



Health services for people with haemoglobin disorders

Overview Report

Version V1

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8831



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Executive Summary

1. This report summarises the findings of the validation of self-assessments of 64 services for people with haemoglobin disorders, and subsequent peer review visits to ten services for adults and 15 services for children and young people (CYP) with these conditions. Peer review visits to services across England and Wales were conducted between June 2019 and March 2020. The self-assessments and peer review visits reviewed compliance with the Quality Standards (QS) for Health Services for People with Haemoglobin Disorders, Version 3 (October 2018), and identified relevant issues. The findings for the peer review visits presented here are those identified at the time of the visits, and action may already have been taken to address the issues identified.
2. People with the haemoglobin disorders sickle cell disease and thalassaemia require life-long care. People with sickle cell disease encounter problems during childhood including pain, acute stroke, recurrent infections and psychosocial issues. These problems continue into adulthood, when chronic complications such as renal disease, chronic cardio-respiratory disease and bone and joint problems also arise. Most people with thalassaemia syndromes require blood transfusions every three to four weeks for life. This results in an overload of iron in the body that, if not appropriately managed, is harmful and usually fatal by the time the patient is in their mid-teens.
3. This programme used a different approach for identifying progress from that followed for the previous three haemoglobinopathy review programmes (2010, 2012, 2014-16). Each service identified during the last programme (2014-16) as providing a specialist or locally accredited service was invited to submit a self-assessment against all 52 Quality Standards (QS) for specialist and local haemoglobinopathy teams, and to provide evidence to show whether it met a subset of 17 of these QS that the steering group had decided were the standards most able to identify effective outcomes.
4. The self-assessment validation process was useful to identify those services who were, by their own admission, not meeting all the key QS. However, during the validation process it was also clear that in some cases teams did not provide appropriate evidence despite providing an adequate quality of care. Further training on how to provide good quality evidence is needed for future reviews.
5. The issue of either insufficient time for the leadership of the service or lack of availability of consultant medical staff has markedly worsened since the 2016 review programme. During the current review programme it was identified as a problem for 84% of services reviewed. In 2016 it had been identified as an issue in 35% of the services reviewed.
6. Nursing roles were diverse, with a high variability in responsibilities. There is no national workload model for the haemoglobinopathy CNS role, which makes it difficult to make a clear case for more support in terms of the complexities of the role.
7. The lack of condition-specific information resources for people with thalassaemia was identified during both the validation exercise and the peer review visits. Access to information about thalassaemia is particularly important in low prevalence areas where peer support may not be readily available.
8. Two thirds of the services reviewed had insufficient or no access to psychology staff with appropriate competences in the care of people with haemoglobin disorders.
9. In general, the availability of clinical guidelines had improved since the previous review programme, but the detail and document control of these guidelines was highly variable.
10. Arrangements for annual reviews of all patients with haemoglobin disorders had improved, but robust arrangements were still not in place in some services, with potentially serious implications for patient outcomes.
11. As was recorded in the last overview report of 2016, progress had been made in improving transition from CYP services to adult services, and some Trusts had excellent arrangements in place. However, many services lacked

the robust processes needed to ensure a safe transfer of care to adult services. Robust transition services will become increasingly important as the number of young people transitioning to adult services increases.

12. The reorganisation of the networking arrangements in haemoglobinopathies (via the formation of specialist haemoglobinopathy teams (SHTs) and haemoglobinopathy coordinating centres (HCCs)) led to many changes being instituted during the peer review process. Many services were in a state of flux and were taking on new roles. The Quality Standards will need to be reviewed in the light of this change.
13. The onset of the COVID-19 pandemic disrupted the peer review process, and three visits scheduled in February and March 2020 had to be cancelled, despite the receiving Trusts having made significant preparations for the visits.
14. In summary, although improvements have been made, services for this vulnerable group of patients are of variable quality across Trusts and remain under-developed in some areas. Growing patient numbers and, in particular, a shortage of specialist medical, nursing and psychology staff threaten the future viability of some services. The following recommendations are therefore suggested by the steering group to improve the quality of services provided for haemoglobinopathies, and thereby to improve patients' outcomes and experience of care:
 - a. The new commissioning structure for haemoglobinopathy in England is likely to allow for more clinical networking, shared learning, equitable access to specialised services, unified protocols and collaborative research. It is therefore important to ensure that innovative commissioning and insightful self-assessment continue to remain a top priority for such services. Future peer review programmes should adapt the Quality Standards to reflect the new national and local commissioning arrangements.
 - b. Organisations such as Health Education England, the medical royal colleges, the Nursing and Midwifery Council, and medical and nursing schools should engage with haemoglobinopathy specialist consultants and nurses to address current shortfalls and to carry out robust specialist workforce planning for the future.
 - c. Significant differences in the quality of haemoglobinopathy services within regions were observed during this review programme. It is very likely that these differences also result in differences in patient outcomes. In future, every effort should be made to ensure that patients, regardless of their area of residence in England and Wales, receive equitable care. This can be achieved by standardising clinical pathways and guidelines, arranging joint specialist clinics, engaging with regional multi-disciplinary meetings, facilitating access to specialist investigations, and conducting patient experience surveys and statutory audits, among other things. The National Haemoglobinopathy Panel (NHP) and the HCC MDTs should facilitate the standardisation of care, undertake discussions around complex patients and facilitate learning from cases involving morbidity and mortality.
 - d. During the review visits, patients with sickle cell disease often reported delayed or inadequate pain management by non-specialised teams in acute vaso-occlusive episodes. It is important that haemoglobinopathy services continue to engage with their emergency teams to establish local processes that improve pain management.
 - e. A large variation was observed in patient access to information about haemoglobinopathy in general. It is recommended that a central repository of patient information is developed, identifying the good quality, reliable information that already exists and allowing that to be shared with all providers and patients. National patient organisations should lead on this work, and this information should be available on their websites. The NHP and/or the National Haemoglobinopathy Registry (NHR) could be utilised to ensure this information is made widely available.
 - f. Access to personal clinical information, in particular, was raised by patients as an issue. It is important that individual clinic letters are shared with patients, together with clear updates and concise instructions to patients and GPs.

- g. The Black Lives Matter movement has highlighted many deep inequities within society in the lived experiences of individuals. It is important that haemoglobinopathy services are aware that systemic changes are required to ensure that healthcare provision is anti-racist and responsive to the needs of this marginalised and vulnerable group of people.

Introduction

1. Sickle cell disease and thalassaemia are a group of inherited haemoglobin disorders causing chronic ill health and reduced life expectancy. Care for individuals with these disorders is life-long. In the UK, sickle cell disease is predominantly prevalent among people of black African, African-Caribbean or Arabic origin, while thalassaemia is prevalent among those of Mediterranean and Asian origin.
2. The prevalence of these disorders in the UK varies according to geographical region, being highest in urban ethnic populations. The NHS Sickle Cell and Thalassaemia Screening Programme reports (2018) that 272 affected babies were born in England, which is a slightly lower number than the 310 reported in the 2016 overview report. Affected babies are born in all regions of England, but approximately 70% of them are born in London. Areas such as the north-east and south-west of England have much lower prevalence.
3. The geographical distribution of transfusion-dependent thalassaemia is different from that of sickle cell disease, reflecting the different communities in which these disorders are encountered.
4. Adults with sickle cell disease are at risk of both acute and chronic complications, the latter becoming more common with increasing age. Pain is a problem for all ages. Problems encountered during childhood, such as acute stroke, recurrent infections and psychosocial issues, continue to require care in adulthood. Transition to adult services is a particular issue for young people entering further education or employment. Chronic complications such as renal disease, chronic cardio-respiratory disease and bone and joint problems are common in adults and require specialist management.
5. People with transfusion-dependent thalassaemia require blood transfusions every three to four weeks for life. Iron chelation therapy is essential to prevent the accumulation of iron in the body. People with thalassaemia who are not being transfused also accumulate iron. Without iron chelation therapy, iron overload is harmful, causing cardiac, liver and endocrine disease, and it may be fatal by the time the patient is in their mid-teens. Standard monitoring for iron overload includes Magnetic Resonance Imaging (MRI) of the liver and heart. Issues of adherence to treatment are important at all ages.
6. The varied prevalence of haemoglobinopathies across England poses a challenge for access to specialist care, particularly in low prevalence areas, leading to different arrangements for the provision of care across the country.
7. During 2019 NHS England (NHSE) undertook a major review of specialist provision, leading to the procurement of 14 Haemoglobinopathy Coordinating Centres (HCCs) for sickle cell disease and thalassaemia across England and the formal designation of 24 Specialist Haemoglobinopathy Teams (SHTs). Since the last QRS Overview report (2016) the Clinical Reference Group (CRG) for Haemoglobin Disorders has continued in operation, providing clinical advice to commissioners including advice on service specifications and policies.
8. As part of the reconfiguration of specialised services by NHSE in 2019, additional funding was made available to enable SHTs to fulfil their specialist function. The review visits identified that without this funding, there would have been little improvement in staffing within some services since the last review programme.
9. The need for improvement to services for people with haemoglobinopathies has been identified repeatedly, including by the All-Party Parliamentary Group for Sickle Cell and Thalassaemia and the following published reports:
 - a. National Confidential Enquiry (2004-2006) into Patient Outcome and Death (NCEPOD) Report "A Sickle Crisis?" (May 2008)

- b. Department of Health sponsored review of haemoglobinopathies (Darbyshire, 2009)
- c. “National Haemoglobinopathies Project: A guide to effectively commissioning high quality sickle cell and thalassaemia services” (NHS East Midlands Specialised Commissioning Group, July 2011)
- d. Services for Children and Young People with Haemoglobin Disorders Peer Review Programme 2010-2011: Overview Report (UK Forum on Haemoglobin Disorders and WMQRS, September 2011)
- e. Services for Adults with Haemoglobin Disorders Peer Review Programme 2012-13 Overview Report (UK Forum on Haemoglobin Disorders and WMQRS, September 2013)
- f. Caring for haemoglobinopathy patients: Report of a national workforce survey (UK Forum on Haemoglobin Disorders, August 2015)
- g. Services for People with Haemoglobin Disorders, Peer Review Programme 2014-16 Overview Report, Version 2 (UK Forum on Haemoglobin Disorders and WMQRS, November 2016)
- h. Not being heard: Barriers to high quality unplanned hospital care during young people’s transition to adult services – Evidence from ‘this sickle cell life’ research. Renedo A, Miles S, Chakravorty S, Leigh A, Telfer P, Warner JO, Marston C. BMC Health Services Research. 2019 Nov 21;19(1):876. doi: 10.1186/s12913-019-4726-5.
- i. Patient-reported experience measure in sickle cell disease. Chakravorty S, Tallett A, Witwicki C, Hay H, Mkandawire C, Ogundipe A, Ojeer P, Whitaker A, Thompson J, Sizmur S, Sathyamoorthy G, Warner JO. Arch Dis Child. 2018 Dec;103(12):1104-1109. doi: 10.1136/archdischild-2018-314955. Epub 2018 Aug 4.

A full list of guidance documents is included in the Quality Standards for Health Services for People with Haemoglobin Disorders V3 2018, which is available via the QRS website qualityreviewservicewm.nhs.uk

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Review programme

Review process



- This report summarises the findings of the peer-led electronic validation of self-assessments submitted by 64 haemoglobin disorder services in England, Wales and Ireland, and subsequent peer review visits to a subset of 10 services for adults and 15 services for children and young people in England and Wales. Services were visited between June 2019 and March 2020. The peer review visits reviewed compliance with all the Quality Standards in the document entitled 'Quality Standards for Health Services for People with Haemoglobin Disorders, Version 3 (October 2018)' and identified relevant issues, whereas the electronic validation of the self-assessments reviewed compliance against only 17 key Quality Standards. The peer review visit findings presented later in this report are those identified at the time of the corresponding visit, and action may already have been taken to address the issues identified. Similarly, actions may also have been taken by organisations following the electronic self-assessment validation exercise in Trusts that were not physically visited.
- Services were reviewed under one of the following categories¹:
 - Specialist Haemoglobinopathy Team (SHT):** A multi-disciplinary team providing specialist care for people with haemoglobinopathies, including annual review and specialist monitoring for patients from across the clinical network. The SHT provides leadership for a geographical area network.
 - Local Haemoglobinopathy Team (or Linked Providers) (LHT):** A team providing local care for people with haemoglobinopathies under the guidance of the Specialist Team, including routine out-patient management, regular blood transfusions, and the management of uncomplicated pain crises and other minor clinical complications.
- At the time of the preparatory phase of this peer review programme in 2018, NHS England (NHSE) was undertaking a large consultation process for the radical modification of the haemoglobinopathy services specialist commissioning process. The UK Forum on Haemoglobin Disorders considered this potential change, but decided to proceed with the review programme based on Quality Standards that were likely not to reflect the new commissioning structures. It was felt that this programme would inform some of the decision making around the reconfiguration. The new structure was subsequently implemented in late 2019, when the peer review programme was already under way.
- The primary purpose of the peer review programme was developmental and supportive, with the aim of improving the quality of services for people with haemoglobin disorders (HD). The objectives of the programme were that:
 - Patients and carers would know more about what services to expect;

¹ The QRS/UKFHD Quality Standards were published prior to the 2019 NHSE Service Specification 170126S Specialist Haemoglobinopathy Services (All ages) - Specialist Haemoglobinopathy Teams. Of note is that the terminology used in the QRS Quality Standards is consistent with that used in the latest NHS service specification.

- b. Commissioners would be supported in assessing and meeting the needs of their populations, improving health and reducing health inequalities;
 - c. Service providers and commissioners would work together to improve service quality;
 - d. Service providers and commissioners would have external assurance of the quality of local services;
 - e. Reviewers would learn from taking part in review visits;
 - f. Good practice would be shared; and
 - g. Service providers and commissioners would have better information to give to the Care Quality Commission and Monitor.
14. The review programme was run under the governance of the Quality Review Service (QRS). Implementation of the review programme (validation and review visits) was overseen by a steering group of multi-disciplinary members from a range of professional staff groups, including representatives from the Sickle Cell Society and the UK Thalassaemia Society. The steering group was chaired by Dr Subarna Chakravorty. Membership of the steering group is given in [Appendix 3](#).
 15. The teams that were selected for inclusion in this review programme were identified from the last peer review visit programme as providing a specialist service or a locally accredited service (providing care for a large number of patients and some shared care with an SHT). Not all teams providing local care for patients with haemoglobin disorders were included in the validation process, but reviewers did enquire about the local networking arrangements during the course of each of the review visits.
 16. For the validation process, all services included in the review programme were invited to submit an electronic self-assessment document against all the Quality Standards and to submit evidence for 17 key standards identified by the UKFHD steering group as being important markers for assessment. Every submission was reviewed by a team consisting of members of UKFHD steering group and QRS, and a decision was made, based on agreed criteria, on whether to undertake a physical review visit. The process of validation is presented in more detail later in this report.
 17. Table 1 summarises the services that submitted a self-assessment and evidence for the validation process, and those services that were then included in the peer review programme. [Appendix 2](#) gives more detail, including the dates of each visit and the type of service provided at each hospital. Data on achievement of the 17 key Quality Standards are therefore based on 32 services for adults and 32 services for children and young people, while data on achievement of the Quality Standards following a peer review visit are based on 10 services for adults and 15 services for children and young people.

Table 1: Services reviewed: Validation process and peer review visits 2019-2020

Type of service	Validation No. reviewed		Peer review visit No. reviewed	
	Adult	Children	Adult	Children
Specialist Haemoglobinopathy Team	24	25	10	13
Local Haemoglobinopathy Team	8	7	0	2
Sub total	32	32	10	15
Total	64		25	

Notes:

Validation: Teams that self-assessed as being an LHT at the time of the validation process included:-

- Adults: BHR, LGT and QEJ, NUHT, RWH, UHBT, UHCW, Whipps X.
- Paediatrics: BHR, L&G-both sites, NUH, RWH, UHCW, Whipps X.

Peer Review visits: BHR and L&G-QEJ were reviewed as CYP LHTs at their request, as they were in the early stages of transitioning to provide a specialist haemoglobinopathy service.

18. The peer review visits to services took the same approach as that used for the 2014-2016 programme (which covered the care of both children and adults). In contrast, the 2010-2011 review only covered services for CYP with haemoglobin disorders, and the 2012-2013 review covered services for adults only. The network and commissioning Quality Standards were not included in this review programme because of the changes in the national configuration of services taking place in 2019.
19. The review visits looked at compliance with the Quality Standards for Health Services for People with Haemoglobin Disorders V3 (June 2018) and identified relevant issues. The review visits were led by Clinical Leads appointed by the UK Forum on Haemoglobin Disorders: Dr Emma Drasar and Dr Rachel Kesse-Adu for adults and Dr Subarna Chakravorty and Dr Mark Velangi for children and young people. The review visits were organised by the QRS on behalf of the UK Forum on Haemoglobin Disorders.
20. Each review visit involved a multi-disciplinary team of clinical staff, service users, managers and commissioners. The team met staff and patients, looked at documentary evidence and case notes, visited facilities and then drew conclusions. Visits usually lasted one day, with teams looking separately at the care of adults and the care of children and young people. Some aspects of the service, for example, Emergency Departments (ED), were visited by both teams. Transition to adult services was also discussed by both teams. Some visits involved teams looking at more than one service; for example, one NHS Trust had one SHT and two LHTs that were visited over two days as they provided an integrated red cell service with shared protocols and consultants working across the Trust sites. The review programme as a whole involved 18 days of visits and 24 'review team days' ([Appendix 2](#)).
21. Invitations to take part as reviewers in this review visit programme were sent to the leads in each service as well as to relevant groups including the UKFHD, the Sickle Cell Society and the UK Thalassaemia Society. As with previous programmes, all new reviewers were required to attend a training session, and existing reviewers could also attend a refresher session. Three existing reviewers attended a refresher training session.
22. A change from the last review programmes was that, in addition to the arrangements to reimburse user and carer reviewers, the travel costs of clinical and managerial reviewers were reimbursed, and overnight accommodation was provided where necessary. Feedback from reviewers about this change was positive, as covering their costs meant that their organisations were more willing to release them to become involved in the programme.
23. New to this programme was the provision of online reviewer training sessions for reviewers. These sessions were much shorter (1¼ hrs) rather than half a day, and did not include any group work, although reviewers could opt to attend a 'face to face' training session at the QRS office in West Bromwich if they preferred. In total 13 training sessions were delivered (four 'face to face' and nine online) over a ten-month period between January and October 2019.
24. A total of 50 new reviewers joined the existing 75 reviewers who had confirmed their agreement to remaining on the QRS review database from previous programmes. Seventy-two reviewers took part in a total of 149 'review team days' in the 2019-2020 review programme, compared with 89 reviewers who provided 284 review team days in the last programme. The number of reviewers involved was slightly fewer, at 72 compared to 89, with each reviewer completing on average two review team days compared to three days previously. The number of reviewers who took part from London-based organisations was broadly similar to the number who took part from other areas across the UK. Table 2 shows the different types of reviewers who were involved. Undertaking reviewer training and acting as a reviewer is Continuing Professional Development for NHS staff, and [Appendix 5](#) gives more detail of the value which reviewers gained from the experience.
25. Online training evaluations generated a 59% response rate following the session. Of those completing the evaluations, 95% considered that the training objectives were 'fully' or 'very well' met. Reviewers were also asked at the end of the visit day if they considered that the online training session had provided enough information about the review process and their responsibilities as a reviewer. Out of 25 reviewers who responded to the question, using a rating of one to five with five being that the training session fully addressed

their needs for undertaking a visit, 92% gave rating of five or four (56% scored 5, and 36% scored 4). See [Appendix 5](#) for more details.

