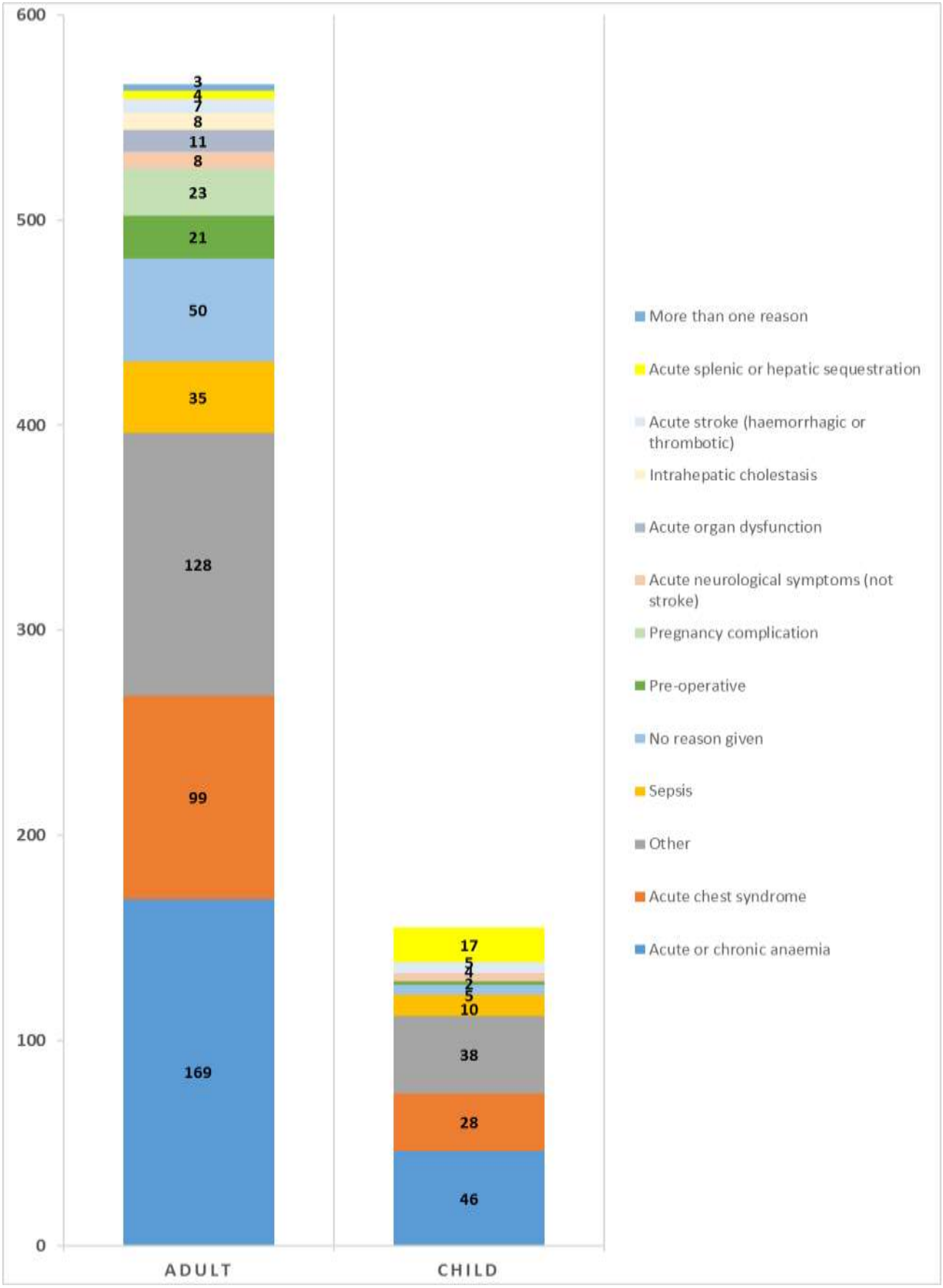
78% (7/9) of sites that provided an out-of-hours service (Table S8).

Figure 3: Indications for elective transfusion episodes (1965 adult & 1834 child transfusion episodes)



See Table S5 (Adults) and Table S6 (Children) for further information

Figure 4: Indications for urgent transfusion episodes (566 adult & 155 child transfusion episodes)



See Table S5 (Adults) and Table S6 (Children) for further information

In adults, all sites that answered the question could perform RCE transfusions on HDU/ITU (19/19), the hospital ward (18/19) or day care during the week (15/19) (Table S9). 1/20 sites did not answer the question.

In children, all sites that answered the question (11/12) could perform RCE transfusions on HDU/ITU (11/11), however 2 sites only performed it on HDU/ITU (Table S9). All other sites performed it on day care or the hospital ward (9/11). 1/12 sites did not answer the question.

In adults, the most common route of venous access was peripheral (55%; 11/20), followed by temporary central venous access (40%; 8/20) and use of permanent central access (5%; 1/20).

In children hospitals were equally likely to use peripheral access (6/12 hospitals) as central access (6/12) for RCEs.

Manual red cell exchange (RCE) services

In adults, junior doctors usually perform urgent procedures (78%; 39/50 weekday: 82%; 40/49 weekend) or elective procedures that occurred out of hours (57%; 8/14 weekend). Specialist nurses and junior doctors performed elective procedures during the week (both 58%; 19/33) (Table S10).

In children, junior doctors usually performed all procedures, whether urgent or elective (89%; 25/28 weekday urgent: 96% 27/28 weekend urgent: 76%; 16/21 week day elective) (Table S10).

Although the majority of sites could perform manual RCE on the ward (76%; 38/50 sites that care for adults: 79%; 22/28 sites that care for children), a significant minority of sites only performed it on HDU/ITU (22%; 11/50 sites that care for adults: 21%; 6/28 sites that care for children) (Table S11).

Similar to automated RCE, the most common route of venous access was peripheral 65%; 28/43 of sites that care for adults: 75%; 21/28 sites that care for children), followed by temporary central venous access (46%; 22/48 sites that care for adults: 25%; 7/28 sites that care for children). Some hospitals did not use temporary central venous access to deliver a manual RCE to adults (2/50) or children (5/28).

Top-up transfusion

Ward nurses usually perform urgent (94%; 64/68 weekday adult: 96%; 64/67 weekend adult; 87% 55/63 weekday child: 92% 57/62 weekend child) and elective (77%; 51/66 weekday adult: 93%; 41/44 weekend adult: 80%; 48/60 weekday child; 82%; 36/44 weekend child) top-up transfusions (Table S12). Patients could receive elective top-up transfusions in day care during working hours at the majority of sites (88%; 60/68) in adults and children (67%; 42/63). (Table S13).

The most common method of administering top up transfusions was by peripheral access (97%; 66/68 adults: 97%; 61/63 children), 16% (10/62) of sites that care for adults said they did not use temporary central venous access to deliver a top-up transfusion. This increased to 30% (16/54) of sites that care for children.

Discussion

Who is being transfused

This is a young population. This overrepresentation of younger patients is also noted in the NHR (National Haemoglobinopathy Registry) (19).

What blood is being transfused

This audit shows that the Rh phenotypes of patients with SCD broadly reflect the BAME (black African/black/Caribbean/black British/other groups) donor populations. NHSBT has targets addressing what percentage of their blood requests from hospitals are supplied "on time in full" (OTIF). This is a continuous audit of what proportion of the requests are delivered in the actual phenotype and other specifics requested. 50% of requests for Ro red blood cell components are not made on time and in full "OTIF" i.e. a compatible substitution had to be made. The most common substitution is O rr for O Ro. While this is acceptable according to matching guidelines, this is the usual group for emergency O rr stocks in the emergency department, theatre and labour ward, thus putting a lot of pressure on this specification. Aside from this, 65% of the Ro donors are Caucasian, and thus may not always match the rarer phenotypes more commonly seen in BAME such as Fya and Fyb negativity.

Size and location of hospital unit and type of transfusion

SCD differs from other inherited disorders in that the geographical distribution of patients is very uneven, with up to 80% patients receiving hospital care in London (data from the National Haemoglobinopathy Registry). 65% (839/1290) of patients in this audit were transfused by hospitals in Greater London.

Overall, the commonest type of transfusion was a top-up transfusion (62%). However, in adults, automated RCE was the most common type of transfusion (50%), whereas it was only performed in 7% of children. This disparity may reflect the fact that most departments do not have access to an apheresis machine for their paediatric population, very few people are trained in paediatric red cell apheresis, or difficulty with adequate venous access or a combination of reasons. Experienced apheresis nurses using ultrasound guided cannulation can reduce the need for central venous access to around 10% of people (adults and children) on regular automated RCE programmes (20).

Indications for transfusion

Most transfusions were elective (84%; 3803/4528). The most common reason for transfusion was stroke prevention (42% of all transfusion episodes). Many adults were receiving transfusions for this indication, perhaps reflecting the increasingly recognised burden of cerebrovascular disease in adults with SCD. It is difficult to predict how this number will change with time. More patients with SCD are living longer, with an accompanying increase in strokes and some of the adult cohort will be children identified by STOP criteria (21) as at risk of stroke who have now reached adulthood. Additionally, more children may be starting transfusions to prevent silent cerebral infarctions (SIT study) (22), although to date this number is thought to be small.

The other major elective reason for transfusion was to prevent recurrent episodes of acute pain in adults (17%; 636/3803). Transfusions have been shown to decrease the frequency of painful crises (23, 24). If hydroxycarbamide does not work or is contraindicated, transfusion is the only currently available alternative disease modifying therapy.

Acute chest syndrome and anaemia were common reasons for urgent transfusion in both adults and children with SCD. As expected, acute anaemia was nearly always treated with top-up transfusion. In

children only 11% (3/27) of transfusions for acute chest syndrome were RCEs (Table S6), whereas in adults RCEs were performed in 45% (45/99) cases (Table S5), this may reflect the more limited provision of RCE services for children.

When are transfusions performed?

Most transfusions occurred on Wednesday to Friday, with fewest at weekends. This may reflect the facts that: most transfusions were elective; and the requirement for a group and save sample within 72 hours of the transfusion.

Recommendations

1. **Blood services need to ensure availability of Ro blood.**

Section 3: Laboratory transfusion practice

Results

NB: Unless specifically stated, this information was derived from the organisational audit rather than the clinical audit.

Phenotype and Genotype

The Rh, Kell and ABO groups broadly matched the groups seen in Black Caribbean/Black British/Black African blood donors.

Most patients (95%, 1227/1290) transfused in the audit had an Rh phenotype or genotype result available.

Laboratory standard 1

Red cells are Rh and Kell matched

99% (79/80) of laboratories Rh matched blood.

98% (78/80) of laboratories Kell matched blood.

96% (77/80) of laboratories Rh and Kell matched blood.

Two laboratories matched for C, E and K, similar to North American protocols.

Laboratory standard 2

Full red cell phenotype is available

Only 71% (904/1282) of patients transfused in the audit had a full red cell phenotype or genotype available at the time of the transfusion. This differed little by site transfusion activity (64%, 54/84 low; 70%, 163/233 medium; 71%, 687/965 high).

Laboratory standard 3

Continuous availability of transfusion services

96% (77/80) hospitals could perform an Rh phenotype on site at any time.

Just under half (45%, 36/80) of the hospitals would perform a full red cell phenotype in-house although 19% (7/36) of those would then send to NHSBT for confirmation. Most hospitals (82%, 65/79) send their genotype to NHSBT though 18% (14/79) do not. It is not clear whether in-house genotypes would include the Rh variants.

Special Requirements

Age of blood

Laboratory standard 4

Age of blood is less than 7 days old for a planned red cell exchange (RCE)

44% (35/80) of hospitals requested blood less than 7 days old for a planned RCE. 20% (16/80) of hospitals did not perform a RCE.

Laboratory standard 5

Age of blood is less than 2 weeks old for a top-up transfusion

26% (21/80) of hospitals requested blood 8 to 14 days old for a top-up transfusion. 28% (22/80) of hospitals requested fresher blood than guidelines suggest (15% (12/80) less than 7 days old; 5% (4/80) less than 10 days old; and 8% (6/80) freshest available).

CMV negative

Laboratory standard 6

Donor cells are not CMV negative for sickle cell disease unless there is another appropriate reason

5% (4/79) of hospitals routinely ask for CMV negative blood for people with SCD.

Cross-matching and antibody screens

Laboratory standard 7

Maximum of 72 hours from group and save sample being received to blood administration if patient was transfused less than 28 days previously

93% (74/80) of hospitals' laboratory acceptance criteria conformed to the standard. In 3 hospitals this could be extended under certain circumstances to one week, also in line with BSH guidance for those on [illegible] transfusions (23).

80% (59/74) of hospitals could provide a cross-match and RCE transfusion on the same day for routine transfusion in adults, and 75% (56/75) for children.

Information technology

Most hospitals were still using paper request forms for a transfusion (88%, 70/80). Although many used more than one mode of communication with 78% (62/80) using telephone calls and 35% (28/80) using an electronic blood order system. In addition, 5% (4/80) mentioned the use of a special requirements form, although this question was not asked directly.

Transfusion laboratories use transfusion LIMS to record information about the patient, their requirements and their transfusion history. In just under half (45%, 36/80) of hospitals, the transfusion LIMS had a field specifying whether the patient had SCD, and it was a mandatory field in a third (36%, 13/36).

55% (44/80) of hospitals used electronic issue in SCD patients with no history of alloimmunisation. There was no correlation between use of electronic issue and transfusion activity of the hospital.

Urgent transfusions

When hospitals were asked about their policy for providing blood when a patient needs an urgent transfusion, most hospitals knew to check current stock for compatible units that were marked sickle negative (91%, 73/80). If compatible units were not marked sickle negative: 26% (21/80) would contact their blood service to ask if donors had been previously tested as sickle negative: 13% (10/80) would look at the electronic delivery note to see if donors had been previously tested as sickle negative; 16% (13/80) would waive the sickle negative requirements.

Hospitals ordering blood from NHSBT (74%, 59/80) reported by 32 hospitals that the emergency delivery time ranged from less than 30 minutes to 2 hours 15 minutes, median time 1 hour 30 minutes.

Communication with NHSBT and SHOT

Only 82% (61/74) of the hospitals in England and North Wales can access NHSBT results on patients electronically using SpICE, when processing a sample from a patient with sickle cell disease. Of these, just over a third (36%, 22/61) would always do this. Of those with access to SpICE, 83% (48/58) of laboratories who answered the question agreed to allow their own tests to be shared on SpiCE.

From 2009 to 2014, 35% (27/77) of hospitals had reported to SHOT a transfusion-related serious adverse event in sickle cell patients. 22% (17/78) of hospitals had reported to SHOT an adverse event related to specific requirements not being met.

Record of transfusion administration

Transfusion volumes were mostly recorded on the prescription chart, though were not in 21% (16/75) of hospitals for children and 15% (11/74) of sites for adults. Other places where transfusions may have been recorded were hospital communication sheets and transfusion laboratories. There were some free text comments about the use of electronic devices, but their use was rarely commented on.

Discussion

Hospitals should allow information sent to their Blood Services about red cell geno/phenotype and alloantibodies to be accessed by other hospitals in accordance with the revised Caldicott principles.

The 50:50 split between hospitals that use electronic issue (EI) and those who do not is likely to reflect the lack of published data on the use of EI in sickle cell disease. While it may well be safe, some of the antigen panels for antibody identification differ between hospitals and may not include those antigens although rare, that are present in those from BAME backgrounds.

Recommendations

1. **Rh and Kell blood groups should be known prior to transfusion. Red cell geno/phenotypes should be sent to the national blood service so that the results will be available throughout the patients' lives wherever they choose to attend for their patients' care.**

2. **Hospitals should ensure that there is clear guidance on how staff inform the transfusion laboratory of patients who have sickle cell disease. This may be through electronic requesting.**

3. **Transfusion laboratories should have a specific SOP on SCD which incorporates:**
    a. **Identification of a patient who has SCD including in an urgent situation**
    b. **Patient who may have been transfused elsewhere**
    c. **Use of electronic dispatch note (EDN) where available**
    d. **Contacting National Blood Service for any additional support in finding appropriate units for transfusion and using SpiCE or equivalent where available**
    e. **When consideration can be made to override age requirements of donor units**
    f. **When to escalate to the senior medical haematology team for support in such decisions**

4. **Hospital should allow transfusion information sent to their National Blood Service to be shared with other hospital laboratories.**

5. **Electronic issue (EI) can be considered where there is no history of alloimmunisation.**

Section 4: Clinical Scenarios

Results

In Part 2 of the clinical audit, we asked sites to audit some of their patients (identified from Part 1 of the clinical audit) in more depth. These were patients who had received a transfusion for one of the following reasons:

- Stroke prevention
- Pregnancy complication prevention
- Acute chest syndrome
- Acute stroke (haemorrhagic or thrombotic)
- Pregnancy complication
- Hyperhaemolysis

Stroke prevention and acute chest syndrome were the two commonest reasons for transfusion. So hospitals did not have to do too much data collection, if a hospital had more than 10 patients transfused to prevent a stroke or to treat acute chest syndrome then a random sample of 10 was chosen, this was done for adults separately to children. Thus the maximum number of patients that a hospital could audit in part 2 was 10 adults and 10 children for either or both categories.

Table 4a: Summary Data

Indication	Cases requested	Cases submitted
Elective		
Stroke Prevention	189	183
Pregnancy complication prevention	12	11
Urgent		
Acute chest syndrome	105	92
Acute stroke	7	7
Pregnancy complication	14	11
Hyperhaemolysis	0	0
Total	**327**	**302**

Stroke Prevention

Stroke prevention was the commonest reason for a transfusion in this audit. More detailed information was available on 183 cases.

Reason(s) for initiating a stroke prevention programme

Table 4b: Rationale for Transfusion

	Total (n = 183)		Adults (n = 81)	Children (n = 102)
Primary stroke prevention	**49%**	**(89)**	**9% (7)**	**80% (82)**
High transcranial Doppler velocity	42%	(76)	4	72
Silent cerebral infarcts	10%	(19)	4	15
Secondary stroke prevention	**51%**	**(94)**	**91% (74)**	**20% (20)**
Arterial thrombosis / embolus	38%	(70)	55	15
Moya-moya	7%	(12)	9	3
Transient ischaemic attack (TIA)	6%	(11)	9	2
Not specified	4%	(8)	5	3
Haemorrhage (bleed)	3%	(6)	6	0
Venous thrombosis	0.5%	(1)	1	0

For primary or secondary stroke prevention more than one reason could be ticked

Primary stroke prevention was common in children (80%, 82/102), but uncommon in adults (9%, 7/81).

Effect of transfusion programme

Transcranial doppler

Children should receive at least yearly transcranial Doppler (TCD) scanning according to national standards. Of those children that were on a transfusion programme because of an abnormal TCD: in 58% (42/72) the TCD velocity had normalised, in 8% (6/72) TCD velocity was conditional (borderline between normal and abnormal), and in 13% (9/72) the TCD velocity remained abnormal. 19% (14/72) had not had a TCD within 12 months.

HbS%

The average pre-transfusion HbS% in the audit period (January 1st to June 30th 2014) was 33% (IQR 25 to 41) (reported for 176/183 cases). 79% (137/173) of cases had a target HbS% of 30% during this time. 13% (23/173) of cases had a higher target HbS% (35 to 50%).

Table 4c: Target HbS% according to type of transfusion

Target HbS%	Type of Transfusion		
	Automated exchange (52)	Manual exchange (11)	Top-up (110)
< 30	19% (10)	9% (1)	2% (2)
30	64% (33)	91% (10)	86% (94)
31 to 40	0% (0)	0% (0)	10% (12)
41 to 50	17% (9)	0% (0)	2% (2)

Duration of transfusion programme

The median age for initiation of a transfusion regimen was 8 years (IQR 5 to 14 years) (reported for 163/183 cases), that is, transfusion regimens for stroke prevention largely commence in early childhood.

Table 4d: Number of years patient has been on a regular transfusion programme

Number of years	Cases (183)	
0 to 5	55%	(101)
6 to 10	26%	(47)
> 10	17%	(31)
Not known	2%	(4)

Type of Transfusion

As in the case capture section, children were more likely to receive a transfusion as a top-up transfusion, and adults as an automated RCE. Manual RCE was uncommon in both adults and children.

Table 4e: Type of transfusion in adults and children

	Automated RCE	Manual RCE	Top-up transfusion	Total
Child (up to 18 years)	6% (6)	4% (4)	90% (92)	102
Adult	62% (50)	9% (7)	30% (24)	81

The mean number of units transfused per episode reflected the type of transfusion used (a RCE required more units) and the size of the individual: 7 (IQR 2 to 8) in adults, 2 (IQR 1 to 2) in children.

26% (47/183) used central venous access to administer the transfusion. The majority of these (57%, 27/47) were via an indwelling line.

Iron overload and iron chelation

The type of transfusion correlated with the amount of iron loading as measured by mean serum ferritin.

Top-up transfusion	1538 µg/l (IQR 1169 to 2427 µg/l, 112 patients)
Manual RCE	992 µg/l (IQR 27 to 2417 µg/l; 11 patients)
Automated RCE	502 µg/l (IQR 74 to 1623 µg/l; 53 patients).

Overall 66% (121/182) of patients were on treatment for iron overload. 15 patients with a ferritin > 1000 µg/l were not on chelation (8/40 adults and 7/75 children with serum ferritin > 1000ug/l).

When patients were treated for iron overload Deferasirox was the preferred chelating agent (93%; 112/121). Use of Desferrioxamine (7%; 8/121), and Deferiprone (0.8%, 1/121) were uncommon.

Transfusion complications

Transfusion complications are a major concern in patients with SCD but only 6 transfusion complications were observed in these 183 cases: 2 alloimmunisation; 1 vasovagal episode; 2 acute haemolytic reactions; and 1 hyperhaemolysis.

Acute Stroke (haemorrhagic or thrombotic)

We audited 9 transfusion episodes for acute stroke in 7 patients (Table 4f). The majority (7/9) of patients arrived at hospital via the Emergency Department, and 7/9 arrived outside normal working hours (9am-5pm Monday -Friday).

Both of the children with acute stroke had had a transcranial Doppler (TCD) in the last 2 years; 1 was normal and the other was abnormal. The latter child was admitted twice, at first admission with a pre HbS% of 34%, then transfused followed by a second admission 4 days later with pre-HbS% of 21%. He was then transfused to a post transfusion HbS of 17%.

Treatment of stroke

None of the patients were given thrombolysis.

Neither of the children were given anti-platelet agents. One adult was already on clopidigrel, another 2 adults were given antiplatelet agents (1 clopidogrel; 1 aspirin).

Consultant haematologists made the decision to transfuse in 8/9 episodes, decided on type of transfusion in 6/8 episodes; and decided the transfusion targets in 7/8 episodes. In all episodes (7/7) which reported it there was evidence of a discussion with a haematologist or a consultant paediatrician within 24 hours of presentation (0 to 21 hours), usually within 12 hours.

The two adults who had not recently received blood did not achieve the desired HbS% according to stroke prevention guidance. These were both adults, each with a single transfusion in the audited period (Table 4g).

One patient was not transfused until 65 hours after admission despite a discussion with a haematologist at the time of arrival.

Table 4f: Characteristics of patients with acute stroke

	Adult (6 episodes) (5 patients)	Child (3 episodes) (2 patients)
Male	3/5	2/2
Type of stroke		
Arterial thrombosis/embolus	1	3
Haemorrhage (bleed)	3	0
Venous thrombosis	1	0
Transient ischaemic attack (TIA)	1	0
Previous cerebrovascular events or problems		
Moya-moya	1	2
Abnormal transcranial Doppler (TCD)	0	2
Arterial thrombosis or embolism	1	2
Haemorrhage (bleed)	1	0
Transient ischaemic attack (TIA)	1	0
None known	4	0
Antihypertensive medication	2	0
Mean blood pressure (within 12 months when well)	128/78	116/54 (1 patient)

Outcomes

There were no transfusion complications during the episodes. None of the patients died, one had invasive ventilation. Data were not collected on post stroke disability.

Acute Chest Syndrome (ACS)

We audited 102 transfusion episodes during 92 admissions in 92 patients (68 adults, 24 children). Most (84%, 77/92) were self-referrals to the Emergency Department, though 8% (7) of patients (3%, 2/68 of adults and 21%, 5/24 of children) were admitted directly to the ward. Most patients were admitted during the day.

Table 4g: Type of Transfusion, pre and post-transfusion Haemoglobin (Hb g/L) and HbS%

Age of patient	Type of Transfusion	Transfused within 24 hours of admission	Pre-transfusion		Post-transfusion	
			Hb g/L	HbS%	Hb g/L	HbS%
Adult	Top-up	N	64	100	85	65
	Not stated	Y	81	100	103	73
	Automated RCE	Y	106	48	136	15
	Automated RCE	Y	126	48	109	30
	Top-up	Y	85	34	105	25
	Automated RCE	N	120	30	119	16
Child	Manual RCE	Y	124	46	137	10
	Manual RCE	Y	84	34	115	21
	Top-up	Y	80	21	105	17

Table 4h: Characteristics of patients with acute chest syndrome (ACS) (92 admissions of 92 patients)

	Adult (68 patients)	Child (24 patients)
Male	51% (35)	58% (14)
Reason(s) for admission		
Pain	93% (63)	67% (16)
Respiratory symptoms	32% (22)	50% (12)
Fever	6% (4)	54% (13)
Feeling unwell	15% (10)	33% (8)
Other	3% (2)	0% (0)
Surgery	1% (1)	0% (0)
Time from admission to diagnosis of ACS		
Same day	19% (11)	50% (11)
Next day	34% (20)	27% (6)
More than 1 day	47% (27)	23% (5)

A median drop in oxygen saturations of 4% from admission was present at the time of diagnosis of ACS, but most patients had normal oxygen saturations on admission (median 98% IQR 96 to 99%).

Treatment of acute chest syndrome

An arterial blood gas was performed in 55% (48/87) of episodes around the time that the decision to transfuse was made. This was much less common in children (18%, 4/22) than adults (68%, 44/65).

Most patients had not had a recent transfusion when ACS was diagnosed (HbS% median 87% IQR 73 to 100).

A consultant haematologist or paediatrician made the decision to transfuse in 85% (85/100) of episodes, decided on type of transfusion in 85% (81/95) of episodes; and decided the transfusion targets in 94% (76/81) of episodes.

Table 4i: Type of transfusion in adults and children

	Automated RCE	Manual RCE	Top-up transfusion	Unknown	Total
Child (up to 18 years)	-	8% (2)	88% (21)	4% (1)	24
Adult	17% (13)	29% (23)	53% (41)	1% (1)	78

Blood was requested the same day (43/96) or the day before (11/96) the diagnosis of acute chest syndrome in 56% (54/96) of transfusion episodes; in 17% (16/96) of transfusion episodes it was requested the day after the diagnosis. Blood was issued the same day (41/98) or the day before (8/98) the diagnosis of acute chest syndrome in 50% (49/98) of transfusion episodes, in 19% (19/98) it was issued the day after.

28% (28/101) of transfusion episodes required central venous access to administer the transfusion but this was only in place in 43% (12/28) of patients when the transfusion was required so this may have contributed to some delays.

The median hospital stay may be shorter for those who had an automated RCE (7 days, IQR 4 to 9, 13 transfusion episodes), than those who had a manual RCE (9 days, IQR 6 to 11, 25 transfusion episodes), or top-up transfusion (8 days, IQR 5 to 11, 62 transfusion episodes). The significance of this cannot be commented on due to the small numbers involved and multiple confounding variables.

Most patients were transfused on the ward (Table 4j). It should be noted that most hospitals do not have a paediatric ICU, although most general paediatric wards do have a dedicated HDU area that will vary between hospitals in the intensity of care that can be offered.

Table 4j: Location of the transfusion episodes for adults and children in ACS

	Children		Adults		Overall	
ICU		-	17%	13	13%	13
HDU	8%	2	10%	8	10%	10
Day care		-	6%	5	5%	5
Ward	92%	22	67%	52	73%	74

Ventilatory support

No ventilatory support was used in 43% (40/92) of patients (30/68 adults; 10/24 children); incentive spirometry was used in 29% (27/92: 17/68 adults; 10/24 children); non-invasive ventilation in 18% (17/92: 14/68 adults; 3/24 children); invasive ventilation in 1% (1/92: 1 adult); and unknown in 8% (7/92: 6/68 adults; 1/24 children).

Transfusion complications

There were 3 cases of transfusion complications during or after this episode of transfusion – one adult with delayed haemolytic reaction and hyperhaemolysis and two children with acute allergic/febrile/hypotensive reactions.

Outcomes

There were two deaths reported, both adults, 22 and 27 days after admission.

Pregnancy

There were two reasons for transfusion in pregnancy in this audit:

1. A one-off acute transfusion (defined as not on a regular transfusion programme)
2. Preventative transfusions as part of a long-term programme with regular transfusions at least every 6 weeks or more frequently.

On the basis of audit transfusion data received it seemed there had been some confusion about this classification. Consequently, and because the questions asked were the same, we combined them in this analysis and conducted data cleaning and re-allocated where it was clear the allocation had been incorrect.

There were 28 transfusion episodes in 25 attendances in 22 pregnancies. One twin and 21 singleton pregnancies. There were 20 recorded deliveries including one with twins (21 babies), outcome was unknown for 2 pregnancies. In 12 women this was their first pregnancy.

12 of the 22 women had a history of significant complications prior to pregnancy: recurrent vaso-occlusive pain (11), acute chest syndrome (4), sickle-related (3), sepsis (2), proteinuria/renal disease (2), thrombosis (1) and other (2).Two patients had been treated with hydroxycarbamide on a regular basis in the six months prior to pregnancy, two had received top-up transfusions, 18 were not on any disease-modifying treatment, and none had been on iron chelation.

The most common reasons stated for transfusion were symptomatic anaemia (13), vaso-occlusive pain (3), pre-operatively (2) and sepsis (2).

Clinical Audit Standard 1

The decision to transfuse in pregnancy should be discussed with a senior haematologist

The consultant haematologist usually decided on whether to transfuse (17/19), the transfusion modality (13/16) and the blood targets (Hb and HbS%) for transfusion (14/14).