Table 2: Reviewers

	Reviewer from previous HD or IABD ² programme	Face to Face (2019)	Online (2019)	Total
Consultant	25	5	17	47
Nurse	27	3	12	42
Psychologist	1	-	5	6
Manager	1	1	2	4
Biomedical Scientist	-	1	-	1
Patient / Carer	18	-	3	21
Commissioner	3	-	1	4
Other	-	-	1	1
Total	75	10	39	125

26. Reports of individual visits are available on the QRS website: qualityreview servicewm.nhs.uk. Many of the services were being reviewed for the third time and so it was possible to demonstrate progress from the findings of the first visit. Service re-configuration in some areas meant that meaningful comparisons could not be made.
27. Issues identified during peer review visits were categorised as follows:
- | | |
|--|----|
| Good practice | GP |
| Immediate risks to clinical safety and clinical outcomes | IR |
| Serious concerns | SC |
| Concerns | C |
| Further consideration | FC |

The number of times particular issues were identified are shown in brackets in the 'Findings' section of this report. For example (C:1; FC:1) would indicate one 'concern' and one 'further consideration'.

28. [Appendix 1](#) lists all the Quality Standards which were used in the 2019-2020 review process. [Appendix 6](#) gives a glossary of terms and abbreviations used in this report.
29. It is hoped that, as for previous review programmes, a 'good practice event' will be organised in the future by the UKFHD at which service providers will be invited to showcase their exemplary areas of work. In the interim, all good practice identified during the visits has been included in the relevant sections of this report.

Acknowledgements

30. This peer review programme could not have taken place without the support of the UK Forum on Haemoglobin Disorders, the UK Thalassaemia Society, the Sickle Cell Society; the commitment and dedication of the programme's Clinical Leads (Dr Emma Drasar and Dr Rachel Kesse-Adu for adults and Dr Subarna Chakravorty and Dr Mark Velangi for children and young people) and the willingness of their NHS Trusts to release them for this work; the cooperation of the teams that were reviewed; the willingness of reviewers to give their time and expertise; the agreement of reviewers' employing organisations to release them; the user and carer representatives who gave their time and expertise and to whom particular thanks are given; and the time of the other members of the peer review steering group. The contribution of all to this programme is gratefully acknowledged.

² IABD: Inherited and acquired bleeding disorders

Part 1: Validation

Validation of Self-Assessment Model

31. The brief from the UKFHD was to undertake a peer review programme with fewer physical visits than in the previous programme in 2014-2016 but without affecting the progress made in the previous programmes and the national focus on the care of people with haemoglobin disorders.
32. The agreed review model was a hybrid process involving a combination of peer-led validation of self-assessment returns against 52 QS from all services participating in the programme, followed by the selection of a small number of participating centres for a physical review visit. A similar process of self-assessment had been implemented nationally for cancer services. For the self-assessment stage of the programme, the steering group agreed that services should complete a self-assessment for all the QS and submit documentary evidence of compliance with a selected sub-group of 17 out of the 52 QS. The self-assessments and evidence for the 17 key QS was reviewed, as a 'desktop' exercise, by a validation panel consisting mainly of members of the UKFHD peer review steering group. It was agreed that about 50% of the services who submitted self-assessment documents would be offered a physical review visit, resulting in approximately 30 review visits. As part of the process, QRS developed a risk-based tool that would enable the recording and grouping of the validation results.
33. The UKFHD peer review steering group identified services to be invited to take part in the review programme: those that provided specialist care for people with haemoglobin disorders, local teams who had been involved in the previous peer review programme in 2014-2016, and local teams who were providing care for a large number of patients but had not been reviewed in the past. The cost of the programme was shared equally across all services regardless of whether a visit took place.
34. In October 2018, services were formally invited to participate in the review programme and were asked to submit, electronically, their self-assessment along with documentary evidence of compliance with a subset of 17 of the 52 QS to QRS, by the 18th January 2019. The deadline for submission was then extended to the 18th February 2019 as some services were being required to submit evidence as part of the NHSE reconfiguration of services review.
35. The file upload system worked well, with only two out of the 64 teams reporting problems with sending their evidence. The quality of the evidence returned was extremely variable. Some returns had minimal evidence whereas others were very comprehensive, with some uploads being as large as 100MB.
36. The criteria triggering a review visit, following evidence review, were as follows:
 - a. Those services who met fewer than 50% of the 17 key QS would automatically receive a peer review visit;
 - b. Up to 50% of those services who met between 50% and 75% of the 17 key QS would be included in the peer review visit programme; and
 - c. Approximately 10% of those services who scored between 75% and 100% would be included in the peer review visit programme to validate the assessment methodology and to enable good and outstanding practice to be shared.
37. All electronic submissions were validated in February 2019 by a panel consisting of UKFHD peer review steering group members and QRS. At the end of March 2019, following the validation meeting, services were notified of the outcome of the validation process.
38. At the time of the validation assessment, some teams were in the process of formal designation and therefore self-assessed as LHTs despite being subsequently designated as SHTs by NHSE.
39. Of the 64 teams whose self-assessments were validated, the percentage compliance with the 17 key quality standards was as follows:-

Table 3: Compliance with the 17 key QS following the desk top validation

Percentage of 17 key standards met	Criteria for a peer review visit (max 30 visits)	Adult Services	CYP Services	No. of services selected for a review visit	
				Adults	CYP
Fewer than 50%	All teams	4	7	4	7
Between 50% and 75%	50% of teams	11	19	5	9
Over 75%	10% of teams	17	6	2	1

Note: one adult and two CYP visits scheduled to take place in March and April 2020 were cancelled due to the Covid -19 pandemic

40. Following the desktop validation exercise, a higher number of services met either fewer than 50% (red) or between 50% and 75% (amber) of the 17 QS. All the teams within the amber category were selected for review by the validation panel as they met fewer than 70% of the key standards and were deemed to be a representative sample. In general, when there were joint services working across two sites/Trusts only one of the services/sites was visited.
41. It was also interesting that more children's and young people's services than adult services met the criteria for a review visit. Initial conclusions from the validation panel were that this was the result of some of the QS not being as closely applicable to children's services as they were to adult services. For example, QS HN-302 'Emergency Department – Staff Competences' was not always met, as many children's services had a direct ward admission policy and emergency attendances at the ED were low; the same was true for HN-304 'Specialist Services – Network', where some of the specialist teams listed were not applicable to children's services.
42. The UKFHD steering group also acknowledged that the desktop validation process did not include any discussions with the clinical teams about their evidence submission. Therefore, a new 'partially met' category was created when there was ambiguous or insufficient documentary evidence. In contrast, during the physical review visits, compliance outcomes were binary, that is, either 'met' or 'not met'.
43. Tables 3, 4, 5, 6 and 7 show the comparison for compliance with the 17 key Quality Standards between each team's self-assessment and following the review of the evidence by the UKFHD validation panel.

Table 4: Comparison of compliance with self-assessment and compliance following review by the validation panel – Adult services chosen for a review visit

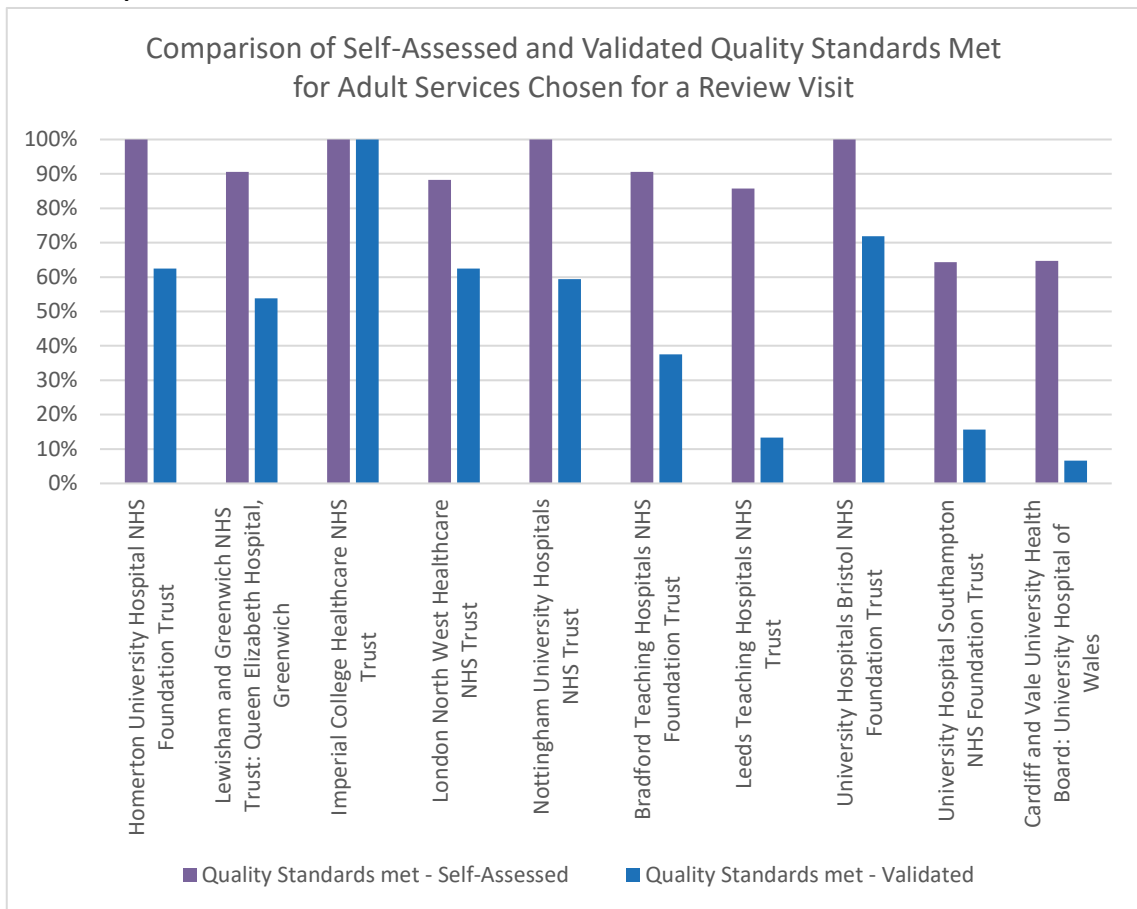
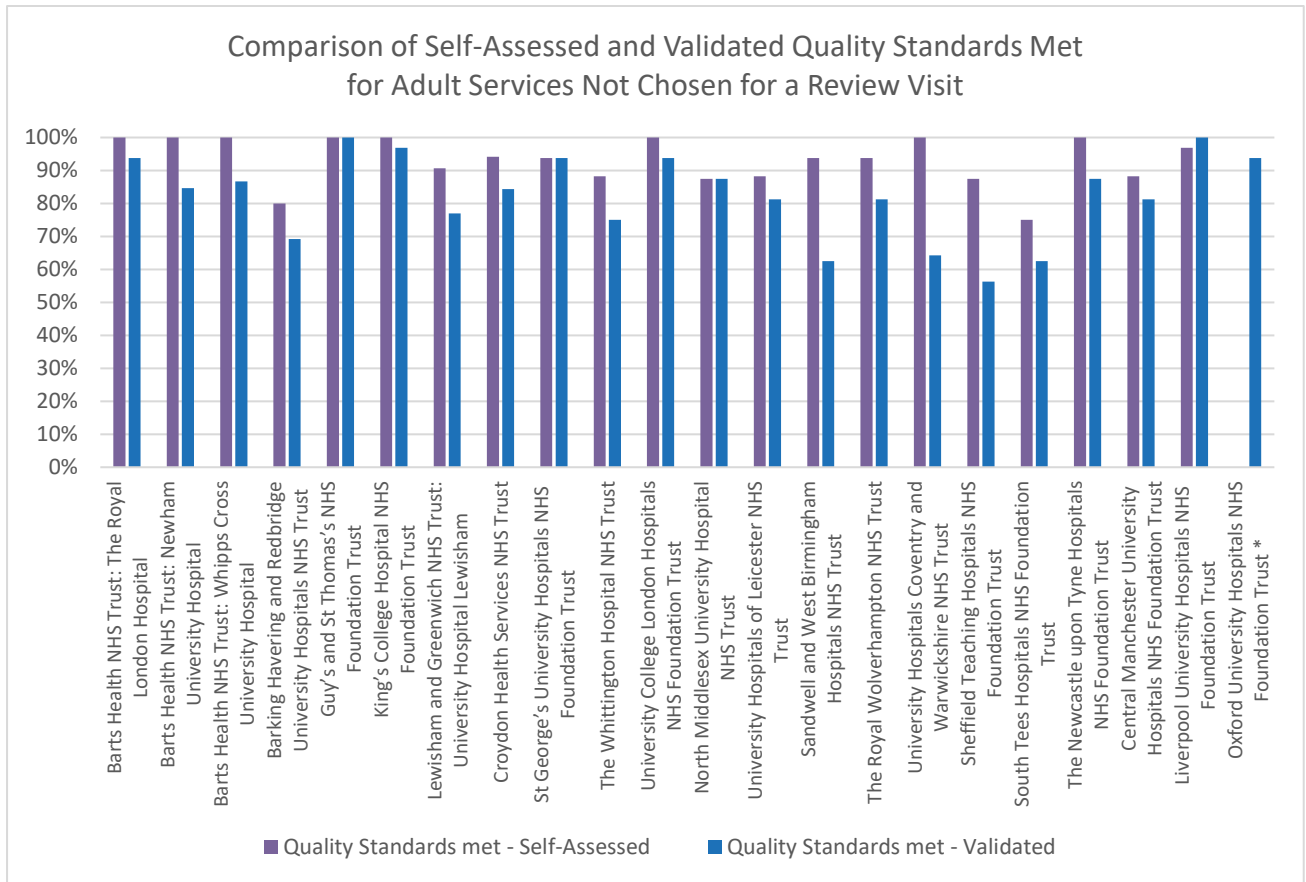
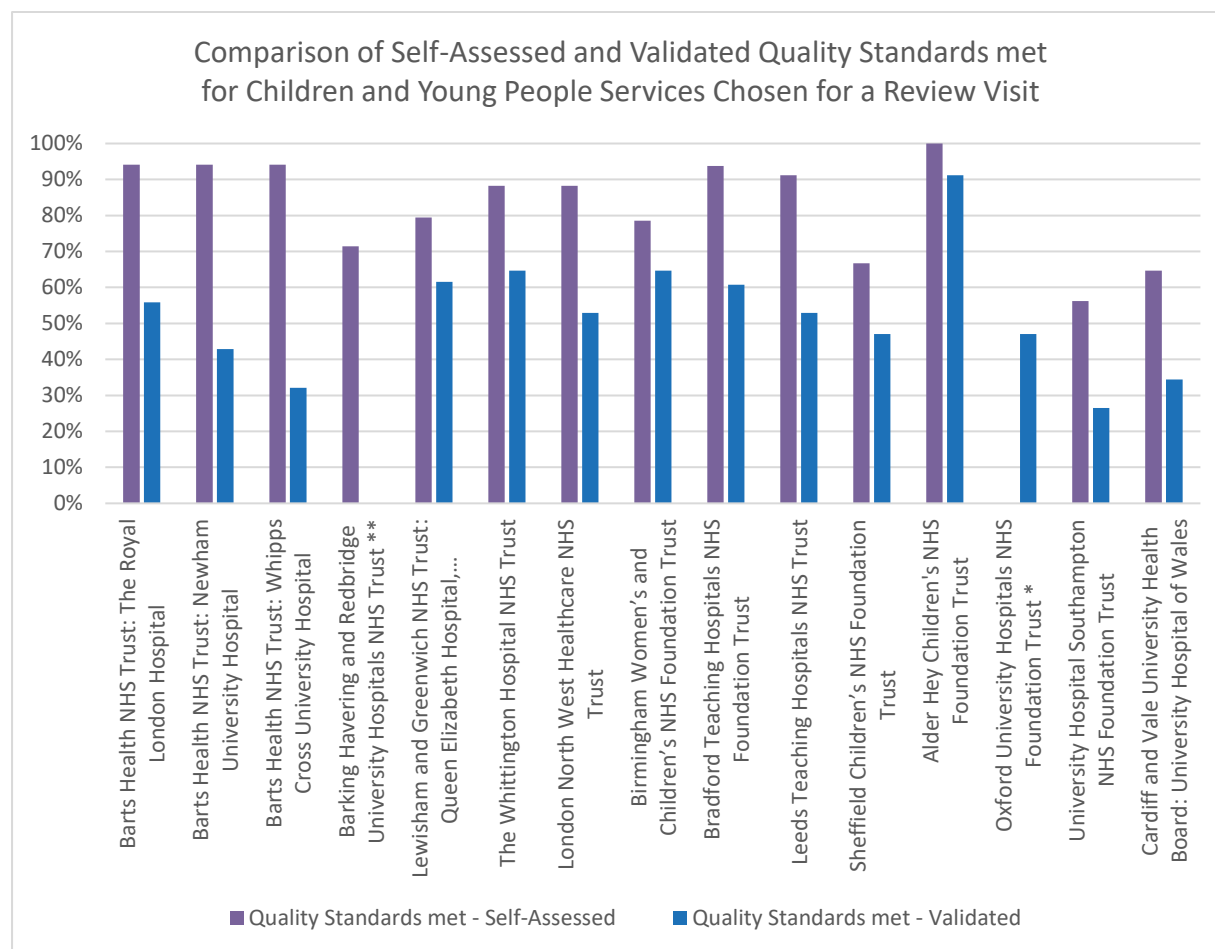


Table 5: Comparison of compliance with self-assessment and compliance following review by the validation panel – Adult services not chosen for review visit



Note: Oxford University Hospitals NHS Foundation Trust sent comments and evidence but did not include a self-assessment of compliance in their submission.

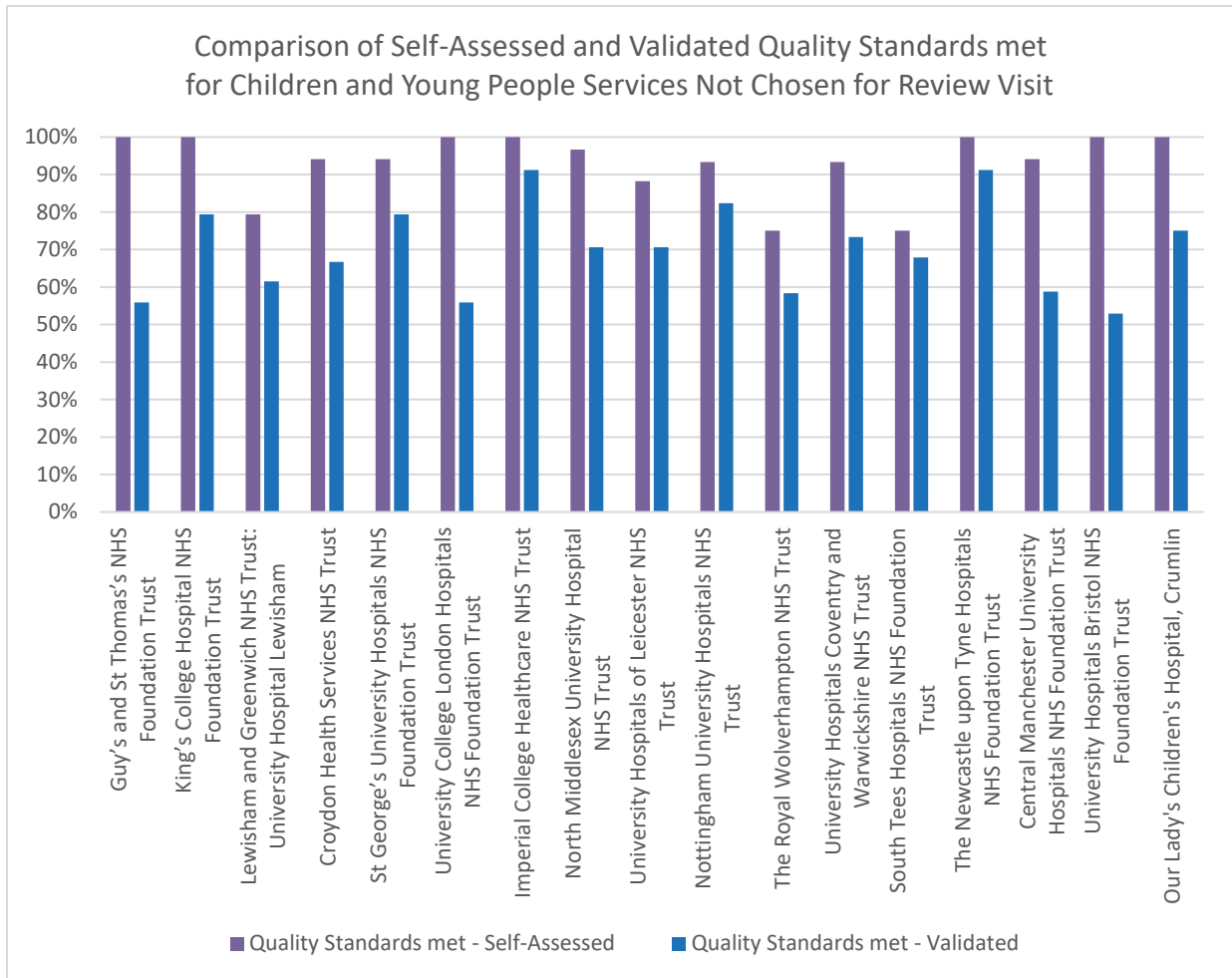
Table 6: Comparison of compliance with self-assessment and compliance following review by the validation panel – Children and young people services chosen for review visit



Notes:

1. *Oxford University Hospitals NHS Foundation Trust sent comments and evidence but did not include a self-assessment of compliance in their submission.*
2. *Barking, Havering and Redbridge University Hospitals NHS Trust completed a self-assessment of their compliance but did not submit suitable evidence to complete the validation.*

Table 7: Comparison of compliance with self-assessment and compliance following review by the validation panel – Children and young people services not chosen for review visit



44. Tables 8 and 9 show, for each of the 17 key QS, the number of teams who self-assessed that they did not meet the QS and the number of teams that the validation panel decided did not meet the QS.

Table 8: Number of teams who self-assessed as not meeting a QS and number of teams the validation panel decided did not meet the QS – Adult services

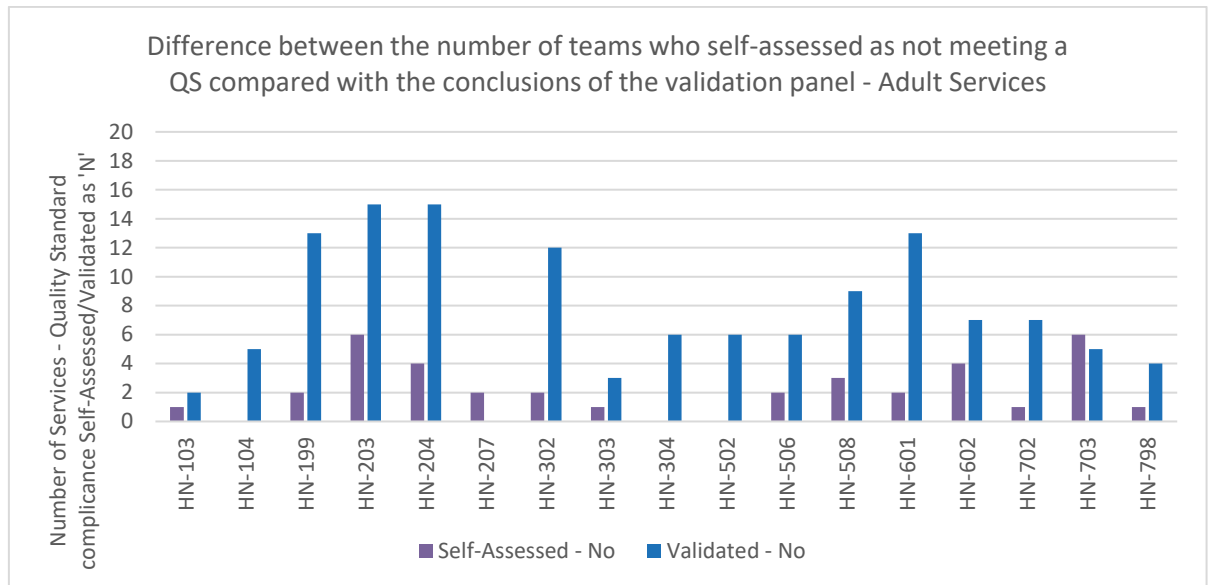
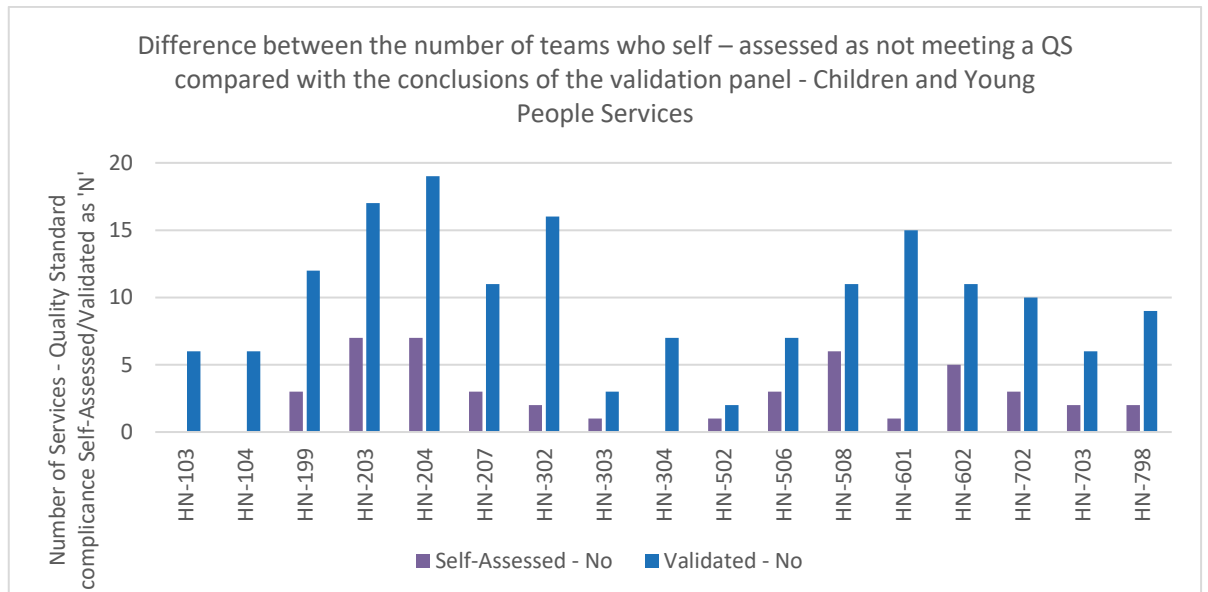


Table 9: Number of teams who self-assessed as not meeting a QS and number of teams the validation panel decided did not meet the QS – Children and young people services



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Compliance with Quality Standards during desktop validation compared to peer review visit findings*

*Only applicable to services where a physical visit took place

Tables 10 & 11: Comparison of compliance with the 17 key Quality Standards assessed through validation and visits

Table 10: Services for adults with haemoglobin disorders

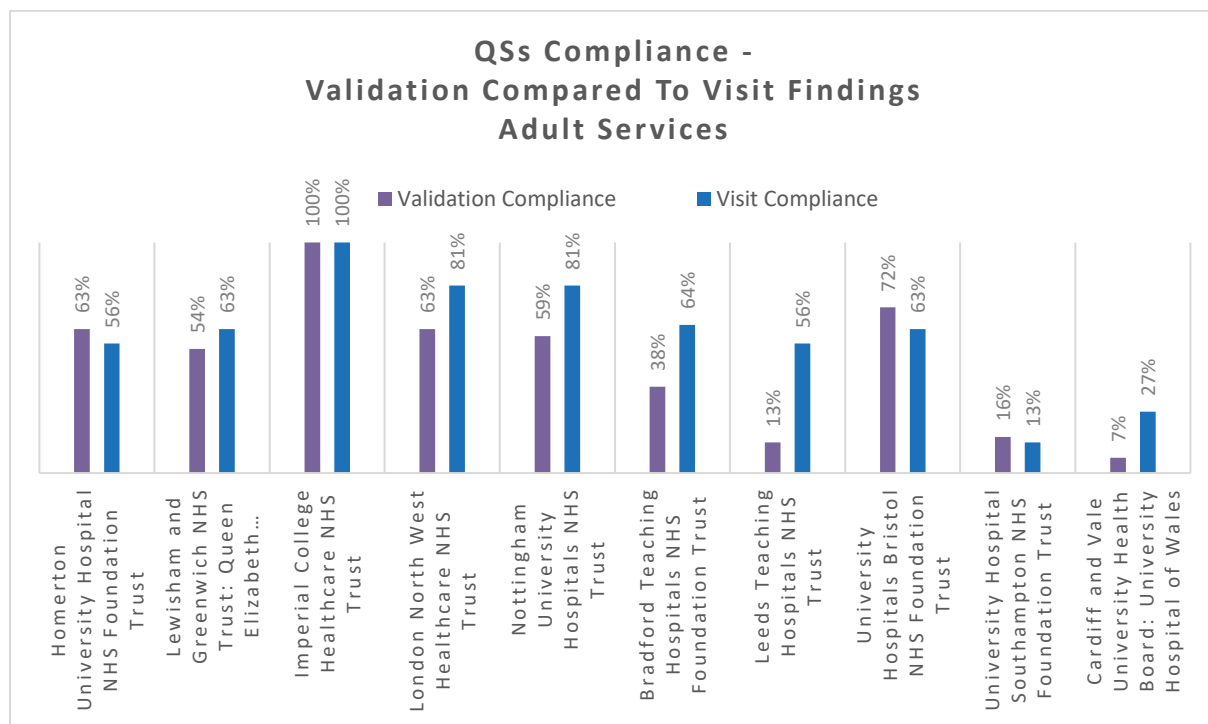
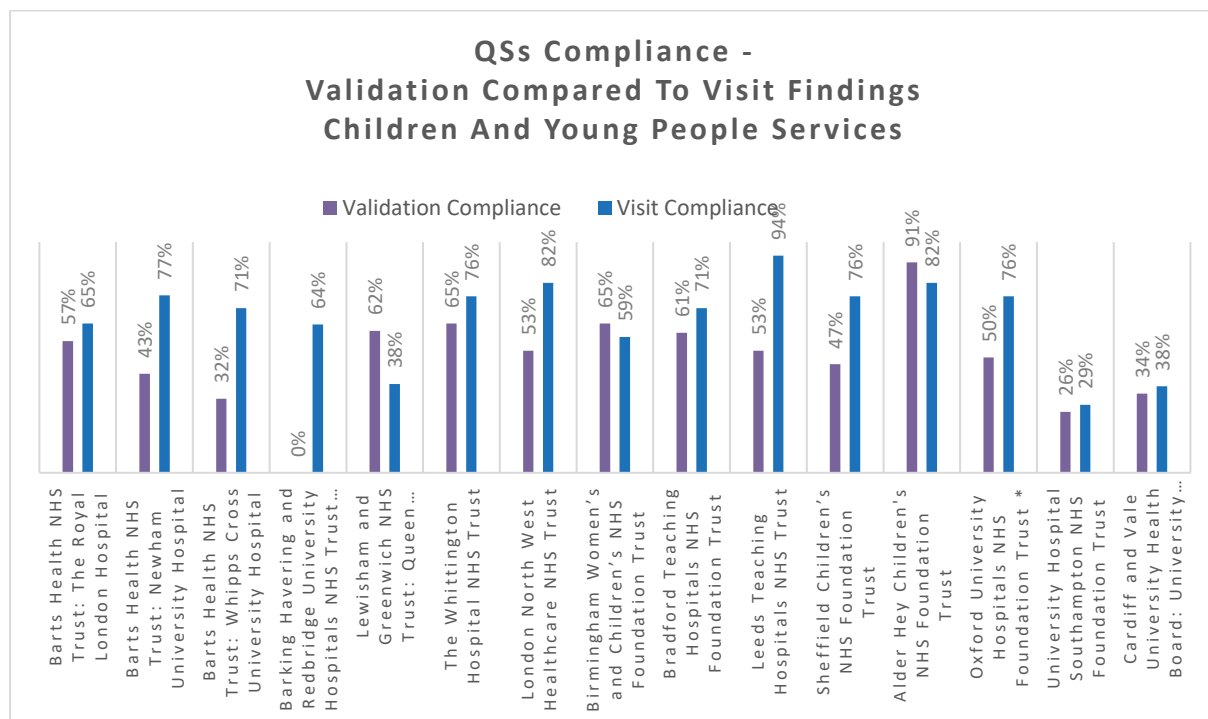


Table 11: Services for children and young people with haemoglobin disorders



reasons for non-compliance at the time of the visit were generally around the lack of guidance and information for GPs relating to sexual health/contraception.

- **HN-199 Involving Patients and Carers:** The increase in compliance from the validation to the visit generally related to the aspect of the QS that required ‘changes as a result of feedback’ to be evidenced. Many teams did not submit evidence of this for the validation, but evidence was subsequently seen at the review visit.
- **HN-203 Medical Staffing and Competences:** The QS required details about medical staffing that are quite difficult to calculate. For the validation process, teams were asked to add the detail in their self-assessment, and if this covered the requirement of the QS then it was accepted as accurate. However at the time of the visit, review teams were able to have more in-depth discussions about staffing with medical teams, which often identified that the medical time available was insufficient.
- **HN-207 Trans-cranial Doppler Ultrasound Competences (Children’s Services Only):** The evidence submitted for the validation process was often incomplete. Evidence of practitioner numbers was presented better during the review visits.
- **HN-302 Emergency Department – Staff Competences:** The changes in compliance (in both directions) related to whether training was delivered for all staff in the ED.
- **HN-502 Monitoring Protocols:** Compliance with this QS improved at the review visit, as evidence was clearer and case notes viewed.
- **HN-508 Clinical Guidelines: Chronic Complications:** Compliance with this QS was often higher at the time of the review visit because of the quality of the evidence submitted. Validation submissions were often missing guidance on the management of some chronic conditions.
- **HN-601 Operational Policy:** The indications were that those who had not met the QS at the time of the validation developed or amended their operational policy at the time of the visit. Four services who met the QS at validation did not then meet this QS at the time of their visit, for two reasons: lack of an operational policy, and clarity in their policy around the ‘fail-safe’ arrangements for neonatal screening/TCD.
- **HN-602 Multi-disciplinary Team Meetings:** Compliance with this QS was higher at the time of the visit for the children’s services reviewed (+6). There is no clear reason for this.
- **HN-798 Multi-disciplinary Review and Learning:** Compliance with this QS was higher at the time of the visit for the children’s services reviewed (+4). There is no clear reason for this.

48. The validation process raised some other issues:

- a. The quality of the submitted evidence was highly variable. It was assumed that as most teams had participated in previous programmes, the teams would be aware of the type of documentary evidence needed for the desktop validation process. In practice, documents were not always collated, some were not appropriately named and some evidence did not relate to any of the key QS. This resulted in considerable time being spent by the QRS team in reviewing each of the 64 submissions prior to the validation meeting, and again after the validation exercise, so that time would be efficiently used by the panel.
- b. As a result of the NHSE national procurement exercise taking place in January 2019, which required services to submit their self-assessments and intentions to be formally recognised as SHTs and HCCs for sickle cell and/or thalassaemia, the date by which services had to submit their self-assessments and evidence was extended to February 2019. This resulted in QRS having only one week to check all of the 64 submissions prior to the validation meeting.

- c. The time allocated for the review of all the submissions by the validation panel was two days, partly to reduce the impact on clinical time of the steering group members. This time would have been sufficient if the evidence had been better filed and collated.
49. For future reviews the following should be considered: -
- a. Include briefing sessions for participating teams about the process and the evidence that is expected to be submitted. This would reduce the time for both the submitting teams and the validation panel.
 - b. Provide a template for attaching evidence. For example, in the 2019 programme two services embedded their evidence documents in a one-sided document, which meant that only evidence that met the particular QS was submitted. This made the process much simpler for submitting teams and for the validation panel.
 - c. Consider whether the validation panel should have access to the evidence prior to the validation meeting. This would be possible if the evidence was uploaded to a portal.
 - d. With the changes in commissioning of specialist services during the 2019-20 programme, it may be helpful to develop the process to include other criteria for selection of services for a peer review visit in future programmes. For example:

Selection Criteria	
V1	New team since the last round of peer review visits
V2	Milestones not met following formal designation as SHT or HCC
V3	Teams identified with Immediate Risks or Serious Concerns at previous peer review visits
V4	Requests from organisations
V5	% compliance with QS within lowest performance grouping
V6	Concerns regarding rigour of self-assessment
V7	Random sample based on % compliance (if available capacity within programme)

Recommendations

1. If the process of validation is repeated then further training and information should be provided for participants on how to provide good quality evidence, and a template should be made available for evidence submission.
2. The UKFHD should consider whether the validation panel should have access to evidence prior to any validation meeting, and should review the criteria for selection of services for a peer review visit.