Clinical Audit Standard 2

Routine prophylactic transfusion not indicated in pregnancy

Only three of the pregnant women were receiving regular transfusions. Two had a previous history of chest crises and recurrent vaso-occlusive pain during previous pregnancies. There was no information on the third case. Central venous access was usually required for two of these.

Eighteen mothers each received one unscheduled transfusion during pregnancy, delivery or puerperium, and three had 2 to 4 episodes during the audit period. No unscheduled transfusion required central venous access. Anaemia was a common feature prior to transfusion with median pre-transfusion Hb 70g/l (IQR 63 to 80 g/l) although it was not clear how this differed from their steady state Hb. In four cases the Hb was not known, this may be due to the fact that blood samples could have been taken by community midwives and sent to a different laboratory, although it is not clear. Sickle percentages were only recorded prior to half (11/21) of the transfusion episodes and the median HbS 78% (IQR 25-98%) suggested most patients were not transfused recently prior to this event.

Transfusion complications

There was one transfusion complication (alloimmunisation) noted in the 28 transfusions.

Outcomes

20 babies were delivered during the audit period (outcome unknown for 2 babies), 10 by normal vaginal delivery, 9 by caesarean section (4 planned, 5 emergency) and one assisted delivery (ventouse/forceps). All were live births. The immediate outcome was recorded in 14 of these 20 births: 11 went straight to the ward and 3 went to SCBU; 2 because of baby problems and one because of maternal problems.

The median weight of the baby was 2.72kg (IQR 2.10 to 3.15kg, data for 20 babies). The median length of time prior to the expected delivery day that the baby was actually delivered was 14 days (range 49 days before to 7 days after; data on 16 babies).

Discussion

From the Clinical Case Audit there were two scenarios (stroke prevention and acute chest syndrome) with sufficient patients to allow some reliable conclusions about the patient journeys and transfusion episodes. However, there were no cases of hyperhaemolysis reported and for acute stroke and pregnancy only a descriptive analysis can be made and no reliable conclusions drawn to allow formal recommendations.

Stroke prevention

Most children on regular transfusion were started as primary prophylaxis due to raised TCD velocities. However, for adults secondary stroke prevention predominated. Despite this transfusions were initiated for both children and adults primarily in childhood at a median of 8 years (IQR 5-14 years). Most patients had been transfused for less than 5 years (55%) and this probably reflects the fact that TCD screening was not fully established in the UK until 2005 so that one may assume that a proportion of the adults who were receiving transfusion for secondary stroke prevention would have been captured by TCD screening had it been available in their childhood.

Top-up transfusion is associated with increased iron loading compared to manual or automated RCE.

The audit has shown some areas of concern about the management of iron overload with 20% (8/40) adults with serum ferritin > 1000ug/l not receiving chelation and 9% (7/75) of children.

Acute stroke

Most patients with acute strokes arrived out of hours. Despite this 7/9 transfusion episodes were within 24 hours of presentation. Three adults received antiplatelet agents, but none received thrombolysis.

Adults with stroke without SCD receive thrombolysis as soon as possible but the evidence for use of thrombolysis in SCD is lacking. In addition, the frequent co-existence of significant cerebral vasculopathy is associated with concern regarding bleeding risk with thrombolysis and there is a paucity of demographic data on what happens to these patients both with or without thrombolysis. Only 2 patients had not been transfused recently prior to the stroke, suggested there was already existing pathology or recent hospital admission that led to these other patients being recently transfused, thus stroke in this cohort was a sequel to other problems.

While it was possible to get the HbS percentage down to levels that are usually aimed at for stroke prevention i.e. <30%, this was not achieved in those two patients who were un-transfused at presentation.

For children the transfusion choice was usually manual RCE (2/3 transfusions).

Acute Chest Syndrome

Most people who developed an acute chest syndrome did so during working hours. Adults presented with pain (93%), and only 32% had respiratory symptoms on admission, whereas children tended to present with pain (67%), respiratory symptoms (50%), or fever (54%).

People who developed acute chest syndrome generally present with pain and normal oxygen levels, much like any other vaso-occlusive crisis. How acute chest syndrome was diagnosed was not asked in the audit.

Incentive spirometry was only used in a 1/3 and this has been proven to decrease the likelihood of developing acute chest syndrome in certain settings. Patients were unlikely to need invasive ventilation (1/92 patients) though non-invasive ventilation was common (18%, 17/92 patients). Another observation is that clinicians clearly are worried about a proportion of these patients, prior to their diagnosis of acute chest syndrome, in that 8% of them have their blood for transfusion ordered the day before diagnosis and that for those who were needing central venous access for the transfusion 43% of already had the CVADS in place.

Pregnancy

Pregnancy in SCD can be challenging and many of the women gave birth to small babies (median 2.7kg) (25). Many women go into pregnancy with a history of substantial complications. This was a small cohort of patients and for obvious reasons did not include those not receiving transfusions.

The role of prophylactic transfusions in pregnancy in sickle cell disease needs to be better understood.

Recommendations

1. **Automated RCE should be more widely available to all those on long term transfusion programmes.**

2. **Transfusion decisions regarding acutely unwell patients should be discussed with the senior haematology or paediatric team.**

3. **There is no evidence that an HDU/ITU bed is needed specifically to perform a RCE procedure. Waiting for a bed to become available is likely to delay the procedure. Patients should be admitted to these areas if clinical needs dictate but not solely for the purpose of the RCE procedure.**

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Appendix One – Organisational Questionnaire

2014 Audit of transfusion in children and adults with Sickle Cell Disease

ORGANISATIONAL QUESTIONNAIRE

Policy

Q1. Does the Hospital have documents relating to the transfusion of SCD patients for the following? *Please answer Yes or No, if you do not offer the services listed please write "not done" in the appropriate box.*

	Training protocol	Guideline regarding indications	Guidelines on how to perform procedure	Prescription/record sheet for the RCE
Automated red cell exchange adults				
Manual red cell exchange adults				
Automated red cell exchange children				
Manual red cell exchange children				

Service

Q2. How would the Hospital define the service to patients with sickle cell disease?

☐ SHT: Specialist Haemoglobinopathy Team ***(go to Q4)***

☐ A-LHT: Accredited Local Haemoglobinopathy Team ***(go to Q3)***

☐ LHT: Local Haemoglobinopathy Teams (or Linked Providers)* ***(go to Q3)***

**If you are not sure of the status of the team then assume you are an LHT*

Q3. What is the name of the SHT?

Q4. Are all Hospital patients offered an annual review by?

the SHT (can be done at local site)	Yes ☐	No ☐
the A-LHT (can be done at local site)	Yes ☐	No ☐
the LHT	Yes ☐	No ☐

Q5. If Hospital is part of a network, what is the name of that network? If not, please state "not part of a network".

Administration

Q6. Where does the Hospital record the volume of blood transfused?

	Place recorded				How is the volume recorded	
	Hospital communication sheet	Transfusion lab	Prescription chart	Other, please state:	In mls?	In units?
In adults	☐	☐	☐		☐	☐
In children	☐	☐	☐		☐	☐

Laboratory transfusion

Q7. Can the Hospital provide a cross match and transfusion on the same day for a routine exchange transfusion?

Children	Yes ☐	No ☐
Adults	Yes ☐	No ☐

Q8. Does the Hospital have a laboratory policy for the transfusion of patients with sickle cell disease?

Children	Yes ☐	No ☐
Adults	Yes ☐	No ☐

Q9. What is the Hospital's acceptance criteria for the group and save sample from arrival in the lab to

the time of issue of blood for transfusion for someone who has been transfused in the last 28 days?

≤ 72 hours ☐ other, please state:

Q10. Does the Hospital electronically issue blood for patients with SCD with:

no transfusion history of alloimmunisation? Yes ☐ No ☐

a transfusion history of alloimmunisation but whose recent antibody screen is unchanged?

Yes ☐ No ☐

Q11. What mechanism(s) is/are used to inform the lab that a patient has SCD? *(Tick as many as apply)*

☐ Paper request form

☐ Order communication (i.e. electronic blood order systems)

☐ Phone call

Other, please state:

Q12. Is there a field for SCD on the Hospital's laboratory facing transfusion system? (i.e. LIMS)

Yes ☐ No ☐ **(go to Q13)**

If, yes is this mandatory? Yes ☐ No ☐

Q13. Can the Hospital perform an RH phenotype in-house at any time? Yes ☐ No ☐

Q14. How does the Hospital complete a full RBC phenotype:

In-house ☐ Send to NHSBT ☐ Other, please state: ☐

Q15. How does the Hospital complete a full RBC genotype: In-house ☐ Send to NHSBT ☐

Selection of blood/phenotype for patients with SCD

Q16. What antigen requirements does the Hospital routinely ask for in sickle cell disease?

ABO compatible ☐ RH matched ☐ Kell matched ☐

Other, please state:

Q17. Does the Hospital routinely ask for CMV negative blood for sickle patients where there is no other indication?

Yes ☐ No ☐

Q18. Does the Hospital routinely ask for irradiated blood for sickle patients where there is no other indication?

Yes ☐ No ☐

Q19. What does the Hospital's policy state about the age that blood should be when requesting blood for a planned red cell top up in sickle cell disease?

Less than 7 days ☐ 8 - 14 days ☐ Age unspecified ☐

Other, please state:

Q20. What does the Hospital's policy state about the age that blood should be when requesting blood for a planned red cell exchange in sickle cell disease?

Less than 7 days ☐ 8 - 14 days ☐ Age unspecified ☐

Other, please state:

Q21. What is the Hospital's policy for providing blood for a patient with sickle cell disease when a patient needs an urgent transfusion? *(Tick as many as apply)*

☐ Look at the current stock and see if any blood is marked as sickle negative and antigen compatible.

☐ Look at the electronic delivery note and see if donor of any units previously tested as sickle-negative.

☐ Call NHSBT and ask if antigen negative units are from donors previously tested as sickle negative.

☐ Order blood from NHSBT (If so, please give the emergency delivery time for the hospital):

☐ Waive the sickle negative requirements as unmarked units very unlikely to be sickle positive.

☐ None of the above.

Staffing: please answer all questions as WTE (whole time equivalents)

Q22. How many NHS WTE (e.g. 0.1 – 1.0) of the following work at the hospital?

Note: If a WTE covers several roles aor both paediatrics and adult services you may wish to consider apportioning their time for this questionnaire so that their time is not double counted.

Nature of post	**WTEs**
Consultant haematologist(s) without special interest (who provides cover for SCD service)	
Consultant haematologist(s) with a special interest in sickle cell disease.	
Consultant Paediatric haematologist(s) with a special interest in sickle cell disease.	
Consultant Paediatrician(s) with a special interest in sickle cell disease.	
Clinical Nurse Specialist(s) with responsibility for adult patients with SCD	
Clinical Nurse Specialist(s) with responsibility for paediatric patients with SCD	
Link ward nurse(s) for haemoglobinopathies *(RCN definition: shares information – provides formal 2-way communication between specialist teams and nurses in the clinical area in **adult** medicine)*	
Link ward nurse(s) for haemoglobinopathies *(RCN definition: shares information – provides formal 2-way communication between specialist teams and nurses in the clinical area in **paediatrics**)*	

Communication with NHSBT and SHOT

Q23. Can the Hospital's transfusion laboratory staff access NHSBT results on patients electronically (i.e. SP-ICE in England)?

Yes ☐ (**go to Q23a**)

No ☐ **(go to Q24)**

Q23a. How often do staff access this?

Always ☐ Sometimes ☐ Never ☐ **(go to Q24)**

Q23b. Does the Hospital allow sharing of their NHSBT results on patients electronically (i.e. SP-ICE in England) to other Hospitals?

Yes ☐ No ☐

Q24. Has the Hospital reported a serious adverse event (SAE) in SCD to SHOT within the last 5 years?

Yes ☐ No ☐

Q25. Has the Hospital reported a transfusion adverse event surrounding specific requirements not met in a sickle patient to SHOT in the last 5 years?

Yes ☐ No ☐

Population overall

Q26. How many adults and children with SCD are 'registered' with the haematology department?

Number of Adults_____ Number of children_____

Q27. How many of these adults and children have had an outpatient's appointment in the last 12 months?

Number of Adults_____ Number of children_____

Q28. Are adult patients with SCD initially admitted under the care of the haematology team for non surgical or non obstetric admissions?

Routinely ☐ **(go to Q31)** Sometimes ☐ **(go to Q29)** Never ☐ **(go to Q29)**

Q29. Are adult patients with SCD transferred to the haematology team (if not admitted to haematology) immediately upon admission for non surgical or non obstetric admissions?

Routinely ☐ **(go to Q30)**

Sometimes ☐ **(go to Q30)**

Never ☐ **(go to Q31)**

Q30. At which point are they transferred to the haematology team if clinically appropriate?

☐ Next working day

☐ Next morning even if weekend

☐ They remain under medical care

Q31. What AUTOMATED red cell exchange services are available at the Hospital for adults with SCD?

	Weekdays 9am -5pm	**Weekends** **Sat 09:00 – Sun 17:00**	**Nights** **(17:01-08.59)**
Urgent	Yes ☐ No ☐	Yes ☐ No ☐	Yes ☐ No ☐
Automated red cell exchange <u>adults</u> *Please tick as many as apply* *(Note: junior doctor is any doctor who is not a consultant)*	If Yes, who usually administers it? ☐ Consultant ☐ Junior doctor ☐ Specialist nurse ☐ Ward nurse ☐ Apheresis team ☐ Day-care nurses	If Yes, who usually administers it? ☐ Consultant ☐ Junior doctor ☐ Specialist nurse ☐ Ward nurse ☐ Apheresis team ☐ Day-care nurses	If Yes, who usually administers it? ☐ Consultant ☐ Junior doctor ☐ Specialist nurse ☐ Ward nurse ☐ Apheresis team ☐ Day-care nurses
Scheduled	Yes ☐ No ☐	Yes ☐ No ☐	Yes ☐ No ☐
Automated red cell exchange <u>adults</u> *Please tick as many as apply* *(Note: junior doctor is any doctor who is not a consultant)*	If Yes, who usually administers it? ☐ Consultant ☐ Junior doctor ☐ Specialist nurse ☐ Ward nurse ☐ Apheresis team ☐ Day-care nurses	If Yes, who usually administers it? ☐ Consultant ☐ Junior doctor ☐ Specialist nurse ☐ Ward nurse ☐ Apheresis team ☐ Day-care nurses	If Yes, who usually administers it? ☐ Consultant ☐ Junior doctor ☐ Specialist nurse ☐ Ward nurse ☐ Apheresis team ☐ Day-care nurses

NOTE *If the Hospital does not offer AUTOMATED red cell exchange for adults at all* ***go to Q31c.***

Q31a. Where, in the Hospital, can adult SCD patients have an AUTOMATED red cell exchange?

Automated red cell exchange <u>adults</u> *Please tick as many as apply*	☐ ITU/HDU ☐ Theatre/recovery ☐ Day care ☐ Regular ward ☐ ED	☐ ITU/HDU ☐ Theatre/recovery ☐ Day care ☐ Regular ward ☐ ED	☐ ITU/HDU ☐ Theatre/recovery ☐ Day care ☐ Regular ward ☐ ED

Q31b. What is the Hospital's usual practice for obtaining intravenous access in order to perform an AUTOMATED red cell exchange for an adult with SCD?