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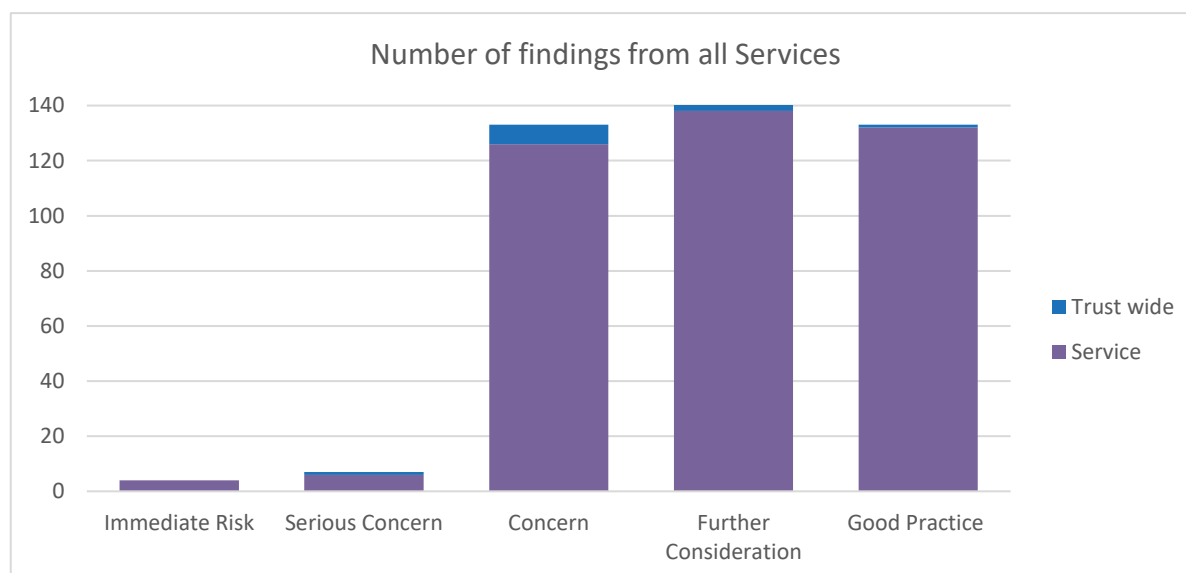
Part 2: Peer Review Visit Findings

Peer Review Visit Findings

50. The following sections summarise the findings from the 25 peer review visits, highlighting good practice and providing recommendations for future action, with the aim of further improving the quality of services being provided. The findings are presented in line with the relevant sections from the Quality Standards.
51. This section of the report does not take into account any good practice that may be in place in services that did not have a peer review visit.

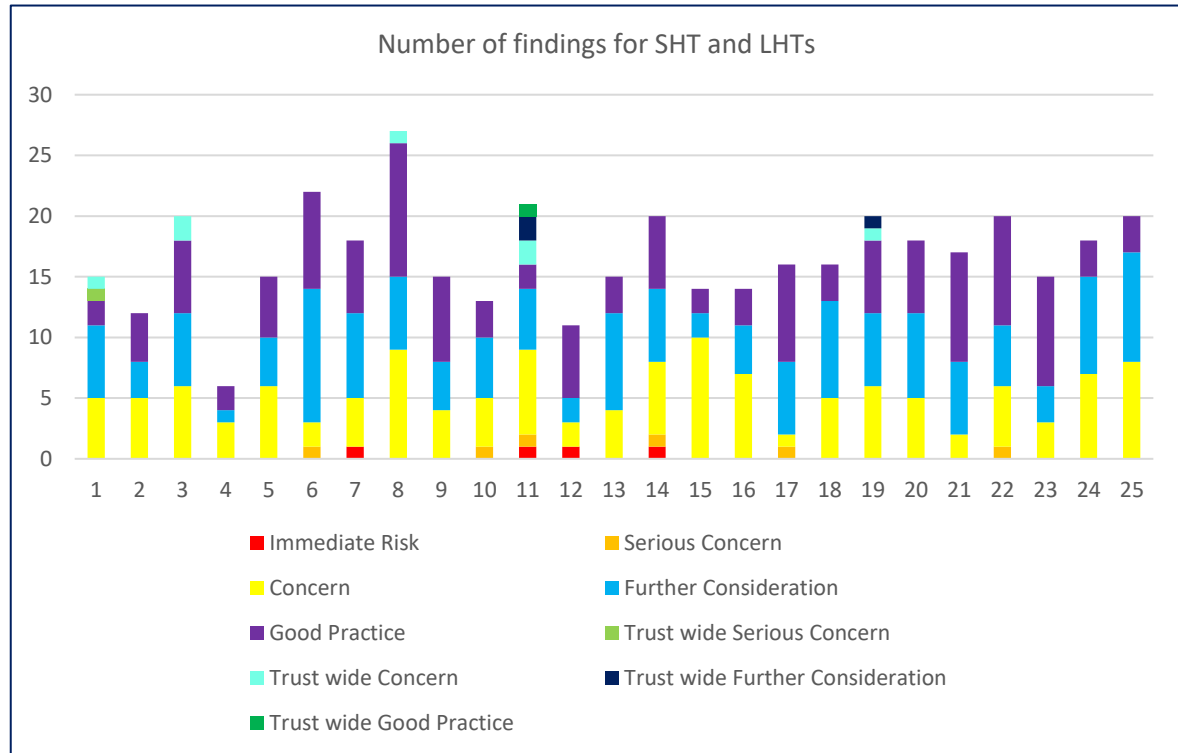
Table 14: Summary of key findings from all visits by category

	Good Practice	Immediate Risk	Serious Concern	Concern	Further Consideration
Service	132	4	6	126	138
Trust-wide	1	0	1	7	3
Total	133	4	7	133	141



52. There were 133 areas of 'good practice', 140 'concerns', of which seven were 'serious concerns', and 141 areas of 'further consideration' identified during the course of the visits. Some issues were raised as 'Trust-wide'; an issue of this nature related to the organisation as a whole and could not easily be resolved by the HD team alone. By raising these issues as Trust-wide issues it was hoped that there would be engagement at a higher level within the Trust so that timely progress could be made.
53. In addition, there were four immediate risks identified (for three services) during the course of the programme. Immediate risks are defined as potential Serious Incidents (SI), that is, situations where an SI could occur in the circumstances found by the reviewers. Immediate risks require urgent attention, and a formal response was expected from the Trust on actions taken to mitigate the risk within ten working days following the day of the visit.
54. The following table (Table 15) shows the number of findings for each of the SHTs and LHTs following their peer review visits. It should be noted that the table does not show the number of findings for Good Practice, Immediate Risks, Concerns and Further Considerations in visit order.

Table 15: Summary of key findings from all visits by category



*Note: The organisations are **not** shown here in visit order and the number of findings should not be seen as a 'score'; rather, they relate to the achievement of the Quality Standards, as identified by the reviewers during the course of the peer review visits.*

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100 Standards: Information and Support for Patients and Carers

Summary

The first group of Quality Standards numbered 100*, focus on written and practical support provided for patients and their families.

On the whole, information was available covering sickle cell disease, but there was limited information available for patients with thalassaemia in a number of the services reviewed.

Patients and carers who met with the visiting teams were extremely appreciative of the care they received from their SHT/LHT.

Not all patients had a plan that covered care in an emergency, and some patients were still not receiving a copy of their care plan.

Despite the overall improvement in the transition process, some patients who met with the reviewing teams were unclear about the processes in place.

Feedback from some patient groups was less complimentary about the care they received and the knowledge of staff about their condition, particularly in the ED and non-specialist wards.

The involvement of patients and carers had improved considerably since the last programme, for both the adult services and the children's services. Most community and acute teams provided some support to service users' meetings, and gave support and advice or training on specific aspects of haemoglobin disorders, but some patients and carers did not have access to a support group in their local area.

55. The Quality Standards describe the range of information that should be available for patients, including general Trust information, information about the local service, how to access care out of hours, the names of core team members, and details of how to contact those team members. This information was available in most Trusts, although it was not clear how systematically it was given to patients (C:3; FC:10).
56. Tables 16, 18 and 19 show the extent to which the visited services met the expected standards for information and support for patients and carers compared with their compliance as recorded in the peer review visits of 2010-2011 and 2014-2016 for children's services and the 2012-2013 and 2014-16 for adult services.
57. Table 17 shows compliance for the visited services compared with compliance for all services reviewed in previous programmes; although the QS used in the 2014-16 review programme were more comparable to those used in the 2019-20 programme, because of the disproportionate sample of services reviewed in the 2019-20 programme compared with the 2014-16 programme, no reliable conclusions can be drawn.

Key to tables

* comparison not possible due to changes in QS

- QS not included in this version

Table 16: Comparison, for each 100 Standard, of the compliance by haemoglobin disorder services reviewed in this programme and their compliance in previous programmes (Note: comparison is only made for Trusts that underwent physical reviews during the current programme)

Ref	Quality Standard – 100s section	% of compliant services					
		Children	Children	Children	Adults	Adults	Adults
		2010/11 (N = 8)	2014/16 (N = 15)	2019/20 (N = 15)	2012/13 (N = 9)	2014/16 (N = 10)	2019/20 (N = 10)
HN-101	Haemoglobin Disorder Service Information	*	80	73	78	50	70

Ref	Quality Standard – 100s section	% of compliant services					
		Children	Children	Children	Adults	Adults	Adults
		2010/11 (N = 8)	2014/16 (N = 15)	2019/20 (N = 15)	2012/13 (N = 9)	2014/16 (N = 10)	2019/20 (N = 10)
HN-102	Information about Haemoglobin Disorders	75	80	47	33	60	40
HN-103	Care Plan	0*	100	73	44	60	70
HN-104	Information for Primary Health Care Team	38	93	47	44	50	70
HN-105	Childrens SHTs only Information about Trans-cranial Doppler Ultrasound	-	67	85	N/A	N/A	N/A
HN-106	School Care Plan (Children's Services Only)	-	80	87	N/A	N/A	N/A
HN-194	Environment (previously HN-401 and HN-402)	100	87	100	67	70	100
HN-195	SHTs only Transition to Adult Services	38	84	69	56	60	50
HN-199	Involving Patients and Carers	75	47	73	67	30	70

Table 17: Comparison, for each 100 Standard, of compliance by haemoglobin disorder services that underwent physical visits in the 2019/20 programme and compliance by all the services reviewed in previous programmes (see comment at 57)

Ref	Quality Standard	% of compliant services					
		Children	Children	Children	Adults	Adults	Adults
		2010/11 (N = 17)	2014/16 (N = 33)	2019/20 (N = 15)	2012/13 (N = 34)	2014/16 (N = 33)	2019/20 (N = 10)
HN-101	Haemoglobin Disorder Service Information	*	85	73	75	76	70
HN-102	Information about Haemoglobin Disorders	88	82	47	38	76	40
HN-103	Care Plan	12	91	73	44	76	70
HN-104	Information for Primary Health Care Team	53	94	47	50	76	70
HN-105	Childrens SHTs only Information about Trans-cranial Doppler Ultrasound	-	73	85	N/A	N/A	N/A
HN-106	School Care Plan (Children's Services Only)	-	76	87	N/A	N/A	N/A
HN-194	Environment (previously HN-401 and HN-402)	100	91	100	85	79	100
HN-195	SHTs only Transition to Adult Services	53	79	69	68	82	50
HN-199	Involving Patients and Carers	88	64	73	56	55	70

Notes for Tables 16 and 17:

1. CYP teams that were not included in the children's peer review programme in 2012: Leeds, NUH and Whipps X, L&G-QEH (L&G-UHL was reviewed)
2. Adult services that were not included in the adult peer review programme 2012/3: Cardiff

3. **Data for 2010/11 were mapped to the Adults QS from 2012 but are no longer comparable in all areas with the relevant QS of 2018 and therefore have not been included in Table 16. For example, Quality Requirement 1 related to Quality Standard HN-101 and HN-102. The Quality Requirements asked for a patient-held record to be agreed for use across all SHTs and LHTs (QR 4) and implemented (QR 5). Compliance with QR 5 was used for the data above.*

Table 18: Graphical presentation showing compliance with the Quality Standards compared with previous programmes – Children and Young People (Note: comparison is only being made among services that were physically reviewed)

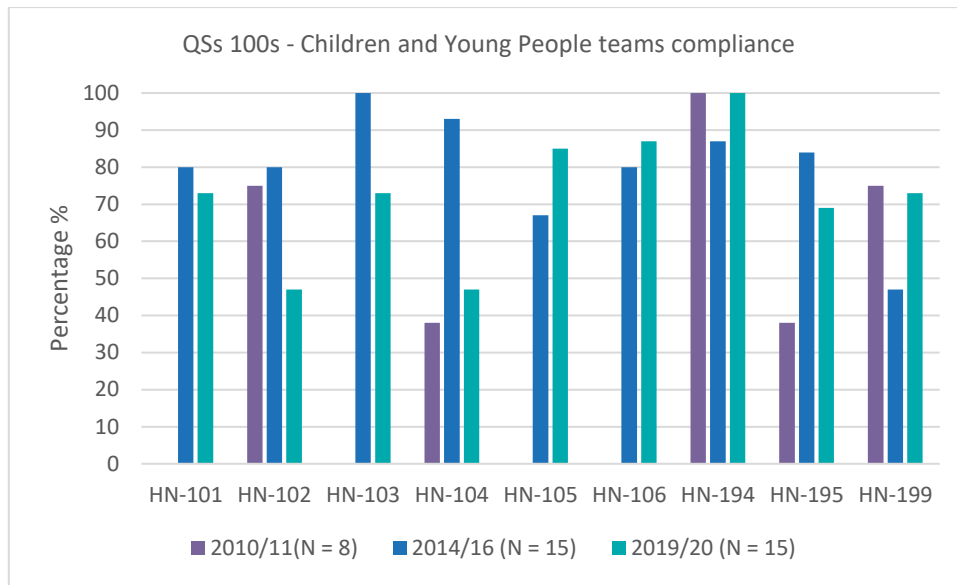
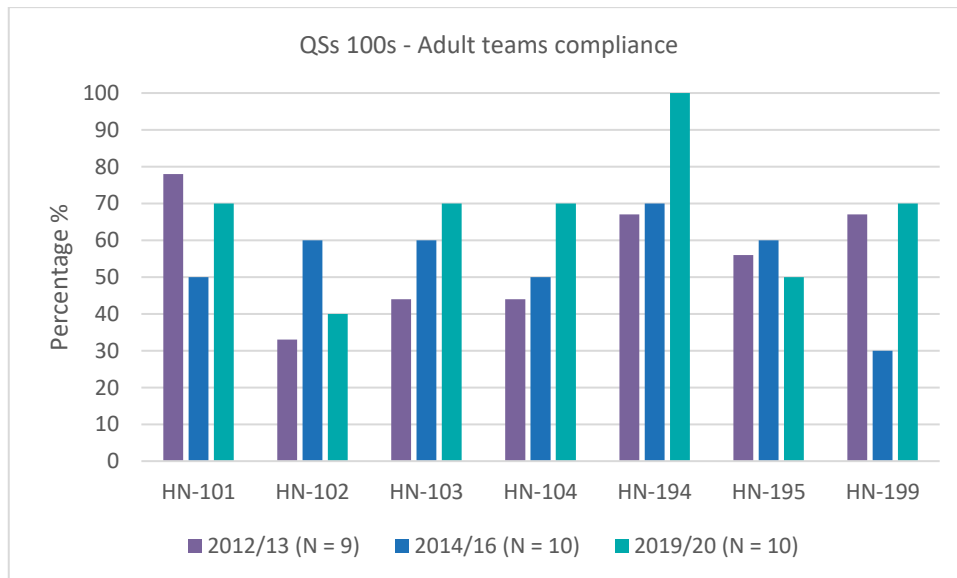


Table 19: Graphical presentation showing compliance with the Quality Standards compared with previous programmes – Adults (Note: comparison is only being made among services that were physically reviewed)



Written information for parents and young people about their long-term condition

Quality Standards for the monitoring of written information have changed significantly since 2010, so compliance may not be comparable with the 2012 CYP programme.

58. Specific information leaflets about haemoglobinopathies, and information for primary health care teams, were available in most services, with many services providing additional information on the hospital website that could be directly accessed by patients. As with previous review programmes, there was generally more information on sickle cell disease than on thalassaemia (C:1; FC:3).
59. Some excellent examples of patient information were seen and are listed in the table of good practice below. The user reviewers were particularly impressed with the patient information booklet for people with sickle cell disease seen during one visit; this listed all the possible crises that patients could experience, and categorised them using a traffic light system so that patients could see clearly when to seek urgent medical advice.
60. Compliance with QS HN-102, which covered information about haemoglobin disorders, was much lower than in 2014-16. The reasons are not clear. Some services had very little information covering thalassaemia.
61. The lack of condition-specific information for people with thalassaemia was identified in four of the services reviewed (C:1; FC:3). This information is particularly important in low prevalence areas where peer support may not be readily available. This issue could be addressed via coordination between the HCCs to provide standardised information for thalassaemia patients, with support from the UKTS and other patient representatives.
62. Condition-specific information did not always include information on contraception and sexual health. With more patients on long-term hydroxycarbamide, reviewers commented that sexual health and the possible side effects of long-term therapy on fertility, including sperm banking, should be clearly explained, particularly for young people transitioning to adult care, to ensure that they have sufficient knowledge to give informed consent.

Care plans / Emergency care plans

63. Compliance with the standard on care plans (QS HN-103) was variable, and the QS was not met for three of the ten adult teams and four of the 15 children's teams reviewed. The teams were non-compliant because they gave insufficient detail about care in an emergency and failed to provide patients with a copy of their care plan (C:2; FC:1).

Annual reviews

64. Although annual clinical reviews were taking place in most services, data submitted by services prior to the visit in support of this QS varied hugely between services and were occasionally of poor quality. Seven centres reported that they were either unable to complete annual reviews on a large proportion of their patients or had issues with submitting and uploading data. Issues with completion rates were subsequently raised at the peer review visits for two services (C:1; FC:1).
65. Some very good practice was identified during the programme. Patient information leaflets highlighted to patients the process and importance of the annual review and, in one case, included a holistic needs assessment for all service users. Other hospital services, such as physiotherapy and respiratory services, were occasionally included during the annual review.

Information for primary health care teams (HN-104)

66. Compliance for this QS was similar to the compliance during the last programme, for adult services, but was lower for children's services, and the QS was not met by eight of the 15 children's services reviewed. The main reasons why the QS was not met were that limited guidance was given to GPs around sexual health and contraception (5), insufficient information was given about hydroxycarbamide or iron chelation if prescribed by the GP (2) and there was insufficient information about the side effects of medication (3). For adult teams the reasons for non-compliance mainly concerned guidance on contraception and sexual health (4).
67. Reviewers considered that some letters to primary care teams were well written and structured, and they were particularly impressed with the examples seen during one visit to an adult service and three to CYP services.

Transition

68. A number of Trusts had adopted the national 'Ready Steady Go' programme for transition of care from paediatric to adult services. Worthy of mention were good transition pathway information, information about education, and the use of an age-specific transition pack. One Trust was also an implementer site for the NHSE transition pathway project (see good practice section).
69. Despite the overall improvement in the transition process, some patients and carers who met the reviewing team were not clear on the arrangements or had not started transition when local guidance had indicated they would. Reviewers also found that the process implemented was not always as robust as defined within the agreed transition policy (FC:8).

Education

70. Liaison with schools and support with school care plans was generally in place. Good practice in this area was noted in a number of Trusts: for example, three of the services visited had good structural processes in place, and another Trust had excellent targeted education plans for different age groups.
71. School teachers were available Monday to Friday within most Trusts to support learning in hospital whilst children were in-patients or attending for their transfusions. Some hospital schools had excellent links with local education services, including young people being marked as 'present' at their school if they were present at the hospital school.

Patient views

72. The number of patients that reviewers met during visits varied widely between Trusts. The majority of users were extremely grateful for the support from the haemoglobin disorder teams. However, some patient views were at odds with the Trust's view and worrying feedback was received from some patients about clinical care and the knowledge and views of staff, particularly in the ED and non-specialist wards (see also sections [88](#): ward staff training and [97](#): care in the ED).

Support for patients, carers, and families

73. The involvement of patients and carers in the service (HN-199) had improved considerably since the last programme, for both the adult services (from 30% to 70%) and the children's services (from 47% to 73%). Reviewers were provided with many examples of changes that had been made as a result of the feedback and involvement of patients and carers.
74. Most community and acute teams provided some support to service users' meetings, giving support and advice or training on specific aspects of haemoglobin disorders. However, in seven of the services reviewed, patients and carers did not have access to a support group in their local area.

Recommendations

- 1a. Teams need to ensure that service and condition-specific information is available in different formats and that it is routinely given to patients, particularly those who have attended the service for some time, so that they are fully aware of any changes in the service and treatments available and are able to make informed decisions about their care.
- 1b. Information about thalassaemia should be available and consistent, regardless of the number of patients cared for by the service. Development of information should be overseen via the thalassaemia HCCs in conjunction with the UKTS and other patient representatives.
- 1c. Access to personal clinical information, in particular, was raised by patients as an issue. It is important that individual clinic letters are shared with patients, together with clear updates and concise instructions to patients and their GPs.

- 1d. Transition processes require further work to ensure patient outcomes and experience of care are regularly measured.
- 1e. A central repository of patient information should be developed, identifying the good quality, reliable information that already exists and allowing that information to be shared with all providers and patients to reduce the variation in information. National patient organisations, working with local patient groups, should lead on this work, and this information should be available on their websites. The National Haemoglobinopathy Panel and/or National Haemoglobinopathy Registry could be utilised to ensure this information is made widely available.

GOOD PRACTICE

Information

Alder Hey Children's NHS Foundation Trust

- There was a 'crisis diary' for those with sickle cell disease, which included prompts for children about each stage of their care so that they could understand more about their condition.
- Information for parents and carers about 'non-affected' siblings provided useful hints and advice.
- Medication advice was given, so that children and young people could understand why they needed to take penicillin and hydroxycarbamide.
- There was information about alternative pain therapies, which provided well-rounded advice such as including regular exercise.

Barts Health NHS Trust – The Royal London Hospital

- The TCD ultrasound information clearly explained how the results were categorised, what each category meant, and what the next steps would be.

Bradford Teaching Hospitals NHS Foundation Trust

- Travel advice covered the period before travelling and what to do in an emergency when away.

Homerton University Hospital NHS Foundation Trust

- The information covered the use of, and the importance of taking, prophylactic antibiotics.
- Information on the benefits of 'incentive spirometry' included the different techniques patients could use to help increase lung capacity.
- Reviewers considered that the advice on the risk of malaria, and preventative treatments when travelling, was very well written and was particularly useful because of the range of misinformation that is available via the internet.

Imperial College Healthcare NHS Trust

- The information on managing symptoms, and particularly fatigue, included a range of treatments that may help.
- The iron chelation information pack was excellent, and the reviewers commented that it was the 'best information which they had seen'.
- The information covered the different treatments available and the benefits of adherence to treatments. The section on the use of long-term opiates for pain control was very comprehensive, and covered advice for those driving (with a link to the Driver and Vehicle Licensing Agency for further information), general advice

for patients in work, advice and information to give to employers and advice for those working with machinery.

- The section on obstetric care was very well written and included possible complications before conception and during pregnancy.

Leeds Teaching Hospitals NHS Trust

- The thalassaemia information for adults was well written, especially the information covering what to expect if long-term blood transfusions were required.

Lewisham and Greenwich NHS Trust – Queen Elizabeth Hospital

- The information was comprehensive, of a good quality, and professionally printed by the Trust.

Nottingham University Hospitals NHS Trust

- The patient information booklet for people with sickle cell disease was very good. The booklet listed all the possible crises that patients could experience, and categorised them using a traffic light system, so that patients could easily see when to seek urgent medical advice. The patient representatives on the reviewing team were so impressed that they suggested that the team should consider making the document available nationally.

Oxford University Hospitals NHS Foundation Trust

- The travel advice information included vaccination advice for patients before travelling and the suggestion that parents should take copies of their child's care plans and clinic letters in case the child required medical assistance when away from home.
- The information written for children, young people and families covering the clinic plan for an annual review process provided clear advice and information about the rationale for the review and what exactly would happen when they attended.
- The information covering priapism was sensitively written and was easy for children and young people to understand.
- The 'Helpful Guidelines for New Carers' provided useful information about the different techniques that may be helpful to parents when administering oral medication to their baby.

Whittington Health NHS Trust

- There was a wide range of information available.
- The checklist for parents to assess their competence in administering chelation therapy was very good.
- There was a vaccination checklist from birth to the age of 17 years.
- The 'Red Cell' newsletter was well written and informative, providing updates and useful local and national information.
- The new patient notification letters to general practitioners were very well structured, with formatted headers, so that the patient's plan of care was clear to the GP. The letters included actions to be progressed by the GP, and set out who, within the acute or primary health care teams, was responsible for each element of the patient's care plan.
- Discharge letters sent to GPs following an in-patient admission were very good, with clear instructions about actions for the GP and details of ongoing treatment following discharge.

Digital technology

Imperial College Healthcare NHS Trust

- The use of the 'Patient knows best' app was regarded as good practice.

Leeds Teaching Hospitals NHS Trust

- The patient care plans were electronic.

Educational support and school care plans

Alder Hey Children's NHS Foundation Trust

- Targeted education sessions for all girls and boys, starting from the age of 11 years, were run throughout the year, and to encourage participation some sessions were scheduled during school holidays.
- There was a teaching programme to support the transition from paediatric to adult services. Each young person was given their own 'transition folder', which they could add information to and use as a resource and to keep their own notes.

Barking, Havering and Redbridge University Hospitals NHS Trust

- School care plans were very detailed and were individualised for each child. They also included specific information about the young person's transition to adult services, and had been developed to target the different educational age groups.
- The 'Harvey's Gang' initiative, in which children and parents were able to visit the blood laboratory to help them understand the laboratory aspects of their transfusion treatment, had been implemented.

Barts Health NHS Trust – The Royal London Hospital and Whipps Cross University Hospital

- The education staff could provide support for children whilst they were in-patients. Arrangements were also in place to liaise with a child's school about attendance and progress made with schoolwork.

Leeds Teaching Hospitals NHS Trust

- The care plans included a wealth of information about what teaching staff should be aware of, including the emotional and psychological impact of treatment on the child and advice on daily management/issues that may arise.

Sheffield Children's NHS Foundation Trust

- The education provision by the hospital school for children who were in-patients had received 'excellent' ratings from OFSTED. Staff would support children who were receiving treatment as in-patients to study for exams and would, if necessary, arrange for them to take exams in hospital.

Transition

Barking, Havering and Redbridge University Hospitals NHS Trust

- The information covered all stages of the disease, for both patients and their families, and included a checklist to ensure that all aspects relating to transition had been covered. The booklet included advice to ED staff about children who were transitioning to the adult service.

Bradford Teaching Hospitals NHS Foundation Trust

- The transition pathway and information were available as part of the team's work with the NHS Improvement collaborative for transition.

London North West University Healthcare NHS Trust

- The information was very thorough in its explanation of the importance of transition and each stage of the transition pathway.

Care plans and annual reviews

Leeds Teaching Hospitals NHS Trust

- The annual review documentation completed for adult patients by the CNS in the nurse-led clinic was very good, all patients had a holistic needs assessment undertaken and the patient's agreement for the sharing of information between services was also documented in the patient's care plan at this time.
- Children's annual review letters were well written. Important information was highlighted at the beginning of the letter, and there was also information about how patients could manage their pain. General health advice was reiterated.

Nottingham University Hospitals NHS Trust

- The care plans covered surgery.
- Care plans were individualised for support for patients needing femoral line insertion and red cell exchange and included relevant patient history, such as whether the patient had experienced any anxiety during previous procedures, patient preferences in terms of the procedure, and advice to staff about preparing patients who required a femoral line to be inserted.
- The annual review template in use for patients with sickle cell disease and those with thalassaemia were well designed and based on the version in use by UCLH.

University Hospitals Bristol NHS Foundation Trust

- The annual review proforma was well designed, and clearly stated who to contact for queries and advice.

Support for service users and carers

Barking, Havering and Redbridge University Hospitals NHS Trust

- The psychology team had developed a website for use by the public that explained how to access support and information and included testimonials from service users.
- The sickle cell disease awareness day was well designed.

Barts Health NHS Trust – The Royal London Hospital

- The community team in Hackney held coffee mornings for parents with newly diagnosed children to meet and share ideas, which had also led to the carers developing a carers' forum.
- There was a mentoring programme for 10- to 24-year olds which was funded by City and Hackney Clinical Commissioning Group and facilitated by the Sickle Cell Society.

Bradford Teaching Hospitals NHS Foundation Trust

- All patients had access to welfare support and advice from a team based at the Bradford Royal Infirmary.

Cardiff and Vale University Health Board

- There was a Saturday club for children and young people run by the Ethnic Minorities & Youth Support Team (EYST).

London North West University Healthcare NHS Trust

- An educational software programme (SickleBuddy App) had been developed for use by children and young people to tell them more about their condition. The App, once piloted, had been made available on social media platforms nationally.

Nottingham University Hospitals NHS Trust

- All patients had access to the haematology complementary therapy service.

Patient views and experience**Alder Hey Children's NHS Foundation Trust**

- All patients and their families were given a patient survey questionnaire when they attended their annual review, which ensured that the views of those patients who were seen less frequently were also captured.

Barts Health NHS Trust – Newham University Hospital

- The teenage room had an 'anonymous map' where young people could give feedback and write any other comments on which they would like advice, and staff would then add an anonymous reply.
- The community children's team provided a wide range of support to both the hospital team and the community, providing training for families and also undertaking blood investigations.

Leeds Teaching Hospitals NHS Trust

- A survey was in progress to enable patients to give feedback on the role of the CNS, in terms of what was working well and any areas the patients thought should be considered in developing the CNS service.

Whittington Health NHS Trust

- The involvement of young people in the development of the paediatric haemoglobinopathy service was well established, with a number of mechanisms to capture feedback, including a young people's forum.
- The Trust information about making a complaint was very clear and detailed about each stage. Reviewers were particularly impressed with the language used, which they considered was supportive rather than confrontational.

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200 Standards: Staffing

Summary

This second group of Quality Standards numbered 200*, focusses on clinical leadership, staffing for the haemoglobinopathy service (SHT or LHT) and the staff training and competences required for the care of patients with haemoglobin disorders.

Shortfalls in the availability of consultant medical staff to care for people with haemoglobin disorders remain of significant concern.

Specialist nursing roles are diverse, with high variability in responsibilities. There is no national workload model for the haemoglobinopathy CNS role, which makes it difficult to make a clear case for more support.

Ward nurse training and competences produced a mixed picture. Of concern was feedback from some patients about the lack of knowledge of some ward staff about their condition when they were admitted in an emergency to the ED and to general wards.

Access to psychology had not improved, with 18 out of the 25 services identified as having no access to psychology.

75. At the sites visited, the review programme identified highly committed teams of medical, nursing and allied health professionals involved in the care of patients with haemoglobinopathies. Patients and carers were extremely positive about the care they received from their lead team. Some excellent models of multi-disciplinary working within services were encountered.

Key to tables

* comparison not possible due to changes in QS

- QS not included in this version

Table 20: Comparison, for each 200 Standard, of the compliance by haemoglobin disorder services reviewed in this programme and their compliance in previous programmes (Note: comparison is only made for Trusts that underwent physical reviews during the current programme)

Ref	Quality Standard	% of compliant services					
		Children	Children	Children	Adults	Adults	Adults
		2010/11 (N = 8)	2014/16 (N = 15)	2019/20 (N = 15)	2012/13 (N = 9)	2014/16 (N = 10)	2019/20 (N = 10)
HN-201	Lead Consultant	100	100	40	100	80	70
HN-202	Lead Nurse	50	47	53	67	50	60
HN-203	Medical Staffing and Competences	*	54	40	22	54	20
HN-204	Nurse Staffing and Competences	*	7	33	22	30	40
HN-205	Psychology Staffing and Competences	-	-	7	-	-	10
HN-206	Training Plan	-	-	20	-	-	50
HN-207	Childrens SHTs only Trans-cranial Doppler Ultrasound Competences ()	-	62	92	N/A	N/A	N/A
HN-299	Administrative, Clerical and Data Collection Support	-	27	60	33	30	50

Table 21: Comparison, for each 200 Standard, of compliance by haemoglobin disorder services that underwent physical visits in the 2019/20 programme and compliance by all services reviewed in previous programmes

Ref	Quality Standard	% of compliant services					
		Children	Children	Children	Adults	Adults	Adults
		2010/11 (N = 17)	2014/16 (N = 33)	2019/20 (N = 15)	2012/13 (N = 34)	2014/16 (N = 33)	2019/20 (N = 10)
HN-201	Lead Consultant	100	94	40	91	91	70
HN-202	Lead Nurse	71	52	53	68	55	60
HN-203	Medical Staffing and Competences	*	24	40	21	24	20
HN-204	Nurse Staffing and Competences	*	48	33	29	58	40
HN-205	Psychology Staffing and Competences	-	-	7	-	-	10
HN-206	Training Plan	59	-	20	-	-	50
HN-207	Trans-cranial Doppler Ultrasound Competences (Children's Services Only)	-	70	92	N/A	N/A	N/A
HN-299	Administrative, Clerical and Data Collection Support	-	39	60	32	42	50

Table 22: Graph showing compliance with the Quality Standards compared with previous programmes – Children and Young People (Note: comparison is only being made among services that were physically reviewed)

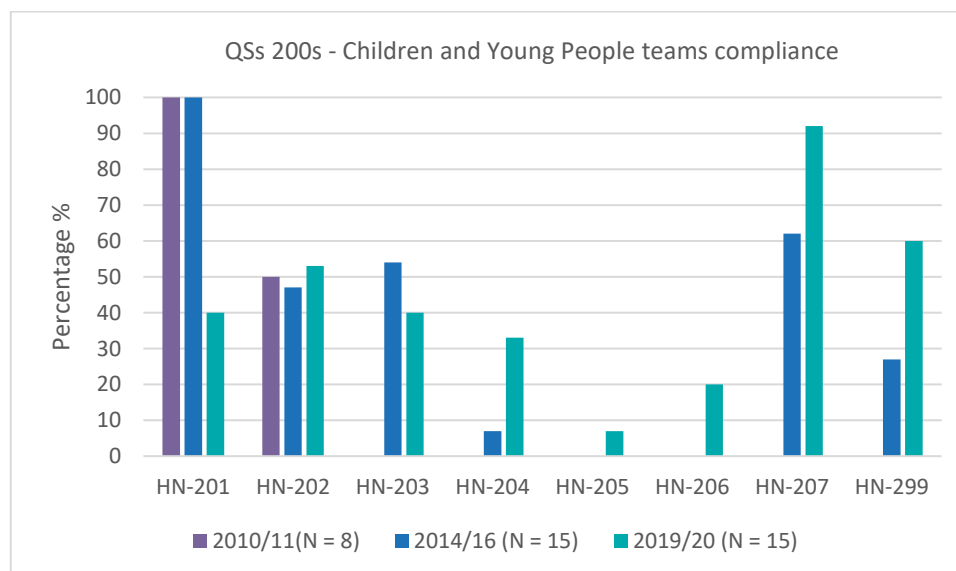
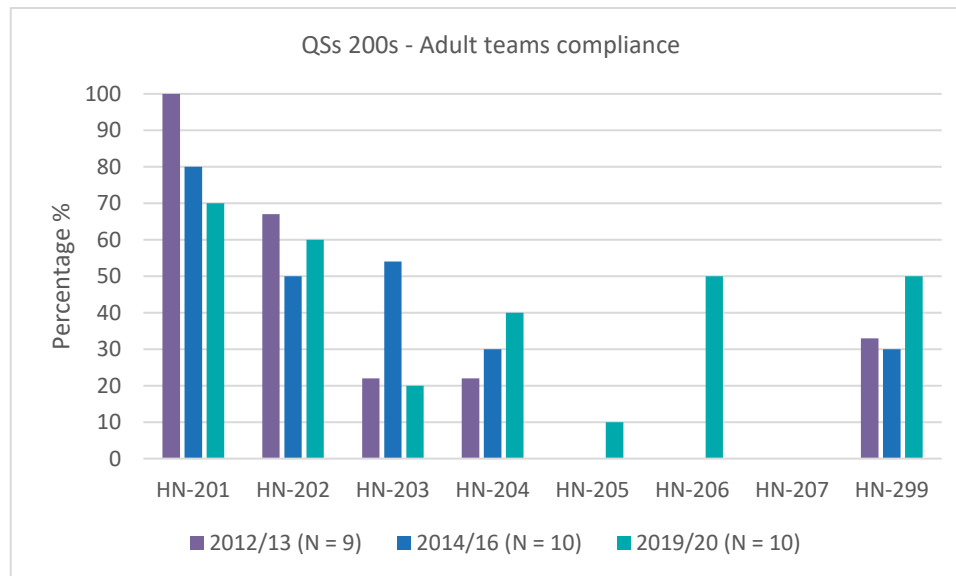


Table 23: Graph showing compliance with the Quality Standards compared with previous programmes – Adults (Note: comparison is only being made among services that were physically reviewed)



76. Quality Standards for staffing training and competences have changed significantly since the 2010 and 2012 programmes so compliance is not comparable in all areas. The 2018 version of the Quality Standards separated out the training plan and competences for each staff group, and placed the cover arrangements for staff absences in one QS. Examples where compliance is not comparable are the medical staffing standard (HN-203), the nurse staffing and competence standard (HN-204), and the psychology staffing and competence standard (HN-205).
77. As with previous review programmes, the sustainability of services remains a significant issue because of staffing shortfalls, although, as part of the re-configuration of SHTs by NHSE, some additional funding has been made available to enable SHTs to fulfil their specialist function. Although a great deal of progress has been made in this area, reviewers noted that, for nine of the 25 services reviewed, staffing shortfalls would not have improved without this funding since their last review visit, and medical staffing remains a concern.