Please tick the score: - Score 1 (most common), 2 (2nd most common), 3 (least common),

4 (we don't use this access here)

	Peripheral	Vascath or CVC line	Vortex port or Portacath
Automated red cell exchange <u>adults</u>	1☐ 2☐ 3☐ 4☐	1☐ 2☐ 3☐ 4☐	1☐ 2☐ 3☐ 4☐

Now go to Q32.

Q31c. Your Hospital does not administer AUTOMATED red cell exchange for adults. Please tell us what is offered to these adult SCD patients should the Hospital think they need an AUTOMATED red cell exchange? *Tick the appropriate sentence(s).*

Weekdays **9am -5pm(urgent)**	**Weekdays** **9am -5pm (scheduled)**	**Weekends** **Sat 09:00 – Sun 17:00**	**Nights** **(17:01 to 08:59)**
☐ We do not offer it	☐ We do not offer it	☐ We do not offer it	☐ We do not offer it
☐ We ring our specialist centre	☐ We ring our specialist centre	☐ We ring our specialist centre	☐ We ring our specialist centre
Please name	Please name	Please name	Please name
☐ We ring around any local hospital	☐ We ring around any local hospital	☐ We ring around any local hospital	☐ We ring around any local hospital
☐ We ask the retrieval service to take them	☐ We ask the retrieval service to take them	☐ We ask the retrieval service to take them	☐ We ask the retrieval service to take them

and expect the receiving hospital to take them	and expect the receiving hospital to take them	and expect the receiving hospital to take them	and expect the receiving hospital to take them

ADULT SECTION

ADULT SECTION– MANUAL

Q32. What MANUAL red cell exchange services are available at the Hospital for adults with SCD?

	Weekdays 9am -5pm	**Weekends** **(Sat 09:00 – Sun 17:00)**	**Nights** **(17:01-08.59)**
Urgent	Yes ☐ No ☐	Yes ☐ No ☐	Yes ☐ No ☐
Manual red cell exchange adults *Please tick as many as apply* *(Note: junior doctor is any doctor who is not a consultant)*	If Yes, who usually administers it? ☐ Consultant ☐ Junior doctor ☐ Specialist nurse ☐ Ward nurse ☐ Apheresis team ☐ Day-care nurses	If Yes, who usually administers it? ☐ Consultant ☐ Junior doctor ☐ Specialist nurse ☐ Ward nurse ☐ Apheresis team ☐ Day-care nurses	If Yes, who usually administers it? ☐ Consultant ☐ Junior doctor ☐ Specialist nurse ☐ Ward nurse ☐ Apheresis team ☐ Day-care nurses
Scheduled	Yes ☐ No ☐	Yes ☐ No ☐	Yes ☐ No ☐
Manual red cell exchange adults *Please tick as many as apply* *(Note: junior doctor is any doctor who is not a consultant)*	If Yes, who usually administers it? ☐ Consultant ☐ Junior doctor ☐ Specialist nurse ☐ Ward nurse ☐ Apheresis team ☐ Day-care nurses	If Yes, who usually administers it? ☐ Consultant ☐ Junior doctor ☐ Specialist nurse ☐ Ward nurse ☐ Apheresis team ☐ Day-care nurses	If Yes, who usually administers it? ☐ Consultant ☐ Junior doctor ☐ Specialist nurse ☐ Ward nurse ☐ Apheresis team ☐ Day-care nurses
NOTE *If the Hospital does not offer MANUAL red cell exchange for adults at all* ***go to Q32c.***			
Q32a. Where, in the Hospital, can adult SCD patients have a MANUAL red cell exchange?			
Manual red cell exchange adults *Please tick as many as apply*	☐ ITU/HDU ☐ Theatre/recovery ☐ Day care ☐ Regular ward ☐ ED	☐ ITU/HDU ☐ Theatre/recovery ☐ Day care ☐ Regular ward ☐ ED	☐ ITU/HDU ☐ Theatre/recovery ☐ Day care ☐ Regular ward ☐ ED

Q32b. What is the Hospital's usual practice for obtaining intravenous access in order to perform a MANUAL red cell exchangefor an adult with SCD?

Please tick the score:- Score 1 (most common), 2 (2nd most common), 3 (least common),

4 (we don't use this access here)

	Peripheral	Vascath or CVC line	Vortex port or Portacath
Manual red cell exchange adults	1☐ 2☐ 3☐ 4☐	1☐ 2☐ 3☐ 4☐	1☐ 2☐ 3☐ 4☐

Now go to Q33.

Q32c. Your Hospital does not administer MANUAL red cell exchange for adults. Please tell us what is offered to these adult SCD patients should the Hospital think they need a MANUAL red cell exchange? *Tick the appropriate sentence(s).*

Weekdays 9am -5pm(urgent)	Weekdays 9am -5pm (scheduled)	Weekends Sat 09:00 – Sun 17:00	Nights (17:01 to 08:59)
☐ We do not offer it	☐ We do not offer it	☐ We do not offer it	☐ We do not offer it
☐ We ring our specialist centre	☐ We ring our specialist centre	☐ We ring our specialist centre	☐ We ring our specialist centre
Please name	Please name	Please name	Please name
☐ We ring around any local hospital	☐ We ring around any local hospital	☐ We ring around any local hospital	☐ We ring around any local hospital
☐ We ask the retrieval service to take them and expect the receiving hospital to take them	☐ We ask the retrieval service to take them and expect the receiving hospital to take them	☐ We ask the retrieval service to take them and expect the receiving hospital to take them	☐ We ask the retrieval service to take them and expect the receiving hospital to take them

ADULT SECTION– TOP UP

Q33. What TOP-UP TRANSFUSION services are available at the Hospital for adults with SCD?

	Weekdays 9am -5pm	**Weekends** **(Sat 09:00 – Sun 17:00)**	**Nights** **(17:01-08.59)**
Urgent	Yes ☐ No ☐	Yes ☐ No ☐	Yes ☐ No ☐
Top up adults *Please tick as many as apply* *(Note: junior doctor is any doctor who is not a consultant)*	If Yes, who usually administers it? ☐ Consultant ☐ Junior doctor ☐ Specialist nurse ☐ Ward nurse ☐ Apheresis team ☐ Day-care nurses	If Yes, who usually administers it? ☐ Consultant ☐ Junior doctor ☐ Specialist nurse ☐ Ward nurse ☐ Apheresis team ☐ Day-care nurses	If Yes, who usually administers it? ☐ Consultant ☐ Junior doctor ☐ Specialist nurse ☐ Ward nurse ☐ Apheresis team ☐ Day-care nurses
Scheduled	Yes ☐ No ☐	Yes ☐ No ☐	Yes ☐ No ☐
Top up adults *Please tick as many as apply* *(Note: junior doctor is any doctor who is not a consultant)*	If Yes, who usually administers it? ☐ Consultant ☐ Junior doctor ☐ Specialist nurse ☐ Ward nurse ☐ Apheresis team ☐ Day-care nurses	If Yes, who usually administers it? ☐ Consultant ☐ Junior doctor ☐ Specialist nurse ☐ Ward nurse ☐ Apheresis team ☐ Day-care nurses	If Yes, who usually administers it? ☐ Consultant ☐ Junior doctor ☐ Specialist nurse ☐ Ward nurse ☐ Apheresis team ☐ Day-care nurses
NOTE *If the Hospital does not offer TOP UP TRANSFUSION for adults at all* ***go to Q33c.*** **Q33a.** Where, in the Hospital, can adult SCD patients have a TOP UP TRANSFUSION?			
Top up adults *Please tick as many as apply*	☐ ITU/HDU ☐ Theatre/recovery	☐ ITU/HDU ☐ Theatre/recovery	☐ ITU/HDU ☐ Theatre/recovery

	☐ Day care ☐ Regular ward ☐ ED	☐ Day care ☐ Regular ward ☐ ED	☐ Day care ☐ Regular ward ☐ ED

Q33b. What is the Hospital's usual practice for obtaining intravenous access in order to perform a TOP UP TRANSFUSION for an adult with SCD?

Please tick the score: -Score 1 (most common), 2 (2nd most common), 3 (least common),

4 (we don't use this access here)

	Peripheral	Vascath or CVC line	Vortex port or Portacath
Top up <u>adults</u>	1☐ 2☐ 3☐ 4☐	1☐ 2☐ 3☐ 4☐	1☐ 2☐ 3☐ 4☐

Now go to Q34.

Q33c. Your Hospital does not administer TOP UP TRANSFUSIONS for adults. Please tell us what is offered to these adult SCD patients should the Hospital think they need a TOP UP TRANSFUSION? *Tick the appropriate sentence(s).*

Weekdays 9am -5pm(urgent)	Weekdays 9am -5pm (scheduled)	Weekends Sat 09:00 – Sun 17:00	Nights (17:01 to 08:59)
☐ We do not offer it	☐ We do not offer it	☐ We do not offer it	☐ We do not offer it
☐ We ring our specialist centre	☐ We ring our specialist centre	☐ We ring our specialist centre	☐ We ring our specialist centre
Please name	Please name	Please name	Please name
☐ We ring around any local hospital	☐ We ring around any local hospital	☐ We ring around any local hospital	☐ We ring around any local hospital
☐ We ask the retrieval service to take them and expect the receiving hospital to take them	☐ We ask the retrieval service to take them and expect the receiving hospital to take them	☐ We ask the retrieval service to take them and expect the receiving hospital to take them	☐ We ask the retrieval service to take them and expect the receiving hospital to take them

ADULT SECTION

Q34. What grade of staff puts lines in for red cell top ups and/or exchanges? *(tick all that apply)*

Consultant refers to consultant physician (haematologist or medic) not consultant radiologists, surgeons, or anaesthetists.

	9-5 Mon-Fri	Weekends (Sat 09:00 – Sun 17:00)	Nights (17:01 - 08.59)
Peripheral	☐ Consultant ☐ Junior doctor ☐ Specialist nurse ☐ Ward nurse ☐ Apheresis team ☐ Day-care nurses ☐ CVC team ☐ Interventional radiology ☐ Anaesthetists ☐ Surgeons	☐ Consultant ☐ Junior doctor ☐ Specialist nurse ☐ Ward nurse ☐ Apheresis team ☐ Day-care nurses ☐ CVC team ☐ Interventional radiology ☐ Anaesthetists ☐ Surgeons	☐ Consultant ☐ Junior doctor ☐ Specialist nurse ☐ Ward nurse ☐ Apheresis team ☐ Day-care nurses ☐ CVC team ☐ Interventional radiology ☐ Anaesthetists ☐ Surgeons
Vascath or CVC line	☐ Consultant ☐ Junior doctor ☐ Specialist nurse ☐ Ward nurse ☐ Apheresis team ☐ Day-care nurses ☐ CVC team ☐ Interventional radiology ☐ Anaesthetists ☐ Surgeons	☐ Consultant ☐ Junior doctor ☐ Specialist nurse ☐ Ward nurse ☐ Apheresis team ☐ Day-care nurses ☐ CVC team ☐ Interventional radiology ☐ Anaesthetists ☐ Surgeons	☐ Consultant ☐ Junior doctor ☐ Specialist nurse ☐ Ward nurse ☐ Apheresis team ☐ Day-care nurses ☐ CVC team ☐ Interventional radiology ☐ Anaesthetists ☐ Surgeons

Q34. continued *(tick all that apply)*

	9-5 Mon-Fri	Weekends (Sat 09:00 – Sun 17:00)	Nights (17:01 - 08.59)
Vortex port or Portacath	☐ Consultant ☐ Junior doctor ☐ Specialist nurse ☐ Ward nurse ☐ Apheresis team ☐ Day-care nurses ☐ CVC team ☐ Interventional radiology ☐ Anaesthetists ☐ Surgeons	☐ Consultant ☐ Junior doctor ☐ Specialist nurse ☐ Ward nurse ☐ Apheresis team ☐ Day-care nurses ☐ CVC team ☐ Interventional radiology ☐ Anaesthetists ☐ Surgeons	☐ Consultant ☐ Junior doctor ☐ Specialist nurse ☐ Ward nurse ☐ Apheresis team ☐ Day-care nurses ☐ CVC team ☐ Interventional radiology ☐ Anaesthetists ☐ Surgeons

Consultant refers to consultant physician (haematologist or medic) not consultant radiologists, surgeons, or anaesthetists.

CHILDREN SECTION - AUTOMATED

Q35. What AUTOMATED red cell exchange services are available at the Hospital for children with SCD?

	9-5 Mon-Fri	**eekends** **(Sat 09:00 – Sun 17:00)**	**Nights** **(17:01 - 08.59)**
Urgent	Yes ☐ No ☐	s ☐ No ☐	Yes ☐ No ☐
Automated red cell exchange <u>children</u> *Please tick as many as apply* *(Note: junior doctor is any doctor who is not a consultant)*	If Yes, who usually administers it? ☐ Consultant ☐ Junior doctor ☐ Specialist nurse ☐ Ward nurse ☐ Apheresis team ☐ Day-care nurses	If Yes, who usually administers it? ☐ Consultant ☐ Junior doctor ☐ Specialist nurse ☐ Ward nurse ☐ Apheresis team ☐ Day-care nurses	If Yes, who usually administers it? ☐ Consultant ☐ Junior doctor ☐ Specialist nurse ☐ Ward nurse ☐ Apheresis team ☐ Day-care nurses
Scheduled	Yes ☐ No ☐	s ☐ No ☐	Yes ☐ No ☐
Automated red cell exchange <u>children</u> *Please tick as many as apply* *(Note: junior doctor is any doctor who is not a consultant)*	If Yes, who usually administers it? ☐ Consultant ☐ Junior doctor ☐ Specialist nurse ☐ Ward nurse ☐ Apheresis team ☐ Day-care nurses	If Yes, who usually administers it? ☐ Consultant ☐ Junior doctor ☐ Specialist nurse ☐ Ward nurse ☐ Apheresis team ☐ Day-care nurses	If Yes, who usually administers it? ☐ Consultant ☐ Junior doctor ☐ Specialist nurse ☐ Ward nurse ☐ Apheresis team ☐ Day-care nurses
NOTE *If the Hospital does not offer AUTOMATED red cell exchange for children at all* ***go to Q35c.*** **Q35a.** Where, in the Hospital, can children SCD patients have an AUTOMATED red cell exchange?			
Automated <u>children</u> *Please tick as many as apply*	☐ ITU/HDU ☐ Theatre/recovery ☐ Day care ☐ Regular ward ☐ ED	☐ ITU/HDU ☐ Theatre/recovery ☐ Day care ☐ Regular ward ☐ ED	☐ ITU/HDU ☐ Theatre/recovery ☐ Day care ☐ Regular ward ☐ ED

CHILDREN SECTION - AUTOMATED

Q35b. What is the Hospital's usual practice for obtaining intravenous access in order to perform an AUTOMATED red cell exchange for a child with SCD?

Please tick the score:- Score 1 (most common), 2 (2nd most common), 3 (least common),

4 (we don't use this access here)

	Peripheral	Vascath or CVC line	Vortex port or Portacath
Automated red cell exchange children	1☐ 2☐ 3☐ 4☐	1☐ 2☐ 3☐ 4☐	1☐ 2☐ 3☐ 4☐

Now go to Q36.