Consultant medical staffing

78. The issue of either insufficient time for the leadership of the service or lack of availability of consultant medical staff has markedly worsened since the 2016 review programme. During the current review programme this was identified as a problem for 84% of services (all but one SHT and three LHTs). In 2016 it had been identified as an issue in 56% of the same services reviewed.
79. Leadership of the service: HN-201 requires a lead consultant who has responsibility for guidelines, training, audit and liaison with other services. It requires this lead to have an appropriate amount of time allocated in their job plan to fulfil this role, although the standard does not specify what amounts to an appropriate amount. This review cycle identified a number of services in which the lead clinician had no time at all allocated in their job plan for this activity. This was a serious concern in two services and was noted as a 'concern' in ten other services.
80. Cover for the lead SHT consultant was often from other adult consultant haematologists who did not always have up to date competences in caring for people with haemoglobin disorders. Compliance with HN-203 required an assessment to be made of whether 'other' consultants had relevant CPD for their work with the haemoglobin disorder service. In practice, this was difficult to assess, but generally when they met the team covering consultants were clear that in the main they would only undertake CPD in their own area of speciality.
81. This review programme also identified that there has been a marked decline in the number of services with a lead haematology consultant who has adequate time in their job plan to care for children with haemoglobinopathies. This is significant change from the 2014-16 review, when 94% of services had a lead

clinician identified who had sufficient time allocated for their role. It is not possible to make comparisons with the 2011 QS (which was met 100%), as the 2011 QS did not include time available for the lead clinician role.

82. This pervasive and persistent issue of a lack of sufficient time allocated in the job plan for haematologist consultants remains a particular concern as most services are managing an increasing number of patients. The continued lack of dedicated consultant haematologist time to manage this patient group, even in specialist teams, raises significant concern about the sustainability of services.

Nursing roles

83. Nursing roles were diverse, with high variability in responsibilities. There is no national workload model for the haemoglobinopathy CNS role, which makes it difficult to make a clear case for more support in terms of the complexities of the role. Nurses were undertaking a wide variety of roles and activities, with significant variability between services. Some were in leadership roles within their service, and some, but not all, were actively involved in nurse-led clinics, such as nurse-led hydroxycarbamide clinics. Some nurses had responsibility for the training and support of other nursing colleagues in haemoglobin disorder patient management, but this was not universal; others had combined hospital and community roles. The patient case load per nurse was also highly variable across services and depended on the extent of their role. A lack of time available to support patients because of capacity within the specialist nursing team was identified as a concern in five of the services reviewed..
84. Some lead nurses were overwhelmed with clinical duties and had little time for their leadership and their service development role (C:2). Some were covering acute and community work as well as general health promotion and genetic counselling duties. This helped with continuity of cover and was highly appreciated by families. In low prevalence areas, nurses often worked part-time in the haemoglobinopathy services and also covered other aspects of haematology (e.g. haemophilia, transfusion or day care). For some services, particularly those with low staff-to-patient ratios, this was proving to be considerably challenging, with community care often suffering at the expense of acute care. Teams with better staffing levels sometimes employed a rotational scheme, with the nursing team interchangeably covering acute and community services. This helped maintain skill sets and allowed appropriate cross cover for absence or sickness.
85. Many day-case facilities were nurse-led, with increasing numbers of nurses who had completed advanced nurse practitioner training with competences in cannulation, prescribing, acute assessment and treatment. There were also many examples of efficiently run nurse-led clinics, including clinics for hydroxycarbamide and chelation monitoring. One adult SHT had implemented nurse-led clinics for patients following discharge from hospital, ongoing monitoring, advice and annual reviews.

Training and competences

86. Within the services reviewed, there had been an improvement since the last review in the number of services that could provide evidence of staff training programmes. Whilst some units had robust training plans, in many these were inconsistent and could not be delivered because of time constraints on the nursing staff. Particular issues were raised about the training of specialist and ward staff and the documentation of competences achieved (SC:1; C:18; FC:1). In general, the lead clinicians for the services had good arrangements in place for the training of junior medical staff.
87. Many services cited the RCN competence framework, which was in the process of being updated. It was hoped that it would be easy to adopt this for local use. In addition, within each HCC it is expected that there will be an identified nursing lead for education, which should in the future result in an improved training plan and schedule, and may also ensure the development of specific competences for haemoglobinopathy nurses over the next few years. Reviewers were, however, impressed at one visit with the competences that had been developed for the delivery of Entonox®, and, as identified during the last peer review programme, the competence framework for one of the services was very comprehensive.

Ward training

88. Training for ward staff presented a more mixed picture. For organisations who had designated wards, compliance was better. It was concerning that patients who met with the reviewing teams were worried about the lack of knowledge of some ward staff about their condition when they were admitted in an emergency and to general wards (SC:1; C:13). Some services also commented that they were not always able to influence other ward areas in terms of the training that was needed.
89. A nurse with cannulation skills should be available when blood transfusions are taking place. However, it was highlighted that it was more difficult for nurses working on wards where the main speciality was oncology to maintain their competences in cannulation, as the majority of in-patients had indwelling devices (C:1; FC:1). Issues with the number of cannulation attempts experienced were raised at two visits (FC:2), but patients at other visits said they were more likely to experience issues with multiple cannulation attempts, often by junior medical staff, when a member of their usual team was not available.

Psychology

90. Once again, this round of review visits identified poor access to psychology services. Eighteen out of the 25 services reviewed had no access to psychology services. Further issues around access to psychology were identified in six of the services who did have some access to psychology (C:3; FC:3). Only one service met the 1:300 psychologist-to-patient ratio recommended by the British Psychological Society Special Interest Group. Reviewers were also told by some people with thalassaemia that they did not consider they had the same level of access to psychology services as others, but those patient representatives who met with the reviewing team and who had accessed their local psychology service were extremely appreciative of the support available. Arrangements for access to neuropsychology provision were also identified as an issue for three of the services reviewed (FC: 3).

Community-based services

91. The lack of, or limited provision of, community services in some areas had not improved since previous reports (C:5; FC:1). Insufficient time available from the community haemoglobinopathy nurse was also identified (C:2).
92. Where community services were in place, the link between community-based nursing teams and acute services was generally good. Some community services were operationally independent of the acute hospital team, whereas some were integrated. Acute hospital teams were not always clear what they could expect from community teams, although communication was improved when regular multi-disciplinary meetings were in place.
93. Service level agreements covering the work of community teams were present in 22% of paediatric and 25% of adult services (QS HN-605). For adult services reviewed in previous programmes, this marked a significant change in compliance, as 50% had previously met this QS.
94. There were some good examples of innovative models of care run through community services, including: a bi-monthly Trans Doppler Saturday clinic; training and investigations undertaken in the community setting; a network-wide community nursing group who worked and liaised with services dealing with complex and challenging issues such as refugees and trafficked children; a community team who held coffee mornings for parents with newly diagnosed children, which had led to the development of a carers' forum; an antenatal 'fail-safe' process led by the community midwife team; and the follow-up of children and young people when discharged from hospital.

Trans-cranial Doppler (TCD) ultrasound staff competences

95. The QS covering trans-cranial Doppler ultrasound staff competences (HN-207) requires SHTs to have access to sufficient staff with the appropriate competences to undertake TCD and to perform more than 40 scans per annum. Compliance with this QS had increased from 62% in 2014-16 to 92% in 2019-20 for the 11 CYP SHTs that had a peer review visit.

Recommendations

- 2a Medical staffing: Trusts designated as providing specialist haemoglobinopathy care must have adequate medical staffing to provide this care safely and to a high standard. For every 150 patients, 0.6 wte of a consultant haematologist's time must be job planned to manage patients safely.
- 2b Organisations such as Health Education England, the medical royal colleges, the Nursing and Midwifery Council, and medical and nursing schools should engage with haemoglobinopathy specialist consultants and nurses to address current shortfalls and to carry out robust specialist workforce planning for the future.
- 2c With the HCC arrangement and the systems around this, including the National Haemoglobinopathy Panel (NHP), now in place, it is essential that nursing competences specific to haemoglobinopathy specialist nurse practice are developed and agreed across HCCs. Additionally, agreement on the essential roles of a clinical nurse specialist in haemoglobinopathy, for practice both in the community and in hospitals, should be instituted either for each HCC or across all HCCs.
- 2d Each HCC must ensure there is adequate provision and access to psychology support for service users.

GOOD PRACTICE

Leadership

Barts Health NHS Trust – Newham University Hospital

- Reviewers were impressed with the enthusiasm of the lead clinician, who had many ideas about involving children, young people and their families. Particularly impressive was the lead clinician's work to create links with a number of charities to help provide ongoing support, especially short breaks for families with sickle cell disease.

Nottingham University Hospitals NHS Trust

- Reviewers were impressed with the leadership, compassion and enthusiasm for the service demonstrated by the lead clinician, who had only been in post for five months. The lead clinician clearly had a vision for the service, and significant changes had been made to its operational delivery, with links being built with referring and specialist services. The lead clinician was also in the process of reviewing all the clinical guidelines.

Sheffield Children's NHS Foundation Trust

- Reviewers were impressed with the leadership from the lead clinician and the amount of progress that had been made to improve the quality of the paediatric haemoglobinopathy service since the consultant had commenced in post in 2018.

Nursing practice

Alder Hey Children's NHS Foundation Trust and Lewisham and Greenwich NHS Trust – Queen Elizabeth Hospital

- An efficient nurse-led hydroxycarbamide service was in operation.

Homerton University Hospital NHS Foundation Trust

- The CNS team rotated between the acute and community services every three months, which had enabled staff to expand their skills and knowledge and improve cross-cover working. Feedback from patients was that they valued the continuity of care that this arrangement provided.

Imperial College Healthcare NHS Trust

- Away days for the non-malignant CNS were held regularly, and included a range of invited speakers and refresher training on the care of people with haemoglobin disorders.
- The pathway in place to support patients with transfusional and non-transfusional iron overload was very good. A weekly nurse-led iron chelation clinic had been established to provide monitoring, education and support for patients and carers.

Nottingham University Hospitals NHS Trust

- Reviewers were impressed by the nursing review and care plan leaflet, which had been developed to provide key advice to staff caring for patients with sickle cell disease.
- The competence framework developed to enable staff to deliver Entonox® to patients in pain on the SRU was very good. The framework was comprehensive, and provided a good balance between theory and practice to support staff in gaining the relevant competences. It included opportunities for staff to reassess their ongoing knowledge and competence.

University Hospital Southampton NHS Foundation Trust

- There was good leadership from the CNS, and significant progress had been made with the operational delivery of the service in the acute Trust and liaison with community colleagues.

University Hospitals Bristol NHS Foundation Trust

- There was good operational working by the CNS team.

Psychology support

Alder Hey Children's NHS Foundation Trust

- Psychology support was available for all patients; specific support was in place for those with long-term conditions or chronic pain and for those who would benefit from a neuropsychology assessment.

Imperial College Healthcare NHS Trust

- Access to psychology support was very rapid. The team were able to respond within two days of the referral being received, and patients could be offered an appointment within a week.

London North West University Healthcare NHS Trust

- The psychologist, with input from children and young people, had developed an educational software programme (SickleBuddy App) for use by children and young people to tell them more about their condition. The App, once piloted, had been made available on social media platforms nationally.

Community care

London North West University Healthcare NHS Trust

- Outreach work was being done by both the SHT and the community team to raise awareness and provide information about haemoglobin disorders across the community; in particular, work was being done with the local councils and churches.

Barts Health NHS Trust – Newham University Hospital

- The community children's team provided a wide range of support to both the hospital team and the community, giving training to families and also undertaking blood investigations.

Barts Health NHS Trust – Whipps Cross University Hospital

- The CNS provided support to the hospital service, attending clinics and visiting children when they attended the day unit for their blood transfusions.

Networking

Alder Hey Children’s NHS Foundation Trust and Sheffield Children’s NHS Foundation Trust

- Nurses were part of the Northern Nurses Group, which met regularly across the region to provide a forum for education and the sharing of good practice.

Birmingham Women’s and Children’s NHS Foundation Trust

- A very good network community nursing group was in operation, with support from the SHT. Reviewers were impressed by the empathic and efficient way in which the group had worked and liaised with services dealing with complex and challenging issues such as refugees and trafficked children.

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300 Standards: Support Services

Summary

This third group of Quality Standards numbered 300*, focus on how accessible support services and colleagues in the specialties, were to haemoglobinopathy service (SHT or LHT).

Access to specialist on-site support had generally improved since the last peer review programme.

Service user reports and audit results confirmed that the patient experience in Emergency Departments remained unsatisfactory, especially when compared to haematology day unit or assessment units. This was contributed to by a high staff turnover, so regular and consistent teaching and training of staff in the ED must be instituted to ameliorate these issues.

96. The requirements of the Quality Standards for support services have changed significantly since 2010. In 2014/16 only 33% of services reviewed met the standard for the expected support services, partly because the standard had become more stringent and included access to psychology. Following the review of the QS in 2018 the psychology staffing was moved to the 200s sections of the QS, which may explain the higher level of compliance with HN-301 for this programme. The new HCC structure, assigning overall responsibility for the provision of network services, should also result in an improvement in the next round of reviews.

Key to tables

* comparison not possible due to changes in QS

- QS not included in this version

Table 24: Comparison, for each 300 Standard, of the compliance by haemoglobin disorder services reviewed in this programme and their compliance in previous programmes (Note: comparison is only made for Trusts that underwent physical reviews during the current programme)

Ref	Quality Standard	% of compliant services					
		Children	Children	Children	Adults	Adults	Adults
		2010/11 (N = 8)	2014/16 (N = 15)	2019/20 (N = 15)	2012/13 (N = 10)	2014/16 (N = 10)	2019/20 (N = 10)
HN-301	Support Services	100	13	73	89	40	70
HN-302	Emergency Department – Staff Competences (previously QS HN-207)	-	47	47	33	50	50
HN-303	SHTs only Specialist On-site Support	100	75	100	-	90	89
HN-304	SHTs only Specialist Services – Network	100	53	80	67	60	56
HN-305	Laboratory Services	-	93	93	100	90	90

Table 25: Comparison, for each 300 Standard, of compliance by haemoglobin disorder services that underwent physical visits in the 2019/20 programme and compliance by all services reviewed in previous programmes

Ref	Quality Standard	% of compliant services					
		Children	Children	Children	Adults	Adults	Adults
		2010/11 (N = 17)	2014/16 (N = 33)	2019/20 (N = 15)	2012/13 (N = 34)	2014/16 (N = 33)	2019/20 (N = 10)
HN-301	Support Services	94	33	73	88	33	70

Ref	Quality Standard	% of compliant services					
		Children	Children	Children	Adults	Adults	Adults
		2010/11 (N = 17)	2014/16 (N = 33)	2019/20 (N = 15)	2012/13 (N = 34)	2014/16 (N = 33)	2019/20 (N = 10)
HN-302	Emergency Department – Staff Competences (previously QS HN-207)	-	55	47	35	55	50
HN-303	SHTs only Specialist On-site Support	93	82	100	-	90	89
HN-304	SHTs only Specialist Services – Network	100	70	80	50	67	56
HN-305	Laboratory Services	-	94	93	94	94	90

Table 26: Graph showing compliance with the Quality Standards compared with previous programmes – Children and Young People (Note: comparison is only being made among services that were physically reviewed)

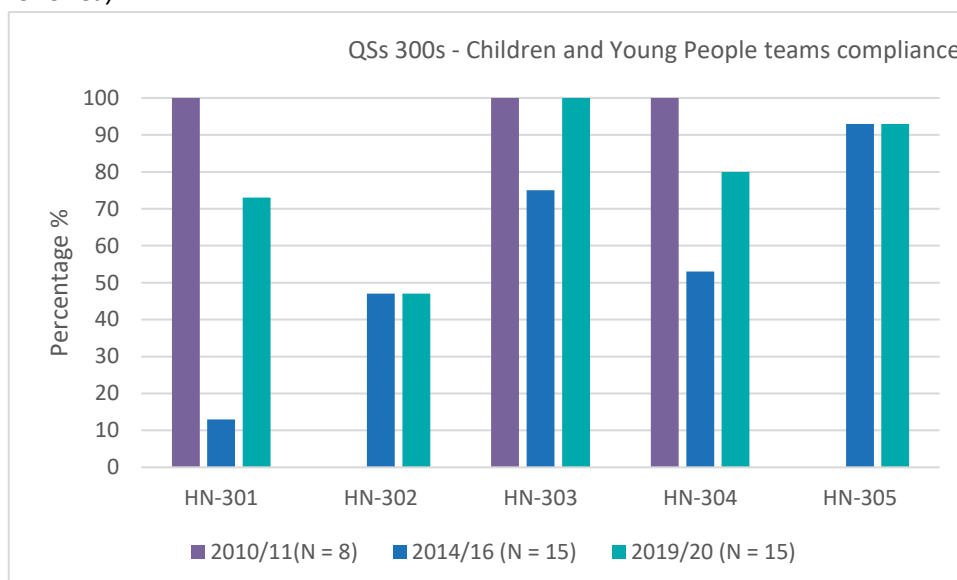
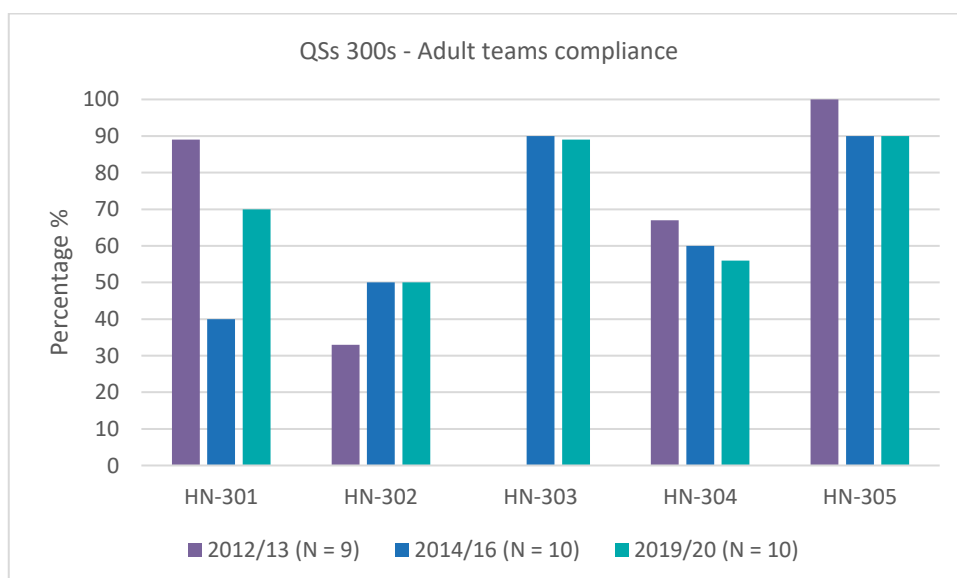


Table 27: Graph showing compliance with the Quality Standards compared with previous programmes – Adults (Note: comparison is only being made among services that were physically reviewed)



Emergency staff training

97. Training on haemoglobin disorders for Emergency Department staff was at about the same level as the previous programme for both adult and children's services. Care in the Emergency Department was still identified as a problem in some services (IR:1; C:4). This problem was highlighted repeatedly in the feedback the review teams received from service users and their families. Reviewers recognised that the low numbers of staff within some of the haemoglobinopathy teams and the high staff turnover in some Emergency Departments meant that ongoing training was more difficult to provide on a regular basis (FC:1).
98. Most Emergency Departments held individualised care plans for adult patients, either on paper or electronically, to ensure personal pain management. Reviewers were particularly impressed with the good leadership and engagement from the ED lead for the SHT at one of the review visits, who had implemented an integrated care pathway that had significantly improved the time to initial assessment, treatment by a senior decision maker and then handover to the clinical team. Many adult services also admitted emergency cases to their day care unit, where guidelines were generally available.
99. Individualised care plans for children were not as common, but almost all Trusts had paediatric sickle cell pain management protocols available, and these were often supported by the acute pain team. Some Trusts also had an effective system of alerting the haemoglobinopathy team when a patient arrived at the Emergency Department. For paediatrics in two of the services reviewed, the haematology team had a process for triaging the patient so that they could be seen quickly.
100. Most Emergency Departments were able to access relevant clinical guidelines through the Trust intranet.
101. Access to specialist on-site support (QS HN-303) was available in all services for adults except one where patients did not have access to red cell apheresis locally. Access to automated erythrocytapheresis had generally improved. Several teams worked with NHS Blood and Transplant to provide good access. Two of the services reviewed had 24/7 access; however, other teams had good access during the working week but not at weekends. Even where automated apheresis was available, some units had limited capacity.
102. All teams could provide emergency manual exchanges. Access to specialist imaging and specialist MRI to assess iron overload had generally improved.