Q35c. Your Hospital does not administer AUTOMATED red cell exchange for children. Please tell us what is offered to these children should the Hospital think they need an AUTOMATED red cell exchange? *Tick the appropriate sentence(s).*

9-5 Mon-Fri (scheduled)	9-5 Mon-Fri (emergency)	Weekends	Nights (17:01 to 08:59)
☐ We do not offer it	☐ We do not offer it	☐ We do not offer it	☐ We do not offer it
☐ We ring our specialist centre	☐ We ring our specialist centre	☐ We ring our specialist centre	☐ We ring our specialist centre
Please name	Please name	Please name	Please name
☐ We ring around any local hospital	☐ We ring around any local hospital	☐ We ring around any local hospital	☐ We ring around any local hospital
☐ We ask the retrieval service to take them and expect the receiving hospital to take them	☐ We ask the retrieval service to take them and expect the receiving hospital to take them	☐ We ask the retrieval service to take them and expect the receiving hospital to take them	☐ We ask the retrieval service to take them and expect the receiving hospital to take them

CHILDREN SECTION

Q36. What MANUAL red cell exchange services are available at the Hospital for children with SCD?

	9-5 Mon-Fri	**Weekends** **(Sat 09:00 – Sun 17:00)**	**Nights** **(17:01 - 08.59)**
Urgent	Yes ☐ No ☐	s ☐ No ☐	Yes ☐ No ☐
Manual red cell exchange <u>children</u> *Please tick as many as apply* *(Note: junior doctor is any doctor who is not a consultant)*	If Yes, who usually administers it? ☐ Consultant ☐ Junior doctor ☐ Specialist nurse ☐ Ward nurse ☐ Apheresis team ☐ Day-care nurses	If Yes, who usually administers it? ☐ Consultant ☐ Junior doctor ☐ Specialist nurse ☐ Ward nurse ☐ Apheresis team ☐ Day-care nurses	If Yes, who usually administers it? ☐ Consultant ☐ Junior doctor ☐ Specialist nurse ☐ Ward nurse ☐ Apheresis team ☐ Day-care nurses
Scheduled	Yes ☐ No ☐	s ☐ No ☐	Yes ☐ No ☐
Manual red cell exchange <u>children</u> *Please tick as many as apply* *(Note: junior doctor is any doctor who is not a consultant)*	If Yes, who usually administers it? ☐ Consultant ☐ Junior doctor ☐ Specialist nurse ☐ Ward nurse ☐ Apheresis team ☐ Day-care nurses	If Yes, who usually administers it? ☐ Consultant ☐ Junior doctor ☐ Specialist nurse ☐ Ward nurse ☐ Apheresis team ☐ Day-care nurses	If Yes, who usually administers it? ☐ Consultant ☐ Junior doctor ☐ Specialist nurse ☐ Ward nurse ☐ Apheresis team ☐ Day-care nurses
NOTE *If the Hospital does not offer MANUAL red cell exchange for children at all* ***go to Q36c.***			
Q36a. Where, in the Hospital, can children SCD patients have a MANUAL red cell exchange?			
Manual <u>children</u> *Please tick as many as apply*	☐ ITU/HDU ☐ Theatre/recovery ☐ Day care ☐ Regular ward ☐ ED	☐ ITU/HDU ☐ Theatre/recovery ☐ Day care ☐ Regular ward ☐ ED	☐ ITU/HDU ☐ Theatre/recovery ☐ Day care ☐ Regular ward ☐ ED

Q36b. What is the Hospital's usual practice for obtaining intravenous access in order to perform a MANUAL red cell exchange for a child with SCD?

Please tick the score:- Score 1 (most common), 2 (2nd most common), 3 (least common),

4 (we don't use this access here)

	Peripheral	Vascath or CVC line	Vortex port or Portacath
Manual red cell exchange children	1☐ 2☐ 3☐ 4☐	1☐ 2☐ 3☐ 4☐	1☐ 2☐ 3☐ 4☐

Go to Q37.

Q36c. Your Hospital does not administer MANUAL red cell exchange for children. Please tell us what is offered to these children should the Hospital think they need a MANUAL red cell exchange? *Tick the appropriate sentence(s).*

9-5 Mon-Fri (scheduled)	9-5 Mon-Fri (emergency)	Weekends	Nights (17:01 to 08:59)
☐ We do not offer it	☐ We do not offer it	☐ We do not offer it	☐ We do not offer it
☐ We ring our specialist centre	☐ We ring our specialist centre	☐ We ring our specialist centre	☐ We ring our specialist centre
Please name	Please name	Please name	Please name
☐ We ring around any local hospital	☐ We ring around any local hospital	☐ We ring around any local hospital	☐ We ring around any local hospital
☐ We ask the retrieval service to take them and expect the receiving hospital to take them	☐ We ask the retrieval service to take them and expect the receiving hospital to take them	☐ We ask the retrieval service to take them and expect the receiving hospital to take them	☐ We ask the retrieval service to take them and expect the receiving hospital to take them

Q37. What TOP UP TRANSFUSION services are available at the Hospital for children with SCD?

	9-5 Mon-Fri	**Weekends** **(Sat 09:00 – Sun 17:00)**	**Nights** **(17:01 - 08.59)**
Urgent	Yes ☐ No ☐	s ☐ No ☐	Yes ☐ No ☐
Top up children *Please tick as many as apply* *(Note: junior doctor is any doctor who is not a consultant)*	If Yes, who usually administers it? ☐ Consultant ☐ Junior doctor ☐ Specialist nurse ☐ Ward nurse ☐ Apheresis team ☐ Day-care nurses	If Yes, who usually administers it? ☐ Consultant ☐ Junior doctor ☐ Specialist nurse ☐ Ward nurse ☐ Apheresis team ☐ Day-care nurses	If Yes, who usually administers it? ☐ Consultant ☐ Junior doctor ☐ Specialist nurse ☐ Ward nurse ☐ Apheresis team ☐ Day-care nurses
Scheduled	Yes ☐ No ☐	s ☐ No ☐	Yes ☐ No ☐
Top up children *Please tick as many as apply* *(Note: junior doctor is any doctor who is not a consultant)*	If Yes, who usually administers it? ☐ Consultant ☐ Junior doctor ☐ Specialist nurse ☐ Ward nurse ☐ Apheresis team ☐ Day-care nurses	If Yes, who usually administers it? ☐ Consultant ☐ Junior doctor ☐ Specialist nurse ☐ Ward nurse ☐ Apheresis team ☐ Day-care nurses	If Yes, who usually administers it? ☐ Consultant ☐ Junior doctor ☐ Specialist nurse ☐ Ward nurse ☐ Apheresis team ☐ Day-care nurses
NOTE *If the Hospital does not offer TOP UP TRANSFUSION for children at all* ***go to Q37c.*** **Q37a.** Where, in the Hospital, can children SCD patients have a TOP UP TRANSFUSION?			
Top up children *Please tick as many as apply*	☐ ITU/HDU ☐ Theatre/recovery ☐ Day care ☐ Regular ward ☐ ED	☐ ITU/HDU ☐ Theatre/recovery ☐ Day care ☐ Regular ward ☐ ED	☐ ITU/HDU ☐ Theatre/recovery ☐ Day care ☐ Regular ward ☐ ED

Q37b. What is the Hospital's usual practice for obtaining intravenous access in order to perform a TOP UP TRANSFUSION for a child with SCD?

Please tick the score:- Score 1 (most common), 2 (2nd most common), 3 (least common),

4 (we don't use this access here)

	Peripheral	Vascath or CVC line	Vortex port or Portacath
Top up <u>children</u>	1☐ 2☐ 3☐ 4☐	1☐ 2☐ 3☐ 4☐	1☐ 2☐ 3☐ 4☐

Now go to Q38.

Q37c. Your Hospital does not administer MANUAL red cell exchange for children. Please tell us what is offered to these children should the Hospital think they need a MANUAL red cell exchange? *Tick the appropriate sentence(s).*

9-5 Mon-Fri (scheduled)	9-5 Mon-Fri (emergency)	Weekends	Nights (17:01 to 08:59)
☐ We do not offer it	☐ We do not offer it	☐ We do not offer it	☐ We do not offer it
☐ We ring our specialist centre	☐ We ring our specialist centre	☐ We ring our specialist centre	☐ We ring our specialist centre
Please name	Please name	Please name	Please name
☐ We ring around any local hospital	☐ We ring around any local hospital	☐ We ring around any local hospital	☐ We ring around any local hospital
☐ We ask the retrieval service to take them and expect the receiving hospital to take them	☐ We ask the retrieval service to take them and expect the receiving hospital to take them	☐ We ask the retrieval service to take them and expect the receiving hospital to take them	☐ We ask the retrieval service to take them and expect the receiving hospital to take them

Q38. What grade of staff puts lines in for red cell top up and /or exchanges? *(tick all that apply)*

Consultant refers to consultant physician (haematologist or medic) not consultant radiologists, surgeons, or anaesthetists.

	9-5 Mon-Fri	**Weekends (Sat 09:00 – Sun 17:00)**	**Nights (17:01 - 08.59)**
Peripheral	☐ Consultant ☐ Junior doctor ☐ Specialist nurse ☐ Ward nurse ☐ Apheresis team ☐ Day-care nurses ☐ CVC team ☐ Interventional radiology ☐ Anaesthetists ☐ Surgeons	☐ Consultant ☐ Junior doctor ☐ Specialist nurse ☐ Ward nurse ☐ Apheresis team ☐ Day-care nurses ☐ CVC team ☐ Interventional radiology ☐ Anaesthetists ☐ Surgeons	☐ Consultant ☐ Junior doctor ☐ Specialist nurse ☐ Ward nurse ☐ Apheresis team ☐ Day-care nurses ☐ CVC team ☐ Interventional radiology ☐ Anaesthetists ☐ Surgeons
Vascath or CVC line	☐ Consultant ☐ Junior doctor ☐ Specialist nurse ☐ Ward nurse ☐ Apheresis team ☐ Day-care nurses ☐ CVC team ☐ Interventional radiology ☐ Anaesthetists ☐ Surgeons	☐ Consultant ☐ Junior doctor ☐ Specialist nurse ☐ Ward nurse ☐ Apheresis team ☐ Day-care nurses ☐ CVC team ☐ Interventional radiology ☐ Anaesthetists ☐ Surgeons	☐ Consultant ☐ Junior doctor ☐ Specialist nurse ☐ Ward nurse ☐ Apheresis team ☐ Day-care nurses ☐ CVC team ☐ Interventional radiology ☐ Anaesthetists ☐ Surgeons

Q38. continued *(tick all that apply)*

	9-5 Mon-Fri	Weekends (Sat 09:00 – Sun 17:00)	Nights (17:01 - 08.59)
Vortex port or Portacath	☐ Consultant ☐ Junior doctor ☐ Specialist nurse ☐ Ward nurse ☐ Apheresis team ☐ Day-care nurses ☐ CVC team ☐ Interventional radiology ☐ Anaesthetists ☐ Surgeons	☐ Consultant ☐ Junior doctor ☐ Specialist nurse ☐ Ward nurse ☐ Apheresis team ☐ Day-care nurses ☐ CVC team ☐ Interventional radiology ☐ Anaesthetists ☐ Surgeons	☐ Consultant ☐ Junior doctor ☐ Specialist nurse ☐ Ward nurse ☐ Apheresis team ☐ Day-care nurses ☐ CVC team ☐ Interventional radiology ☐ Anaesthetists ☐ Surgeons

Consultant refers to consultant physician (haematologist or medic) not consultant radiologists, surgeons, or anaesthetists.

Appendix Two – Case capture audit tool

2014 Audit of transfusion in children and adults with Sickle Cell Disease

Case Capture form

Audited patient no. 22

Q1. What was the patient's year of birth? ☐

Q2. What was the patient's gender? Male ☐ Female ☐

Q3. What was the patient's ABO group, Rh and Kell phenotype or genotype?

		Tick one from one or other of these columns	
Tick one from this column	*Tick one from this column*	*Patient has:*	*We request:*
A	*K-*	*R_1r or CDe*	*cE neg*
B	*K+*	*R_2r or cDE*	*Ce neg*
O		*R_0r or cDe*	*CE neg*
AB		*Other*	*Other*
Don't know	*Don't know*	*Don't know*	

Q4. Was the full or extended red cell phenotype or genotype available?(do not give the actual results) *(e.g. O Rh D positive, C+ c+ E- e+ K- M+, N-, S-, s+, P1+, Lua- Lub+, K-, k+, Kpa-, Kpb+, Lea-, Leb-, Fya-, Fyb-, Jka+, Jkb-)*

Yes ☐ No ☐

Clinical details

Q5. What was the patient's sickle genotype? *(Tick one)*

HbSS

HbSC

HbSBeta zero (B^0) thalassaemia

HbSBeta plus (B^+) thalassaemia

HbSD

HbSO Arab

HbS/HPFH

Other, please state

Q6. Has this patient ever had an episode of hyperhaemolysis before Jan 2014?

Yes ☐ No ☐

Please use the table below to tell us what the primary reason for transfusion and transfusion modality was for each transfusion episode for this patient in the period 1st January to 30th June 2014. Please see the example in the guidance notes, where you will find the reason codes. *(NB: A transfusion episode is defined as a period of up to 72 hours during which a patient received one or more transfusions for the same indication and for the same modality)*

Q7	Top up	Manual exchange	Automated exchange	Unknown modality of transfusion	Admission/ attendance date	Transfusion date	Discharge date	Reason* code
	Tick one column as appropriate							
Episode 1								

Supplementary table for reason codes requiring additional information

Episode No	**Reason Code**	**Additional information**

Reason codes

	Unscheduled/emergency admission
A	Acute chest syndrome
B	Acute on chronic anaemia
C	Acute organ dysfunction (specify which)
D	Acute neurological symptoms other than stroke (specify)
E	Acute splenic or hepatic Sequestration
F	Acute stroke (haemorrhagic or thrombotic)
G	Hyperhaemolysis
H	Intrahepatic cholestasis
J	Pregnancy complication
K	Pre-op
L	Sepsis
M	No reason given
N	Other, please state
	Elective admission
P	Pregnancy
Q	Pre-op
R	Recurrent VOC
T	Renal disease
U	Stroke prevention
V	No reason given
W	Other, please state

2014 Audit of transfusion in children and adults with Sickle Cell Disease

CASENOTE AUDIT TOOL SET

USEFUL INFORMATION

Admitted/Attended on:

Was transfused on:

Mode of transfusion:

Was discharged on:

Reason code A – Acute Chest Syndrome

Q1. How did the patient present? *(Tick one option)*

- ☐ Via GP
- ☐ Self-referral to Emergency Department (ED) (includes 999)
- ☐ Directly to the ward
- ☐ Directly to haematology day care
- ☐ Via haematology clinic
- ☐ From another speciality in the hospital
- ☐ Tertiary transfer

Q2. At what time did they present? ☐☐ ☐☐

Q3. For what reason did they present? *(Tick as many as apply)*

- ☐ Pain
- ☐ Feeling unwell
- ☐ Respiratory symptoms
- ☐ Surgery
- ☐ Fever
- ☐ Other, please state

Q4. What was the most **recent** steady state saturations/saturations in health on air recorded?

☐ **%** Don't know ☐

Q5. What were the first saturations on air measured on presentation?

☐ **%** Don't know ☐

Q6. On what date on this admission was the diagnosis of chest syndrome made?

☐☐☐☐**1**☐**4**

Q7. Is there documented evidence of discussion with a consultant/SpR haematologist or a consultant paediatrician with a special interest in sickle cell disease?

Yes ☐ No ☐

Q8. If yes, what was the date and time of that discussion?

☐☐☐☐**1**☐**4**

☐☐ ☐☐

Date and/or time not recorded? ☐

Q9. What were the saturations on air when the diagnosis of chest syndrome was made?

☐ **%**

Q10. What were the saturations on air when the decision to transfuse was made?

☐ **%**

Q11. Did you perform an arterial blood gas around the time of the decision to transfuse was made?

Yes ☐ No ☐ Don't know ☐

Q12. What were the pre & post transfusion Hb?

Pre ☐☐☐ g/L Post ☐☐☐ g/L

Q13. What were the pre & post transfusion HbSx%? *(Assume 100% pre if not transfused in the last 3 months)*

Pre ☐☐☐ % Post ☐☐☐ %

Q14. On what date was the blood requested? ☐☐☐☐**1**☐**4** Don't know ☐

Q15. At what time was the blood requested? ☐☐ ☐☐ Don't know ☐

Q16. On what date was a valid crossmatch sample received in the lab?

☐☐☐☐**1**☐**4**

Q17. At what time was a valid crossmatch sample received in the lab?

☐☐ ☐☐

Q18. On what date was the blood issued? | | | | | 1 | 4 |

Q19. At what time was the blood issued? | | | | | | | | |

Q20. Was central venous access required for the transfusion? Yes ☐ No ☐

If yes go to Q21, if no go to Q24.

Q21. Was central venous access already in place? Yes ☐ No ☐

If yes go to Q24, if no go to Q22.

Q22. On what date was IV access sufficient for the transfusion established? | | | | | 1 | 4 |

Q23. At what time was IV access sufficient for the transfusion established? | | | | | | | | |

Q24. What was the start time of the 1st unit of transfusion? | | | | | | | | |

Q25. How many red cells were transfused? ☐ Units **OR** ☐ mls

Q26. Who made the decision to transfuse? *(Tick one option)*

☐ Clinical nurse specialist

☐ Nurse

☐ Junior doctor

☐ Consultant physician

☐ Consultant haematologist

☐ Consultant paediatrician ☐ Don't know

Q27. Where was most of the transfusion performed? *(Tick one option)*

- ☐ ICU
- ☐ HDU
- ☐ Day care
- ☐ Ward
- ☐ Emergency Department
- ☐ Theatre/recovery

Q28. Who decided on the transfusion target for HbS percentage and Hb *(Tick one option)*

- ☐ Clinical nurse specialist
- ☐ Nurse
- ☐ Junior doctor
- ☐ Consultant physician
- ☐ Consultant haematologist
- ☐ Consultant paediatrician
- ☐ Don't know

Q29. Who decided on the transfusion modality *(manual/automated/Top-up)*? *(Tick one option)*

- ☐ Clinical nurse specialist
- ☐ Nurse
- ☐ Junior doctor
- ☐ Consultant physician
- ☐ Consultant haematologist
- ☐ Consultant paediatrician
- ☐ Don't know

Q30. Were there any transfusion complications during the admission?

(Tick as many as apply)

- ☐ None noted
- ☐ Acute haemolytic reaction
- ☐ Delayed haemolytic reaction
- ☐ Hyperhaemolysis
- ☐ Acute allergic/febrile/hypotensive reaction
- ☐ Alloimmunisation

Respiratory complications

- ☐ Transfusion-associated circulatory overload
- ☐ Transfusion-related acute lung injury

Other rare complication such as

- ☐ Post-transfusion purpura
- ☐ Transfusion-transmitted infection

Complications of exchange transfusion

- ☐ Sepsis
- ☐ Stroke
- ☐ Thrombosis – line induced

Other, please state

Q31. What ventilatory support was used? *(Tick as many as apply)*

- ☐ Incentive spirometer
- ☐ Non-invasive ventilation
- ☐ Invasive ventilation
- ☐ None used
- ☐ Don't know

Q32. If the patient died on or soon after the admission, what was the date of death?

END

2014 Audit of transfusion in children and adults with Sickle Cell Disease

CASE NOTE AUDIT TOOL SET

USEFUL INFORMATION

Admitted/Attended on:

Was transfused on:

By top up/manual/don't know:

Was discharged on:

Reason Code F – Acute Stroke (haemorrhagic or thrombotic)

Q1. How did the patient present? *(Tick one option)*

- ☐ Via GP
- ☐ Self-referral to Emergency Department (ED) (includes 999)
- ☐ Via haematology clinic
- ☐ Directly to haematology ward
- ☐ From another speciality in the hospital
- ☐ Tertiary transfer

Q2. At what time did they present? ☐☐ ☐☐

Q3. What was the patient's most recent blood pressure in health (within 12 months of attendance)?

☐☐☐ mm/Hg ☐ Not available

Q4. Was the patient on antihypertensive medication prior to admission?

Yes ☐ No ☐

Q5 What type was the initial stroke on this admission? *(Tick one option)*

- ☐ Arterial Dissection
- ☐ Arterial thrombus or embolism
- ☐ Haemorrhage (bleed)
- ☐ Venous thrombosis
- ☐ Transient-ischaemic-attack
- ☐ None noted

Q6. Does the patient have a history of any of the following cerebrovascular events or problems? *(Tick as many as apply)*

- ☐ Moyamoya
- ☐ Conditional Transcranial Doppler (TCD)
- ☐ Abnormal Transcranial Doppler (TCD)
- ☐ Arterial Dissection
- ☐ Arterial thrombus or embolism
- ☐ Haemorrhage (bleed)
- ☐ Venous thrombosis
- ☐ Transient-ischaemic-attack
- ☐ None noted

Q7. If the patient had a Transcranial Doppler in the last 2 years, what was the result? *(Tick one option)*

- ☐ Normal
- ☐ Low
- ☐ Conditional
- ☐ Abnormal
- ☐ Inadequate
- ☐ Not known or performed but result unknown
- ☐ Not performed in last 2 years

Q8. Was thrombolysis given? *(if no go to question 11)*

Yes ☐ No ☐

Q9. If yes, what date and time was thrombolysis given?

				1	4

Q10. What thrombolytic drug was given?

Q11. Was an antiplatelet agent given? *(if no go to question 14)* Yes ☐ No ☐

Q12. If yes, what anti platelet drug was given?

Q13. If yes, what date and time was the first dose given?

				1	4

Q14. Is there documented evidence of discussion with a consultant/SpR haematologist or a consultant paediatrician with a special interest in sickle cell disease?

Yes ☐ No ☐

Q15. If yes, what was the date and time of that discussion?

				1	4

Q16. Was central venous access required for the transfusion? Yes ☐ No ☐

If yes go to Q17, if no go to Q20.

Q17. Was central venous access already in place? Yes ☐ No ☐

If yes go to Q20, if no go to Q18.

Q18. On what date was IV access sufficient for the transfusion established? ☐☐☐☐**1**☐**4**

Q19. At what time was IV access sufficient for the transfusion established? ☐☐ ☐☐

Q20. What was the start time of the 1st unit of transfusion? ☐☐ ☐☐

Q21. How much blood was transfused? ☐ Units **OR** ☐ mls

Q22. Who made the decision to transfuse? *(Tick one option)*

- ☐ Clinical nurse specialist
- ☐ Nurse
- ☐ Junior doctor
- ☐ Consultant physician
- ☐ Consultant haematologist
- ☐ Consultant paediatrician
- ☐ Don't know

Q23. Who decided the modality for transfusion? (top-up/manual/automated) tick one option

- ☐ Clinical nurse specialist
- ☐ Nurse
- ☐ Junior doctor
- ☐ Consultant physician
- ☐ Consultant haematologist
- ☐ Consultant paediatrician
- ☐ Don't know

Q24. What ventilatory support was used? *(Tick as many options as apply)*

- ☐ Incentive spirometer
- ☐ Non-invasive ventilation
- ☐ Invasive ventilation
- ☐ None used
- ☐ Don't know

Q25. Who decided the parameters for transfusion (post HbS% and post Hb g/l)?

- ☐ Clinical nurse specialist
- ☐ Nurse
- ☐ Junior doctor
- ☐ Consultant physician
- ☐ Consultant haematologist
- ☐ Consultant paediatrician
- ☐ Don't know

Q26. What were the pre & post transfusion Hb?

Pre ☐☐☐ g/L Post ☐☐☐ g/L

Q27. What were the pre & post transfusion HbSx%? (note if no transfusion in last 3 months estimate as 100% pre HbSx%)

Pre ☐☐☐ % Post ☐☐☐ %

Q28. Were there any transfusion complications during the admission?

(Tick as many as apply)

- ☐ None noted
- ☐ Acute haemolytic reaction
- ☐ Delayed haemolytic reaction
- ☐ Hyperhaemolysis
- ☐ Acute allergic/febrile/hypotensive reaction
- ☐ Alloimmunisation

Respiratory complications

- ☐ Transfusion-associated circulatory overload
- ☐ Transfusion-related acute lung injury

Other rare complication such as

- ☐ Post-transfusion purpura
- ☐ Transfusion-transmitted infection

Complications of exchange transfusion

- ☐ Sepsis
- ☐ Stroke
- ☐ Thrombosis – line induced

Other, please state

Q29. If the patient died during or soon after admission, what was the date of death?

END

2014 Audit of transfusion in children and adults with Sickle Cell Disease

CASE NOTE AUDIT TOOL SET

USEFUL INFORMATION

Admitted/Attended on:

Was transfused on:

Mode of transfusion:

Was discharged on:

Reason code: J & P – Pregnancy

(defined as reaching a gestational age of 14 weeks or more)

SECTION A: TO BE COMPLETED FOR ALL WOMEN

Q1. How many live births has this woman had previously?

Number ☐ or Don't know ☐

Q2. Does her previous medical history include any of the following?

(Tick as many as apply)

- ☐ Acute chest syndrome
- ☐ Sickle related complications in pregnancies prior to this one
- ☐ Proteinuria / renal disease
- ☐ Pulmonary hypertension
- ☐ Recurrent vaso occlusive crises
- ☐ Retinopathy
- ☐ Sepsis
- ☐ Stroke
- ☐ Thrombosis
- ☐ Other, please state

Q3. Was she regularly on any of the following disease modifying treatments on a regular basis in the 6 months prior to pregnancy? *(Tick as many as apply)*

- ☐ Top up transfusion
- ☐ Manual exchange
- ☐ Automated exchange
- ☐ Hydroxyurea (hydroxycarbamide)

When you have completed up to Q16 in this section, please go to Section C

Q4. Was she on chelation immediately prior to pregnancy? ☐ Yes ☐ No

(If yes go to Q5. If no, go to Q6)

Q5. Which chelation therapy was she receiving? *(Tick as many as apply)*

☐ Deferiprone (Ferriprox)

☐ Desferrioxamine (Desferal)

☐ Deferasirox (ExJade)

Q6. Was the pregnancy:

☐ A singleton?

☐ Multiparous?

Q7. What was the primary reason for transfusion?

Primary pregnancy problems

- ☐ Pregnancy induced hypertension
- ☐ Haemorrhage
- ☐ Other (specify)

Primary sickle problems

- ☐ Acute chest syndrome
- ☐ Acute splenic or hepatic sequestration
- ☐ Acute stroke
- ☐ Acute neurological symptoms other than stroke (specify which)
- ☐ Other (specify)

☐ Problems with the foetus

- ☐ IUGR
- ☐ Foetal compromise
- ☐ Other (specify)

☐ Symptomatic anaemia

☐ Acute organ dysfunction (specify which)

☐ Pre-op

☐ Sepsis

☐ Other, please state

Q8. Who made the decision to transfuse? *(Tick one option)*

- ☐ Clinical nurse specialist
- ☐ Nurse
- ☐ Junior doctor
- ☐ Consultant physician
- ☐ Consultant haematologist
- ☐ Consultant obstetrician
- ☐ Don't know

Q9. Who decided on the transfusion target for HbS percentage and Hb?

(Tick one option)

- ☐ Clinical nurse specialist
- ☐ Nurse
- ☐ Junior doctor
- ☐ Consultant physician
- ☐ Consultant haematologist
- ☐ Consultant paediatrician
- ☐ Don't know

Q10. Who decided on the transfusion modality *(manual/automated/Top-up)*?

(Tick one option)

- ☐ Clinical nurse specialist
- ☐ Nurse
- ☐ Junior doctor
- ☐ Consultant physician
- ☐ Consultant haematologist
- ☐ Consultant obstetrician
- ☐ Don't know

Q11. Were there any transfusion complications during the admission?

(Tick as many as apply)

- ☐ None noted
- ☐ Acute haemolytic reaction
- ☐ Delayed haemolytic reaction
- ☐ Hyperhaemolysis
- ☐ Acute allergic/febrile/hypotensive reaction
- ☐ Alloimmunisation

Respiratory complications

- ☐ Transfusion-associated circulatory overload
- ☐ Transfusion-related acute lung injury

Other rare complication such as

- ☐ Post-transfusion purpura
- ☐ Transfusion-transmitted infection

Complications of exchange transfusion

☐ Sepsis

☐ Stroke

☐ Thrombosis – line induced

Other, please state

Q12. What was the estimated delivery date? ☐☐☐☐☐☐

Q13. Did she deliver a baby? Yes ☐ No ☐

If yes continue below, if no go SECTION B if the transfusion was a one-off, or SECTION C if the woman is on a regular transfusion programme

Q14. What was the actual delivery date? ☐☐☐☐☐☐

Q15. What was the mode of delivery?

☐ Normal vaginal delivery

☐ Elective caesarean section

☐ Semi elective caesarean section

☐ Emergency caesarean section

☐ Assisted delivery (ventouse/forceps)

Q16. What was the pregnancy outcome?

☐ live birth:

☐ baby went to SCBU/neonatal intensive care (baby problems)

☐ baby went to SCBU/neonatal intensive care,

(mother not able initially to look after but baby well)

☐ baby went straight to ward with mother

☐ baby was stillborn *(go to either SECTION B or SECTION C, as appropriate.)*

Q17. What was the birth weight/s (kgs)? *Please give weights for all babies delivered*

Baby one ☐ Baby two ☐

Now please give us some details about the transfusion episodes during pregnancy and for the first month post partum:

If this was a one-off transfusion please complete Section B

Or

If this woman was on a regular transfusion programme please complete Section C

Section B: One-off transfusion during pregnancy, delivery or puperium:

Q18. When was the decision made to transfuse her? | | | | | 1 | 4 |

Q19. Was central venous access required for the transfusion? Yes ☐ No ☐

If yes go to Q20, if no go to Q23.

Q20. Was central venous access already in place? Yes ☐ No ☐

If yes go to Q23, if no go to Q21.

Q21. On what date was IV access sufficient for the transfusion established?