Pain management

103. In line with National Institute for Health and Care Excellence (NICE) guidance on providing analgesia within 30 minutes where indicated, most services had completed an audit.
104. Like previous review programmes, this review programme identified issues with pain management in Emergency Departments (C:6). Service users who met the visiting teams often reported unacceptable delays in receiving analgesia in some Emergency Departments and, from discussions with patient groups, reviewers learned that there seemed to be an unwillingness by ED staff to refer to their emergency care plans. Care was considered to be better where hospitals were able to offer day care analgesia or direct access to haematology assessment, and some patients would wait to attend their day unit rather than attend the Emergency Department.
105. Patient controlled analgesia (PCA) was not available in all areas where patients were admitted, and availability was sometimes restricted to particular wards or times of day. Nursing experience in the use of PCA was also highly variable. Some teams operated good training schemes for areas where PCA was available, and ensured training needs were regularly reviewed and met. Other teams were exploring the use of buccal analgesia instead of PCA.
106. Although most services had access to specialist services that had an appropriate level of specialist expertise in the care of people with haemoglobin disorders (HN-304), not all services had links to a named specialist within the service to which they referred patients, where this was indicated in the QS.

Recommendations

- 3a Training for ED staff: service user reports and audit results confirmed that the patient experience in EDs remained unsatisfactory, especially when compared to haematology day unit or assessment units. This was contributed to by high staff turnover, so regular and consistent teaching and training of staff in the ED departments must be instituted to ameliorate these issues.
- 3b Haemoglobinopathy services should continue to engage with their emergency teams and any other emergency receiving teams to establish local processes that improve pain management.
- 3c Virtual training modules should be instituted for areas with a high staff turnover or infrequent haemoglobinopathy in-patients to reduce the time spent by specialist nurses giving tutorials, and these modules should be developed by HCCs for their networks.
- 3d Consideration should be given to amending the QS that requires patients to receive analgesia within 30 minutes of arrival at the ED so that it applies to patients arriving at any area that has been designated to receive emergencies.

GOOD PRACTICE

Barts Health NHS Trust – The Royal London Hospital

- With the acute pain service, the team had developed an innovative approach of using oral morphine slow release tablets and intranasal diamorphine spray for the management of acute pain, which had greatly reduced the need for parenteral opiates. The acute pain team also ran a monthly 'drop in' education session for staff.

Barts Health NHS Trust – Newham University Hospital

- The ED pathway worked well. Children and young people had 'passports' that enabled them to bypass the initial 'streaming' process so that they were seen quickly. Staff who met with the reviewing team were knowledgeable about haemoglobin disorders, and a training programme for ED staff was in place.
- A designated phlebotomist was assigned to attend the day unit when children and young people attended for blood investigations.

Birmingham Women's and Children's NHS Foundation Trust

- The approach to pain management was good, and the acute pain service was available to review patients from 8am to 5pm on weekdays and 8am to 2pm at weekends and on bank holidays.

Cardiff and Vale University Health Board

- Reviewers were impressed that a physiotherapist attended the annual review and TCD clinics. Children and young people had a musculoskeletal assessment and a respiratory function test undertaken so that advice could be given and effective early interventions commenced.
- Reviewers were impressed with the good leadership and engagement from the ED lead and the team who, with the SHT, had implemented an integrated pathway. Patients attending the ED would initially be seen in the 'majors' area, and quickly referred to the on-call haematologist for ongoing care. The integrated pathway had significantly improved the time to initial assessment, treatment by a senior decision maker and then handover to the clinical team. All known patients with haemoglobin disorders had an emergency care plan documented, which could be accessed by ED staff.

Homerton University Hospital NHS Foundation Trust

- The team worked with the staff in the ED, intensive care unit and admitting wards in order to improve the recognition and management of patients with acute chest syndrome (ACS) who may present out of normal working hours. A standard operational policy had been developed and a teaching programme delivered, with each area identifying a 'champion' who would then deliver ongoing training about ACS to staff in their own area. Reviewers were impressed that posters about ACS, which included key information and who to contact for further advice, were displayed in the ED.

Imperial College Healthcare NHS Trust

- A pain management programme (based on the St George's University Hospitals NHS Foundation Trust model), had commenced, with the aim of improving outcomes for patients with chronic or complex pain. Course and information materials had been developed by the clinical psychologist, and training was facilitated by the physiotherapist. The programme was delivered over eight weeks, with some individual sessions available for patients if required.

Lewisham and Greenwich NHS Trust – Queen Elizabeth Hospital

- The pathway for adults attending in an emergency to the ED was very efficient. Patients were assessed quickly and a patient group direction (PGD) was in place for giving opiate analgesia. Patients reported that they only had to wait ten minutes for their initial triage assessment.
- The pathway for children and young people attending in an emergency had greatly improved, and parents commented that they were seen within 15 minutes of arrival.

London North West University Healthcare NHS Trust

- Arrangements had been made for patients to show their NHR card at the ED reception so that they could be fast tracked for assessment and analgesia if required.
- The team had started sharing patient stories with ED staff as part of the ED team's review and learning sessions.
- The pathway for adults with haemoglobin disorders who required orthopaedic surgery was good.

Sheffield Children's NHS Foundation Trust

- The acute pain team was available on Saturdays to undertake a ward round and review any child who had been admitted with acute pain.

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400 Standards: Facilities and Equipment

Summary

This fourth group of Quality Standards numbered 400*, focus on the suitability of the environments for caring for people with haemoglobin disorders, equipment for providing patient care and the IT systems that are available to staff in order for them to deliver integrated care.

Most of the services reviewed had appropriate facilities and equipment to deliver care.

Some patients identified issues when they were cared for in other speciality areas.

Key to tables

* comparison not possible due to changes in QS

- QS not included in this version

Table 28: Comparison, for each 400 Standard, of the compliance by haemoglobin disorder services reviewed in this programme and their compliance in previous programmes (Note: comparison is only made for Trusts that underwent physical reviews during the current programme)

Ref	Quality Standard	% of compliant services					
		Children	Children	Children	Adults	Adults	Adults
		2010/11 (N = 8)	2014/16 (N = 15)	2019/20 (N = 15)	2012/13 (N = 9)	2014/16 (N = 10)	2019/20 (N = 10)
HN-401	Facilities and Equipment	100	87	100	67	70	100

Note: Data for environment QS from 2012-16 is also included for HN-194.

Table 29: Graph showing compliance with the Quality Standards compared with previous programmes – Children and Young People (Note: comparison is only being made among services that were physically reviewed)

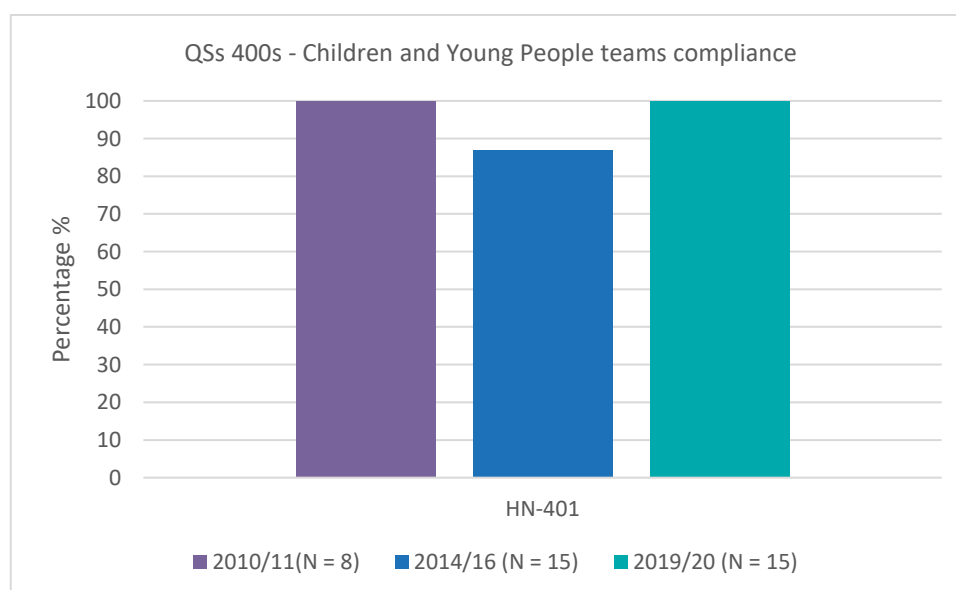
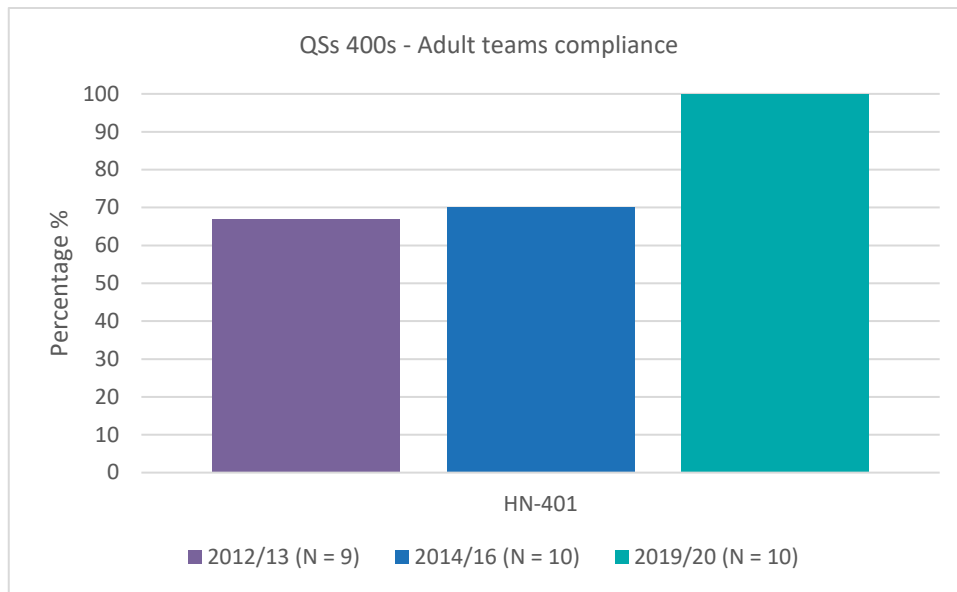


Table 30: Graph showing compliance with the Quality Standards compared with previous programmes – Adults (Note: comparison is only being made among services that were physically reviewed)



107. The quality of facilities and equipment available to patients with haemoglobin disorders were generally appropriate for the number of patients cared for.
108. Most Trusts were able to provide day care services for blood transfusion and reviews, including pain management services, in dedicated facilities. When available, these facilities were universally praised by patients and provided excellent care. However, some of the day care units were hampered by restricted opening hours and limited capacity.
109. Some haemoglobinopathy services were co-located with haemato-oncology wards and areas. Where this was the case, some feedback was received from patients and carers saying that they felt that oncology patients took priority.
110. See also section [118](#) about out of hours elective care.

Recommendations

- 4a Wherever possible, patients should have access to designated wards with staff who have appropriate training to care for patients with haemoglobin disorders.
- 4b Teams should work with their service users to understand their views about being cared for in other specialist areas.

GOOD PRACTICE

Barts Health NHS Trust – Newham University Hospital

- There was a well-planned environment which worked as a 'hub'. The ED was adjacent to the main paediatric area, with all other services such as phlebotomy, out-patients, in-patient wards, the day unit, and parents' and teenage rooms co-located.

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500 Standards: Guidelines and Protocols

Summary

This fifth group of Quality Standards numbered 500*, focus on the guidelines and documentation that should be available to staff in order to reduce variation within clinical teams, and to give guidance to more junior members of the MDT and to staff providing out-of-hours cover.

In general, the availability of clinical guidelines had improved, but the detail and document control of these guidelines was highly variable.

Key to tables

* comparison not possible due to changes in QS

- QS not included in this version

Table 31: Comparison, for each 500 Standard, of the compliance by haemoglobin disorder services reviewed in this programme and their compliance in previous programmes (Note: comparison is only made for Trusts that underwent physical reviews during the current programme)

Ref	Quality Standard	% of compliant services					
		Children	Children	Children	Adults	Adults	Adults
		2010/11 (N = 8)	2014/16 (N = 15)	2019/20 (N = 15)	2012/13 (N = 9)	2014/16 (N = 10)	2019/20 (N = 10)
HN-501	SHTs only Transition Guidelines	86	67	87	67	50	80
HN-502	Monitoring Protocols	100	87	87	56	60	70
HN-503	LHTs only Clinical Guidelines: LHT Management and Referral	100	100	71	78	50	50
HN-504	Transfusion Guidelines	88	80	80	78	80	80
HN-505	Chelation Therapy	75	87	80	67	50	60
HN-506	Clinical Guidelines: Acute Complications	63	67	73	33	60	60
HN-507	Specialist Management Guidelines	-	73	87	78	70	60
HN-508	Clinical Guidelines: Chronic Complications	86	60	73	67	50	50
HN-509	Children's SHTs only (from 2018) Referral for Consideration of Bone Marrow Transplantation	63	87	100	-	70	N/A
HN-510	Non-Transfusion Dependent Thalassaemia (nTDT)	88	73	73	44	50	70
HN-599	Clinical Guideline Availability	88	80	87	56	60	90

Table 32: Comparison, for each 500 Standard, of compliance by haemoglobin disorder services that underwent physical visits in the 2019/20 programme and compliance by all the services reviewed in previous programmes

Ref	Quality Standard	% of compliant services					
		Children	Children	Children	Adults	Adults	Adults
		2010/11 (N = 17)	2014/16 (N = 33)	2019/20 (N = 15)	2012/13 (N = 34)	2014/16 (N = 33)	2019/20 (N = 10)
HN-501	SHTs only Transition Guidelines	73	70	87	68	70	80
HN-502	Monitoring Protocols	94	91	87	48	76	70
HN-503	LHTs only Clinical Guidelines: LHT Management and Referral	100	67	71	65	90	50
HN-504	Transfusion Guidelines	82	79	80	74	85	80
HN-505	Chelation Therapy	76	94	80	62	82	60
HN-506	Clinical Guidelines: Acute Complications	76	70	73	53	67	60
HN-507	Specialist Management Guidelines	-	70	87	79	76	60
HN-508	Clinical Guidelines: Chronic Complications	93	61	73	56	63	50
HN-509	Children's SHTs only (from 2018) Referral for Consideration of Bone Marrow Transplantation	71	88	100	-	69	N/A
HN-510	Non-Transfusion Dependent Thalassaemia (nTDT)	71	67	73	61	76	70
HN-599	Clinical Guideline Availability	94	79	87	71	79	90

Table 33: Graph showing compliance with the Quality Standards compared with previous programmes – Children and Young People (Note: comparison is only being made among services that were physically reviewed)

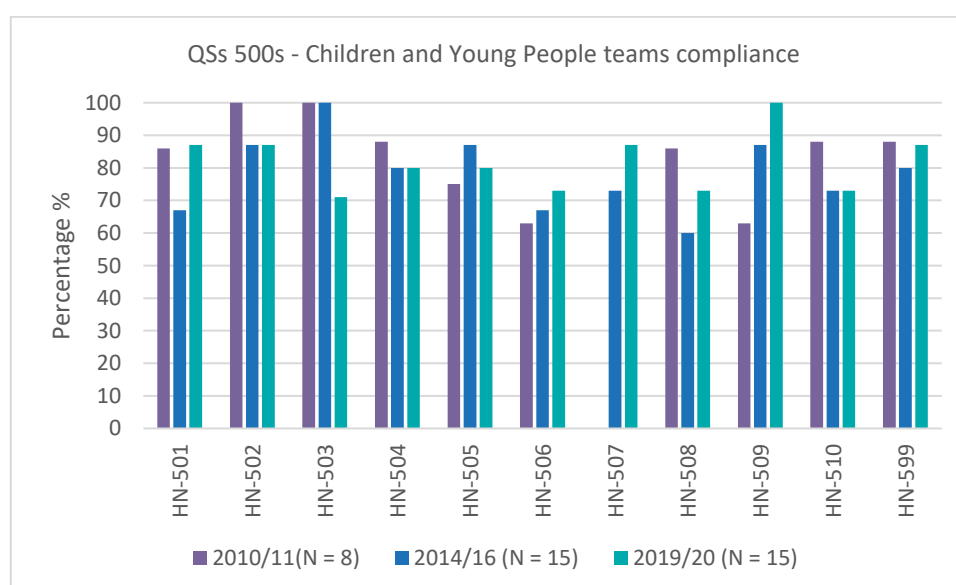
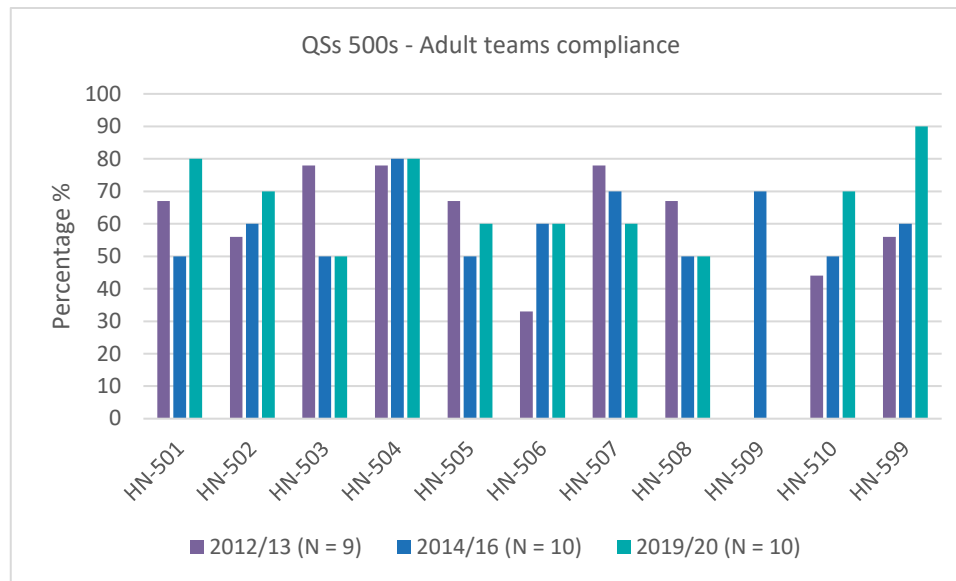


Table 34: Graph showing compliance with the Quality Standards compared with previous programmes – Adults (Note: comparison is only being made among services that were physically reviewed)



Guidelines

111. As part of each review visit, reviewers looked in detail at the clinical and referral guidelines in use in each service. The Quality Standards are clear about which guidelines should be available in order to reduce variation within clinical teams and give guidance to more junior members of the multi-disciplinary team and to staff providing out of hours cover.
112. The chelation guidance was of variable quality across services (HN-505), but this should improve with the publication of the British Society for Haematology (BSH) chelation guidance currently in production. The new SHT and HCC structures should also lead to greater uniformity of guidelines within Trust guideline structures, and this will improve concordance particularly with regard to low prevalence conditions, for example non-transfusion dependent thalassaemia (nTDT).
113. The compliance with the QS guidelines (HN-500's) for the services reviewed had improved overall compared with compliance in the 2014-16 review programme, from 78% to 82% for children's and young people's services and 61% to 67% for adult services. In some services, however, the lack of up-to-date guidelines, incomplete/absent guidelines and the following of standard Trust governance processes for managing guidelines were worrying (IR:3; SC:1; C:1). It is important that this is followed up even in lower prevalence areas and for lower prevalence conditions such as nTDT.
114. Some chronic complications mainly occur in adults, but were included in the paediatric QS guidelines, resulting in non-compliance in many cases. Reviewers' views varied about whether these guidelines should be applicable to children. It will be important to revise the QS in the future to reflect the disparate prevalence of certain chronic complications among the different age groups.