				1	4

Q22. At what time was IV access sufficient for the transfusion established?

Q23. What was the start time of the 1st unit of transfusion?

Q24. How many units of red cells were transfused? | | Units

Q25. What were the pre & post transfusion Hb?

Pre ☐☐☐ g/L Post ☐☐☐ g/L

Q26. What were the pre & post transfusion HbSx%? *(Assume 100% pre if not transfused in the last 3 months)*

Pre ☐☐☐ % Post ☐☐☐ %

Section C: Part of a regular transfusion programme during pregnancy.

Q27. Was central venous access usually required for the transfusion?

Yes ☐ No ☐

If yes, was it usually:

☐ an indwelling line

☐ a neck line

☐ a groin line

☐ a percutaneous line (PICC)

Q28. What was the average number of red cells given per transfusion episode? ☐

Q29. What was the average pre-transfusion HbSx% in the period (January 1st to June 30th 2014)?

Q30. What was the target HbSx% during this period?

End

2014 Audit of transfusion in children and adults with Sickle Cell Disease

CASE NOTE AUDIT TOOL SET U

USEFUL INFORMATION

Admitted/Attended on:

Was transfused on:

By top up/manual/don't know:

Was discharged on:

Reason code U – Stroke Prevention

Q1. What the rationale for transfusion? (Tick one option)

- ☐ Primary stroke prevention with high Transcranial Doppler
- ☐ Primary stroke prevention with silent infarcts
- ☐ Secondary stroke prevention:
- ☐ Arterial thrombosis / embolus
- ☐ Haemorrhage (bleed)
- ☐ Venous thrombosis
- ☐ Moyamoya
- ☐ Transient ischaemic attack (TIA)

Q2. Are there any other reasons for this patient being on a regular transfusion regimen?

- ☐ Recurrent VOC
- ☐ Recurrent chest crises
- ☐ Renal disease
- ☐ Other, please state:

Q3.On average, how many units or mls of packed red blood cells were transfused in each of the transfusion episodes during the period 01 Jan to 30 June 2014?

☐ Units **OR** ☐ mls

Q4. Were there any transfusion complications during any of the admissions?

(Tick as many as apply)

- ☐ None noted
- ☐ Acute haemolytic reaction
- ☐ Delayed haemolytic reaction
- ☐ Hyperhaemolysis
- ☐ Acute allergic/febrile/hypotensive reaction
- ☐ Alloimmunisation

Respiratory complications

- ☐ Transfusion-associated circulatory overload
- ☐ Transfusion-related acute lung injury

Other rare complication such as

- ☐ Post-transfusion purpura
- ☐ Transfusion-transmitted infection

Complications of exchange transfusion

- ☐ Sepsis
- ☐ Stroke
- ☐ Thrombosis – line induced

Other, please state

Q5. How old was the patient when they had their first stroke/silent infarct/high Transcranial Doppler/cerebral event that initiated the decision to start the regular transfusion programme?

☐ Years ☐ Don't know

Q6. For how many years has this patient been on regular transfusions?

☐ 0-5 ☐ 6-10 ☐ >10 ☐ Don't know

Q7. What was the average pre-transfusion Hb SX% in the period January 1st to June 30th 2014?

Q8. What was the target Hb SX% during this period?

Q9. What was the last ferritin result when not acutely unwell? *(This should be a result obtained between 1st January to 30th June 2014)*

Q10. Was the patient on chelation? ☐ Yes ☐ No

(If yes, go to Q11. If no, go to Q12)

Q11. What was used for chelation? *(Tick as many as apply)*

☐ Deferasirox (ExJade)

☐ Desferrioxamine (Desferal)

☐ Deferiprone (L1/Ferriprox)

Q12. Was central venous access usually required for the transfusion?

Yes ☐ No ☐

If yes, was it usually:

☐ an indwelling line

☐ a neck line

☐ a groin line

☐ a percutaneous line (PICC)

Q13. What was the result of the most recent Transcranial Doppler?

- ☐ Normal
- ☐ Low
- ☐ Conditional
- ☐ Abnormal
- ☐ Inadequate
- ☐ Transcranial Doppler not done in the 12 months prior to transfusion.

END

Appendix Four – Sites that participated in the audit

SITES THAT REGISTERED (106)

7 sites did not provide any data.

99 sites provided data, either to the organisational audit or to the clinical audit.

14/99 of these sites were “nil returns” meaning that there were no eligible cases to be audited.

1/99 of these sites were “no response” meaning we are unsure as to why no clinical audit cases were submitted.

	WITH ORGANISATIONAL AUDIT DATA	AUDIT CLINICAL CASES
(Former) Heatherwood and Wexham Park Hospitals NHS Foundation Trust	Yes	3
Aintree University Hospitals NHS Foundation Trust	Yes	2
Airedale NHS Foundation Trust	No	Nil return
Alder Hey Children's NHS Foundation Trust	Yes	5
Altnagelvin Area Hospital	No	Nil return
Barking Havering and Redbridge University Hospitals NHS Trust	Yes	33
Basildon and Thurrock University Hospitals NHS Foundation Trust	Yes	11
Belfast Health and Social Care Trust	No	1
Birmingham Children's Hospital	No	10
Blackpool Teaching Hospitals NHS Foundation Trust	Yes	1
Bolton NHS Foundation Trust	Yes	1
Bradford Teaching Hospitals NHS Foundation Trust	Yes	7
Burton Hospitals NHS Foundation Trust	Yes	1
Calderdale and Huddersfield NHS Foundation Trust	Yes	4
Cardiff and Vale University Health Board	Yes	7
Chelsea and Westminster Hospital NHS Foundation Trust	Yes	3
Chesterfield Royal Hospital	Yes	Nil return
Colchester Hospital University NHS Foundation Trust	Yes	4
Conquest Hospital	No	Nil return
Craigavon Area Hospital	No	1
Croydon Health Services NHS Trust	Yes	33
Dartford and Gravesham NHS Trust	Yes	11
Derriford Hospital	Yes	1

Doncaster and Bassetlaw Hospitals NHS Foundation Trust	No	Nil return
Ealing Hospital NHS Trust	Yes	6
East Lancashire Hospitals NHS Trust	Yes	4
Epsom and St. Helier University Hospitals NHS Trust	Yes	2
Foresterhill Site - Aberdeen Royal Infimrary	Yes	1
Freeman Hospital	Yes	Nil return
Frimley Health NHS Foundation Trust	Yes	1
George Eliot Hospital NHS Trust	Yes	Nil return
Glasgow Royal Infirmary	Yes	2
Gloucestershire Hospitals NHS Foundation Trust (Cheltenham General Hospital & Gloucestershire Royal Hospital)	Yes	3
Great Ormond Street Hospital For Children NHS Foundation Trust	Yes	Nil return
Greater Glasgow and Clyde Health Board	No	1
Guys and St Thomas' NHS Foundation Trust	Yes	151
Hammersmith Hospital	Yes	71
Hinchingbrooke Health Care NHS Trust	No	Nil return
Homerton University Hospital NHS Foundation Trust	Yes	35
Kettering General Hospital NHS Foundation Trust	Yes	1
King's College Hospital NHS Foundation Trust	Yes	130
Lancashire Teaching Hospitals NHS Foundation Trust	Yes	1
Lister Hospital	No	5
Luton and Dunstable Hospital	Yes	16
Manchester Royal Infirmary	Yes	27
Medway NHS Foundation Trust	Yes	5
Newham University Hospital	Yes	31
North Middlesex University Hospital NHS Trust	Yes	52
North Tees and Hartlepool NHS Foundation Trust	Yes	1
Northampton General Hospital NHS Trust	Yes	7
Nottingham University Hospitals NHS Trust	Yes	21
Our Lady's Children's Hospital, Crumlin	Yes	72
Oxford University Hospitals NHS Trust	No	7
Peterborough City Hospital	Yes	No response
Queen Alexandra Hospital	Yes	7

Queen Elizabeth Hospital Woolwich	Yes	35
Royal Berkshire NHS Foundation Trust	Yes	8
Royal Devon and Exeter Hospital	Yes	2
Royal Manchester Children's Hospital	Yes	29
Royal National Orthopaedic Hospital NHS Trust	Yes	1
Royal Surrey County Hospital NHS Foundation Trust	Yes	1
Royal United Hospital Bath	Yes	2
Royal Victoria Infirmary Newcastle	Yes	3
Sandwell and West Birmingham Hospitals NHS Trust	Yes	31
Sheffield Children's Hospital	Yes	2
Sheffield Teaching Hospitals NHS Foundation Trust	Yes	8
South Tees Hospitals NHS Foundation Trust	Yes	5
South Warwickshire NHS Foundation Trust	No	Nil return
Southport and Ormskirk Hospital NHS Trust	No	Nil return
St. George's Hospital	Yes	45
St. Mary's Hospital Paddington	Yes	28
St. Peter's Hospital	Yes	1
Surrey and Sussex Healthcare NHS Trust	Yes	1
Taunton & Somerset Hospital	No	Nil return
The Dudley Group of Hospitals NHS Foundation Trust	Yes	3
The Hillingdon Hospital	No	3
The Ipswich Hospital NHS Trust	Yes	2
The Leeds Teaching Hospitals NHS Trust	Yes	14
The North West London Hospitals NHS Trust	Yes	37
The Princess Alexandra Hospital NHS Trust	No	4
The Royal Bournemouth Hospital	Yes	2
The Royal Liverpool & Broadgreen University Hospitals NHS Trust	Yes	8
The Royal Wolverhampton Hospitals NHS Trust	Yes	15
The Shrewsbury and Telford Hospital NHS Trust	Yes	3
The Whittington Hospital NHS Trust	Yes	10
University College Hospital Galway	Yes	3
University College London Hospitals NHS Foundation Trust	Yes	84
University Hospital Lewisham	Yes	47

University Hospital of North Staffordshire	No	2
University Hospital Southampton NHS Foundation Trust	Yes	4
University Hospitals Bristol NHS Foundation Trust	Yes	13
University Hospitals Coventry and Warwickshire NHS Trust	Yes	10
University Hospitals Leicester NHS Trust	Yes	14
Watford General Hospital	No	Nil return
West Middlesex University Hospital NHS Trust	Yes	4
William Harvey Hospital	Yes	1
Withybush General Hospital	No	1
Wye Valley NHS Trust	Yes	Nil return
Yorkhill Children's Hospital Glasgow	Yes	5

SITES THAT DECLINED

59 sites declined participation in the audit. Most of them felt themselves ineligible due to small numbers of patients with the condition. Most of these hospitals had Emergency Departments and several of these said they “don’t treat patients with sickle cell”. As they did not complete the audit it is unclear what would happen if a patient did arrive through their Emergency Department.

Appendix Five - Additional Tables

Table S1: Sites categorised by transfusion activity

		Low		Medium		High	
Type of site	**SHC**	10% (4/40)		50% (11/22)		78% (14/18)	
	LHT	88% (35/40)		41% (9/22)		22% (4/18)	
	Not stated	3% (1/40)		9% (2/22)		0% (0/18)	
		Median (IQR)	**n**	**Median (IQR)**	**n**	**Median (IQR)**	**n**
Adults with SCD	**Registered**	5 (1-19)	35	84 (28-100)	18	300 (225-421)	15
	Outpatients appointments ≤ 12 months	4 (0-15)	31	38 (20-86)	18	257 (169-431)	14
Children with SCD	**Registered**	3 (0-20)	31	50 (28-61)	19	250 (195-337)	14
	Outpatients appointments ≤ 12 months	1 (0-18)	25	47 (23-60)	18	250 (180-396)	11

Table S2: Availability of automated RCE on site according to time, transfusion activity, and urgency

Urgency	Age of Patient	Transfusion Activity	Weekdays 9am -5pm	Weekends Sat 09:00 – Sun 17:00	Nights 17:01-08.59
Urgent	**Adult**	**Low**	6% (2/36)	3% (1/36)	0% (0/36)
		Medium	41% (7/17)	12% (2/17)	6% (1/17)
		High	53% (8/15)	7% (1/15)	7% (1/15)
Elective	**Adult**	**Low**	11% (4/36)	11% (4/36)	8% (3/36)
		Medium	44% (8/18)	28% (5/18)	28% (5/18)
		High	53% (8/15)	20% (3/15)	20% (3/15)
Urgent	**Child**	**Low**	9% (3/34)	3% (1/34)	3% (1/34)
		Medium	21% (4/19)	21% (4/19)	21% (4/19)
		High	33% (4/12)	33% (4/12)	33% (4/12)
Elective	**Child**	**Low**	9% (3/33)	3% (1/33)	3% (1/33)
		Medium	21% (4/19)	5% (1/19)	5% (1/19)
		High	42% (5/12)	8% (1/12)	8% (1/12)

Table S3: Type of transfusion according to urgency, size of patient cohort and age.

	Sites with 1-4 cases	Sites with 5-24 cases	Sites with ≥ 25 cases	Total
All Transfusions	210	692	3626	4528
Children	129	329	1532	1990
Urgent	16% (20)	14% (45)	6% (90)	8% (155)
Elective	84% (109)	86% (284)	94% (1441)	92% (1834)
Adults	81	363	2090	2534
Urgent	75% (61)	35% (127)	18 % (378)	22% (566)
Elective	25% (20)	65% (233)	82% (1712)	78% (1965)
Children: Urgent				
Automated RCE	-	4% (2)	8% (7)	6% (9)
Manual RCE	10% (2)	2% (1)	9% (8)	7% (11)
Top-up	90% (18)	89% (40)	80% (72)	84% (130)
Modality not known	-	4% (2)	3% (3)	3% (5)
Children: Elective				
Automated RCE	6% (6)	2% (5)	8% (110)	7% (121)
Manual RCE	-	3% (9)	4% (60)	4% (69)
Top-up	94% (103)	94% (268)	86% (1234)	88% (1605)
Modality not known	-	0.7% (2)	3% (37)	2% (39)
Adult: Urgent				
Automated RCE	3% (2)	9% (11)	16% (62)	13% (75)
Manual RCE	15% (9)	9% (12)	11% (42)	11% (63)
Top-up	82% (50)	82% (104)	71% (267)	74% (421)
Modality not known	-	-	2% (7)	1% (7)
Adult: Elective				
Automated RCE	10% (2)	43% (101)	64% (1093)	61% (1196)
Manual RCE	30% (6)	6% (15)	6% (97)	6% (118)
Top-up	60% (12)	50% (117)	29% (496)	32% (625)
Modality not known	-	-	2% (26)	1% (26)

Urgency not stated for 2 patients (4 episodes) and age for 1 patient (4 episodes)

Table S4: Transfusion indications according to type of transfusion (1290 cases)

Reason for transfusion	Cases	Episodes	Type of Transfusion			
			Automated RCE	Manual RCE	Top-up	Not known
Unscheduled/emergency						
Acute or chronic anaemia	174	215	5	6	200	4
Acute chest syndrome	113	127	15	33	78	1
Other	106	166	17	13	135	1
Sepsis	40	45	-	6	38	1
No reason given	35	55	30	1	20	4
Pre-operative	21	23	5	3	15	-
Acute splenic or hepatic sequestration	16	21	2	-	19	-
Pregnancy complication	14	23	1	1	21	-
Acute neurological symptoms (not stroke)	10	12	3	4	5	-
Acute stroke (haemorrhagic or thrombotic)	8	12	4	4	4	-
Acute organ dysfunction	6	11	1	-	9	1
Intrahepatic cholestasis	5	8	1	1	6	-
More than one reason	3	3	-	2	1	-
Hyperhaemolysis	-					
Elective admission						
Stroke prevention	356	1914	467	69	1377	1
Recurrent veno-occlusive crisis	195	636	386	49	194	7
No reason given	163	563	295	37	201	30
Other	132	422	110	16	278	18
Pre-operative	57	74	22	6	44	2
Renal disease	32	157	32	8	110	7
Pregnancy	12	20	5	-	15	-
More than one reason	4	17	4	2	11	-

Cases add up to more than 1290 because during the audit period a person may have had separate transfusion episodes with different reasons for transfusion

Urgency not known for 4 episodes (all top-up)

Table S5: Transfusion Indications for adults according to type of transfusion (853 cases)

ADULTS			**Type of Transfusion**			
Reason for transfusion	**Cases**	**Episodes**	**Automated RCE**	**Manual RCE**	**Top-up**	**Not known**
Unscheduled/emergency admission						
Acute or chronic anaemia	130	169	4	3	159	3
Acute chest syndrome	85	99	15	30	54	-
Other	81	128	13	13	102	-
Sepsis	31	35	-	5	30	-
No reason given	30	50	29	-	18	3
Pre-operative	19	21	5	3	13	-
Pregnancy complication	14	23	1	1	21	-
Acute neurological symptoms (not stroke)	7	8	2	3	3	-
Acute organ dysfunction	6	11	1	-	9	1
Intrahepatic cholestasis	5	8	1	1	6	-
Acute stroke (haemorrhagic or thrombotic)	5	7	3	2	2	-
Acute splenic or hepatic sequestration	3	4	1	-	3	-
More than one reason	3	3	-	2	1	-
Hyperhaemolysis	-	-	-	-	-	-
Elective admission						
Recurrent VOC	175	543	373	46	117	7
Stroke prevention	143	620	407	35	178	-
No reason given	116	337	267	17	45	8
Other	92	234	90	7	133	4
Pre-operative	35	44	18	3	23	-
Renal disease	31	150	32	8	103	7
Pregnancy	12	20	5	-	15	-
More than one reason	4	17	4	2	11	-

Cases add up to more than 853 because during the audit period an adult may have had separate transfusion episodes with different reasons for transfusion

Table S6: Transfusion Indications for children according to transfusion modality (436 cases)

CHILDREN			**Type of transfusion**			
Reason for transfusion	**Cases**	**Episodes**	**Automated RCE**	**Manual RCE**	**Top -up**	**Not known**
Unscheduled/emergency admission						
Acute or chronic anaemia	44	46	1	3	41	1
Acute chest syndrome	28	28	-	3	24	1
Other, please state	25	38	4	-	33	1
Acute splenic or hepatic Sequestration	13	17	1	-	16	-
Sepsis	9	10	-	1	8	1
No reason given	5	5	1	1	2	1
Acute neurological symptoms (not stroke)	3	4	1	1	2	-
Acute stroke (haemorrhagic or thrombotic)	3	5	1	2	2	-
Pre-operative	2	2	-	-	2	-
Intrahepatic cholestasis	-					
Pregnancy complication	-					
Hyperhaemolysis	-					
Acute organ dysfunction	-					
More than one reason	-					
Elective admission						
Stroke prevention	212	1290	56	34	1199	1
No reason given	47	226	28	20	156	22
Other	40	188	20	9	145	14
Pre-operative	22	30	4	3	21	2
Recurrent VOC	20	93	13	3	77	-
Renal disease	1	7	-	-	7	-
Pregnancy	-					
More than one reason	-					

Cases add up to more than 436 because during the audit period a child may have had separate transfusion episodes with different reasons for transfusion

Table S7: Day of week by different parameters

	Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Total
Adults	65	251	384	517	564	631	117	2529
Children	47	242	246	435	419	465	129	1983
Sites with low transfusion activity	9	10	23	26	75	42	25	210
Sites with medium transfusion activity	20	89	87	142	130	160	62	690
Sites with high transfusion activity	83	394	520	784	778	898	159	3616
Automated RCE	5	158	190	299	320	419	14	1405
Manual RCE	10	30	35	46	55	73	9	258
Top-up	94	301	396	584	590	590	221	2776
Modality not known	3	4	9	23	18	18	2	77
Emergency	62	83	125	121	129	115	81	716
Acute chest syndrome	13	18	21	18	18	19	18	125
Acute or chronic anaemia	15	25	39	40	29	31	36	215
Acute organ dysfunction	-	2	5	-	3	1	-	11
Acute neurological symptoms (not stroke)	1	2	1	3	1	4	-	12
Acute splenic or hepatic sequestration	3	3	3	4	4	2	2	21
Acute stroke (haemorrhagic or thrombotic)	1	1	5	-	3	2	-	12
Hyperhaemolysis	-	-	-	-	-	-	-	-
Intrahepatic cholestasis	-	1	1	1	1	4	-	8
Pregnancy complication	1	-	3	6	5	2	4	21
Pre-op	1	5	4	1	6	5	1	23
Sepsis	3	4	10	8	10	5	4	44
No reason given	3	5	10	14	7	14	2	55
Other, please state	20	16	22	26	42	26	14	166
More than one reason	1	1	1	-	-	-	-	3
Routine	50	410	505	830	852	984	165	3796
Pregnancy	1	1	-	4	4	9	1	20
Pre-op	4	15	15	13	12	13	2	74
Recurrent VOC	6	61	76	137	151	191	14	636
Renal disease	2	11	15	48	41	34	6	157
Stroke prevention	23	215	267	424	446	434	98	1907
No reason given	2	68	67	105	115	183	23	563
Other, please state	12	38	60	99	79	114	20	422
More than one reason	-	1	5	-	4	6	1	17

Table S8: Who can perform automated RCE under different circumstances?

Age of patient	Urgency	Who administers the transfusion	Weekdays 9am -5pm	Weekends Sat 09:00 – Sun 17:00	Nights 17:01-08.59
Adult	**Urgent**		29% (20/69)	17% (12/69)	16% (11/69)
		Consultant	5% (1)	8% (1)	9% (1)
		Junior doctor	5% (1)	0% (0)	0% (0)
		Specialist nurse	35% (7)	17% (2)	18% (2)
		Ward nurse	5% (1)	8% (1)	9% (1)
		Apheresis team	80% (16)	100% (12)	100% (11)
		Day-care nurses	15% (3)	8% (1)	9% (1)
	Elective		25% (17/67)	5%: (4/67)	3% (2/67)
		Consultant	0% (0)	0% (0)	0% (0)
		Junior doctor	6% (1)	0% (0)	0% (0)
		Specialist nurse	35% (6)	50% (2)	50% (1)
		Ward nurse	6% (1)	25% (1)	50% (1)
		Apheresis team	76% (13)	100% (4)	100% (2)
		Day-care nurses	29% (5)	50% (2)	50% (1)
Children	**Urgent**		17% (11/65)	14% (9/65)	14% (9/65)
		Consultant	18% (2)	22% (2)	22% (2)
		Junior doctor	9% (1)	11% (1)	11% (1)
		Specialist nurse	27% (3)	33% (3)	33% (3)
		Ward nurse	18% (2)	0% (0)	0% (0)
		Apheresis team	82% (9)	78% (7)	78% (7)
		Day-care nurses	9% (1)	0% (0)	0% (0)
	Elective		19% (12/64)	5% (3/64)	5% (3/64)
		Consultant	0% (0)	33% (1)	33% (1)
		Junior doctor	0% (0)	33% (1)	33% (1)
		Specialist nurse	33% (4)	33% (1)	33% (1)
		Ward nurse	17% (2)	0% (0)	0% (0)
		Apheresis team	75% (9)	33% (1)	33% (1)
		Day-care nurses	8% (1)	0% (0)	0% (0)

Note: junior doctor is any doctor who is not a consultant

Table S9: Where automated red cell exchange (RCE) can be performed

Age of patient	Where in hospital	Weekdays 9am -5pm	Weekends Sat 09:00 – Sun 17:00	Nights 17:01-08.59
Adults		29% (20/69)	17% (12/69)	16% (11/69)
	ITU/HDU	95% (19)	83% (10)	91% (10)
	Theatre/recovery	40% (8)	50% (6)	45% (5)
	Day care	75% (15)	25% (3)	27% (3)
	Regular ward	90% (18)	92% (11)	91% (10)
	Emergency department	25% (5)	33% (4)	36% (4)
Children		17% (11/65)	14% (9/65)	14% (9/65)
	ITU/HDU	100% (11)	100% (9)	100% (9)
	Theatre/recovery	27% (3)	33% (3)	33% (3)
	Day care	64% (7)	22% (2)	22% (2)
	Regular ward	73% (8)	77% (7)	77% (7)
	Emergency department	18% (2)	22% (2)	22% (2)
Denominator is those sites that responded to the question and performed automated RCE				

Table S10: Who can perform manual RCE under different circumstances?

Age of patient	Urgency	Who administers the transfusion	Weekdays 9am -5pm	Weekends Sat 09:00 – Sun 17:00	Nights 17:01-08.59
Adult	**Urgent**		70% (50/71)	69% (49/71)	68% (48/71)
		Consultant	36% (18)	43% (21)	42% (20)
		Junior doctor	78% (39)	82% (40)	81% (39)
		Specialist nurse	46% (23)	12% (6)	10% (5)
		Ward nurse	20% (10)	27% (13)	23% (11)
		Apheresis team	2% (1)	2% (1)	2% (1)
		Day-care nurses	14% (7)	4% (2)	4% (2)
	Elective		46% (33/71)	20% (14/70)	17% (12/70)
		Consultant	15% (5)	21% (3)	17% (2)
		Junior doctor	58% (19)	57% (8)	58% (7)
		Specialist nurse	58% (19)	29% (4)	25% (3)
		Ward nurse	18% (6)	36% (5)	33% (4)
		Apheresis team	3% (1)	7% (1)	8% (1)
		Day-care nurses	33% (11)	14% (2)	17% (2)
Children	**Urgent**		44% (28/64)	44% (28/64)	44% (28/64)
		Consultant	64% (18)	71% (20)	71% (20)
		Junior doctor	89% (25)	96% (27)	96% (27)
		Specialist nurse	21% (6)	7% (2)	4% (1)
		Ward nurse	36% (10)	29% (8)	29% (8)
		Apheresis team	4% (1)	0% (0)	0% (0)
		Day-care nurses	11% (3)	0% (0)	0% (0)
	Elective		34% (21/62)	15% (9/62)	13% (8/62)
		Consultant	52% (11)	33% (3)	25% (2)
		Junior doctor	76% (16)	78% (7)	75% (6)
		Specialist nurse	48% (10)	33% (3)	38% (3)
		Ward nurse	29% (6)	22% (2)	25% (2)
		Apheresis team	5% (1)	0% (0)	0% (0)
		Day-care nurses	14% (3)	0% (0)	13% (1)

Note: junior doctor is any doctor who is not a consultant

Table S11: Where manual RCE can be performed

Age of patient	Where in hospital	Weekdays 9am -5pm	Weekends Sat 09:00 – Sun 17:00	Nights 17:01-08.59
Adults		70% (50/71)	69% (49/71)	68% (48/71)
	ITU/HDU	94% (47)	88% (43)	88% (42)
	Theatre/recovery	26% (13)	27% (13)	27% (13)
	Day care	60% (30)	29% (14)	27% (13)
	Regular ward	76% (38)	69% (34)	67% (32)
	Emergency department	22% (11)	22% (11)	23% (11)
Children		44% (28/64)	44% (28/64)	44% (28/64)
	ITU/HDU	89% (25)	89% (25)	86% (24)
	Theatre/recovery	29% (8)	25% (7)	25% (7)
	Day care	50% (14)	11% (3)	14% (4)
	Regular ward	79% (22)	64% (18)	61% (17)
	Emergency department	21% (6)	18% (5)	18% (5)
Denominator is those sites that responded to the question and performed automated RCE				

Table S12: Staff administration of top-up transfusion

Age of patient	Urgency	Who administers the transfusion	Weekdays 9am -5pm	Weekends Sat 09:00 – Sun 17:00	Nights 17:01-08.59
Adult	**Urgent**		96% (68/71)	96% (67/70)	93% (66/71)
		Consultant	4% (3)	3% (2)	5% (3)
		Junior doctor	12% (8)	10% (7)	12% (8)
		Specialist nurse	37% (25)	13% (9)	14% (9)
		Ward nurse	94% (64)	96% (64)	95% (63)
		Apheresis team	1% (1)	1% (1)	2% (1)
		Day-care nurses	53% (36)	12% (8)	11% (7)
	Elective		93% (66/71)	63% (44/70)	49% (34/70)
		Consultant	3% (2)	5% (2)	6% (2)
		Junior doctor	8% (5)	11% (5)	12% (4)
		Specialist nurse	32% (21)	16% (7)	18% (6)
		Ward nurse	77% (51)	93% (41)	88% (30)
		Apheresis team	2% (1)	2% (1)	3% (1)
		Day-care nurses	65% (43)	25% (11)	26% (9)
Children	**Urgent**		96% (63/66)	94% (62/66)	92% (60/65)
		Consultant	11% (7)	8% (5)	8% (5)
		Junior doctor	25% (16)	23% (14)	23% (14)
		Specialist nurse	33% (21)	15% (9)	12% (7)
		Ward nurse	87% (55)	92% (57)	90% (54)
		Apheresis team	2% (1)	2% (1)	3% (2)
		Day-care nurses	43% (27)	13% (8)	10% (6)
	Elective		91% (60/66)	67% (44/66)	48% (32/66)
		Consultant	7% (4)	7% (3)	9% (3)
		Junior doctor	20% (12)	20% (9)	25% (8)
		Specialist nurse	23% (14)	16% (7)	19% (6)
		Ward nurse	80% (48)	82% (36)	88% (28)
		Apheresis team	2% (1)	2% (1)	3% (1)
		Day-care nurses	45% (27)	18% (8)	16% (5)

Note: junior doctor is any doctor who is not a consultant

Table S13: Where top-up transfusion can be performed

Age of patient	Where in hospital	Weekdays 9am -5pm	Weekends Sat 09:00 – Sun 17:00	Nights 17:01-08.59
Adults		96% (68/71)	96% (67/70)	93% (66/71)
	ITU/HDU	78% (53)	79% (53)	82% (54)
	Theatre/recovery	66% (45)	64% (43)	67% (44)
	Day care	88% (60)	45% (30)	39% (26)
	Regular ward	97% (66)	97% (65)	95% (63)
	Emergency department	57% (39)	58% (39)	59% (39)
Children		96% (63/66)	94% (62/66)	92% (60/65)
	ITU/HDU	54% (34)	52% (32)	53% (32)
	Theatre/recovery	44% (28)	42% (26)	43% (26)
	Day care	67% (42)	39% (24)	33% (20)
	Regular ward	86% (54)	87% (54)	88% (53)
	Emergency department	33% (21)	32% (20)	33% (20)
Denominator is those sites that responded to the question and performed automated RCE				