Recommendations

- 5a The HCCs should aim to have standard guidelines across the UK that can be easily adapted by services for the local context.
- 5b Guidelines should be reviewed and ratified according to standard Trust procedures and with appropriate version control to ensure that version control is maintained.
- 5c For the next version of the Quality Standards, the UK Forum should undertake a review of standards with regard to the appropriate information, particularly on complications, that is relevant to paediatric populations.

GOOD PRACTICE

Alder Hey Children's NHS Foundation Trust

- The clinical guidelines were well written and were easy to follow, especially for junior staff. Each guideline documented clear information and the steps that staff would need to take. The one page 'acute management pathway' was particularly clear, providing, at a glance, information on how to manage a child experiencing a sickle cell crisis.

Birmingham Women's and Children's NHS Foundation Trust

- The chelation guidelines were very comprehensive, were easy to read and follow, and contained advice for staff.
- The clinical guidelines for thalassaemia were also very well written and comprehensive.

Leeds Teaching Hospitals NHS Trust

- The acutely unwell sickle cell guidance was very comprehensive, detailing investigations, diagnosis, analgesia guidance, treatment, and management. The guidelines also included a very good summary flow chart, which included generic pain management guidance as well as information about other key medications. Reviewers were particularly impressed with the written advice in the guideline addressed to other health professionals about the patient being the 'expert' about their condition.
- The guidelines covering the 'acutely unwell thalassaemia patient' were also very well written and clear. Reviewers were particularly impressed with the table checklist, with key questions for staff to cover when seeing a patient who was acutely unwell. The checklist also included additional prompts about 'what to consider' and 'what to remember to do'.

Whittington Health NHS Trust

- The non-transfusion dependent thalassaemia (nTDT) guidance was very detailed, and included a comprehensive review of chelation agents and clear guidance on the management of patients with increasing iron overload.

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600 Standards: Service Organisation and Liaison with Other Services

Summary

This sixth group of Quality Standards numbered 600*, focus on the organisation of the service and multi-disciplinary working within the haemoglobinopathy team and with other services.

Most, but not all, services had a written operational policy. Service level agreements between various interdependent organisations were often absent.

Trans-cranial Doppler competences were difficult to maintain in low prevalence areas. Some practitioners were highly competent in vascular ultrasound in general but fell short in their TCD experience because of the low number of patients cared for by the haemoglobin disorder service.

Out of hours elective care was desired by users in many services but was not always available. Some services were reducing the out of hours services that had been provided at the time of earlier reviews.

Key to tables

* comparison not possible due to changes in QS

- QS not included in this version

Table 35: Comparison, for each 600 Standard, of the compliance by haemoglobin disorder services reviewed in this programme and their compliance in previous programmes (Note: comparison is only made for Trusts that underwent physical reviews during the current programme)

Ref	Quality Standard	% of compliant services					
		Children		Children	Adults		Adults
		2010/11 (N = 8)	2014/16 (N = 15)	2019/20 (N = 15)	2012/13 (N = 10)	2014/16 (N = 10)	2019/20 (N = 10)
HN-601	Service Organisation	45	47	53	33	30	60
HN-602	Multi-disciplinary Team Meetings	50	47	87	56	70	60
HN-603	SHTs only Delegation of Annual Reviews	*	*	57	*	*	0
HN-604	Out of Hours Elective Care (previously HN-402)	0	40	60	56	60	56
HN-605	Service Level Agreement with Community Services	17	38	22	25	75	25
HN-606	Children's SHTs only Trans-cranial Doppler Ultrasound Standard Operating Procedure	-	54	60	N/A	N/A	N/A
HN-607	Network Review and Learning Meetings	50	60	93	-	50	78
HN-608	Children's SHTs only Neonatal Screening Programme Review Meetings	100	100	82	N/A	N/A	N/A

Table 36: Comparison, for each 600 Standard, of compliance by haemoglobin disorder services that underwent physical visits in the 2019/20 programme and compliance by all the services reviewed in previous programmes

Ref	Quality Standard	% of compliant services					
		Children	Children	Children	Adults	Adults	Adults
		2010/11 (N = 17)	2014/16 (N = 33)	2019/20 (N = 15)	2012/13 (N = 34)	2014/16 (N = 33)	2019/20 (N = 10)
HN-601	Service Organisation	52	55	53	44	52	60
HN-602	Multi-disciplinary Team Meetings	60	67	87	47	73	60
HN-603	SHTs only Delegation of Annual Reviews	*	*	57			0
HN-604	Out of Hours Elective Care (previously HN-402)	12	55	60	52	50	56
HN-605	Service Level Agreement with Community Services	24	50	22	30	53	25
HN-606	Children's SHTs only Trans-cranial Doppler Ultrasound Standard Operating Procedure	-	67	60	N/A	N/A	N/A
HN-607	Network Review and Learning Meetings	60	70	93	-	55	78
HN-608	Children's SHTs only Neonatal Screening Programme Review Meetings	87	83	82	N/A	N/A	N/A

Table 37: Graph showing compliance with the Quality Standards compared with previous programmes – Children and Young People (Note: comparison is only being made among services that were physically reviewed)

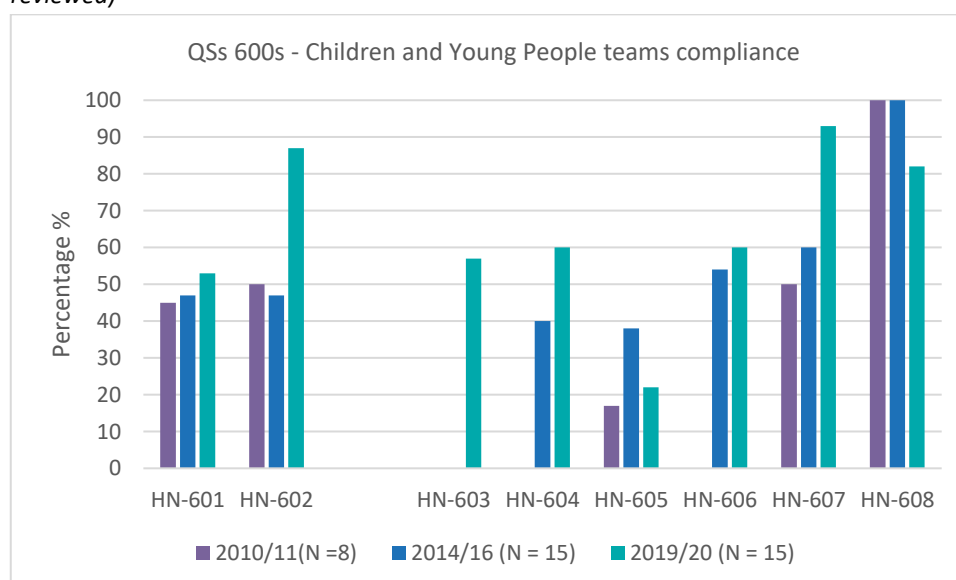
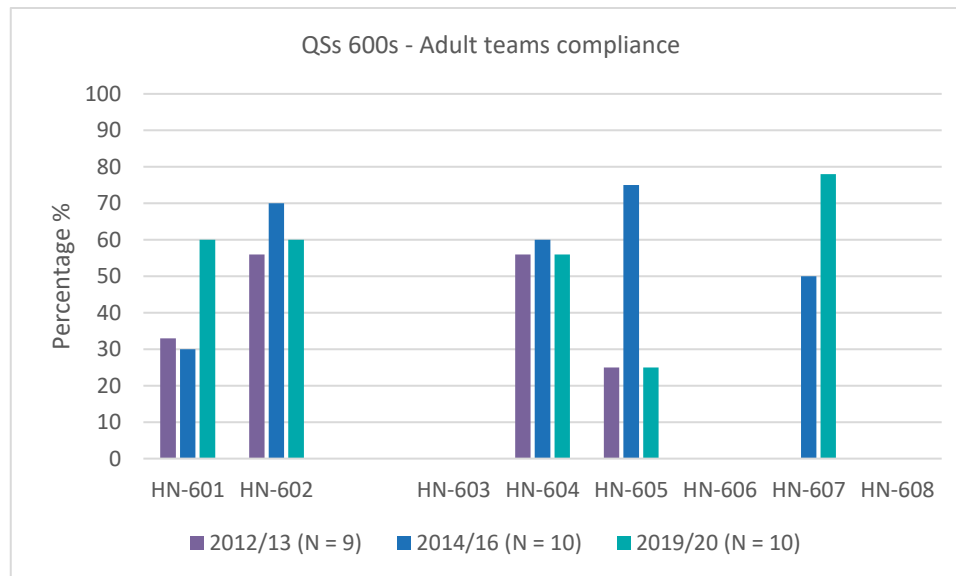


Table 38: Graph showing compliance with the Quality Standards compared with previous programmes – Adults (Note: comparison is only being made among services that were physically reviewed)



115. Operational policies (QS HN-601) were in place in 53% of the paediatric services and 60% of the adult services. Compliance for adult services had increased significantly.
116. Multi-disciplinary meetings were happening in most Trusts (87% paediatrics, 60% adults). For adult services, this was lower than was found in the previous programme (2016).
117. With the onset of the COVID-19 pandemic it is likely that multi-disciplinary meetings and network learning events will continue via virtual platforms, and that this will be established as a regular feature following the establishment of HCCs.

Out of hours elective care

118. The expected standard for out of hours care (HN-604) is that all services provide facilities for 'out of hours' transfusion, phlebotomy and out-patient clinics. Facilities for out of hours phlebotomy and transfusion were limited for both children and adults, but compliance with the standard had improved slightly from the previous programme. Four of the services reviewed were providing evening and extended clinics. However, lack of access to out of hours services was one of the most important issues in the patient feedback. Weekend transfusions were becoming available and were highly appreciated by families and patients; some units were providing Saturday clinics. Outreach blood testing, where a nurse visited the patient at home to take pre-transfusion or hydroxycarbamide monitoring samples, was highly valued by families but was uncommon. As a result, many children having monthly transfusions missed up to one and a half school days each month. Many adult patients were in a similar situation, often needing to make multiple hospital visits during working hours for cross-matching, transfusion, scans and clinic attendance.

Trans-cranial Doppler ultrasound

119. It was harder for services with fewer patients to maintain the necessary competences (40 scans per practitioner per year) in trans-cranial Doppler ultrasounds. For example, this was identified as an area of concern in one service because of the low numbers of patients needing annual scans.
120. In order to ensure competences are maintained in smaller service, a robust external quality assurance programme should be established nationally. The process for internal QA was raised as an area of further consideration in one service (FC:1).
121. The pathway for further investigating an abnormal trans-cranial Doppler ultrasound was not clear in many services, and practice varied widely (FC:4).

Recommendations

- 6a Many out-patient appointments, including annual reviews, have been converted to virtual appointments (telephone or video) during the pandemic. Anecdotally, this has resulted in fewer clinic non-attendances. Other innovative interventions, such as satellite phlebotomy clinics and the home delivery of goods and services, have also been beneficial to patients. It will be important for haemoglobin disorder teams to assess their own working patterns during the pandemic and to continue with pathways that provide high quality care while requiring less time and effort from users and providers alike.
- 6b A programme of external quality assurance for trans-cranial Doppler services should be established. This could utilise the new HCC structure.

GOOD PRACTICE

Pathways

Barts Health NHS Trust – Newham University Hospital

- Work to reduce the number of children and young people who were ‘not brought’ for appointments had resulted in the percentage of appointments missed being reduced from 27% to 11%. When appointment letters were returned to the Trust, families were telephoned, and all parents were sent a text message 48 hours before their scheduled appointment. The community team were also notified when families missed appointments, and worked with families to provide support and to encourage families to keep review appointments.

Barking, Havering and Redbridge University Hospitals NHS Trust

- Frequencies and times of out-patient clinics had been reviewed following an increase in the ‘did not attend / was not brought’ rates (DNA). Feedback from patients and families using the ‘what matters to me’ initiative identified a lack of flexibility in appointment times. The clinics were rescheduled, their frequency was increased to weekly from monthly, and the clinic times were extended to run until 6pm.

Bradford Teaching Hospitals NHS Foundation Trust

- A ‘rapid access triage’ process had been implemented so that children and young people with chronic conditions had direct access to the admissions unit for assessment and urgent care. Patients could either attend directly by phoning in advance or be referred by their GP.

Homerton University Hospital NHS Foundation Trust

- The pathway for frequent attendance at the medical day unit or the ED as an out-patient had been revised. Patients could only attend twice in any week before they had to be reviewed by a senior decision maker and, if appropriate, admitted for symptom management.

London North West University Healthcare NHS Trust

- The antenatal ‘fail-safe’ process was very robust. If women did not attend their appointments, the community midwife was notified and would then liaise with and see the patient as necessary.
- There was a ‘fail-safe’ process for affected newborn babies to ensure that these babies commenced on prophylactic antibiotics as soon as possible. If babies were not brought for their clinic appointments, the community team were notified and would then liaise with the family.
- A good process for discharge from the ward was in place: the community team were notified, and they would then make contact with the family to check on their progress and provide additional support.

Nottingham University Hospitals NHS Trust

- The pathway for people with thalassaemia allowed them to get appointments so they could be seen on the day unit, and evening and weekend times were available for them to attend for blood transfusions.

University Hospitals Bristol NHS Foundation Trust

- The pathway for patients who required an emergency assessment or pain management enabled them to attend the day unit on Sundays from 9am to 5pm.

Whittington Health NHS Trust

- The ambulatory paediatric care model pathway enabled many patients with acute complications to be treated as day patients.

Liaison

Barts Health NHS Trust

- Good arrangements were in place with the SHT based at the RLH to provide support to the LHTs and community services across the network.

Cardiff and Vale University Health Board

- There was a good working relationship with the senior management team and the Welsh Health Specialist Services Committee.

Homerton University Hospital NHS Foundation Trust

- There was collaborative working across the local health economy. The Hackney Sickle Cell Board, which included representatives from primary care, commissioners, and the Trust team, had developed a pathway for the care of patients with haemoglobin disorders to help reduce attendances at the Trust for care that could be provided in a primary care setting. Also impressive was the work undertaken by GPs to engage with patients with haemoglobin disorders registered at their practices, so that they were screened on a regular basis and encouraged to access help in primary care.

University Hospitals Bristol NHS Foundation Trust

- There were arrangements in place with the community and local university medical providers, who would alert the team when new patients moved into the area; the team would then contact the students to offer ongoing care locally during term time. The information contained in the letters to the primary health care team was also well written and included clear guidance for GPs.

Whittington Health NHS Trust

- There were good links with both local and specialised commissioners, who were very engaged and supportive about the development of the service.

Trans-cranial Doppler ultrasound

Alder Hey Children's NHS Foundation Trust

- The investigation of abnormal trans-cranial Doppler (TCD) ultrasounds was well organised. A dedicated neuroradiologist had oversight of the TCD service and the neuroradiology MRI reporting, which helped with the imaging of this group.

Barts Health NHS Trust – The Royal London Hospital

- There was a good internal quality assurance process for TCD ultrasound.
- A bi-monthly Saturday TCD clinic was held at the Newham Community Service Centre.

Operational

University Hospitals Bristol NHS Foundation Trust

- The service organisation policy was well written, included clear advice and was regularly updated.

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700 Standards: Governance, Data and Audit

Summary

This seventh group of Quality Standards numbered 700*, focus on the clinical governance arrangements that should be in place to ensure that qualitative and quantitative information is collected and reviewed. This will help to demonstrate the quality of the service being provided and to provide evidence that appropriate action was taken in response to any identified concerns, including those raised by any incidents or complaints.

Submission of data to the NHR had improved.

Compliance with the standards for other recommended audits was variable, and the standards were not met by a number of services.

122. Quality Standards for data and audit have changed significantly since 2010 and so compliance may not be comparable, but the inference of these QS for each programme is the same: teams should be using data and undertaking audits on a regular basis to provide information for ongoing quality monitoring.

Key to tables

* comparison not possible due to changes in QS

- QS not included in this version

Table 39: Comparison, for each 700 Standard, of the compliance by haemoglobin disorder services reviewed in this programme and their compliance in previous programmes (Note: comparison is only made for Trusts that underwent physical reviews during the current programme)

Ref	Quality Standard	% of compliant services					
		Children		Adults		Adults	
		2010/11 (N = 8)	2014/16 (N = 15)	2019/20 (N = 15)	2012/13 (N = 9)	2014/16 (N = 10)	2019/20 (N = 10)
HN-701	National Haemoglobinopathy Registry	17	13	64	0	50	70
HN-702	Activity Data	-	67	60	22	60	70
HN-703	SHTs only Quality Dashboard (not comparable with previous version of the QS)	33	29	80	-	-	75
HN-704	Children's SHTs only Other Quality Data (not comparable with previous version of the QS)	-	-	100	N/A	N/A	N/A
HN-705	Other Audits (not comparable with previous version of the QS)	-	20	27	-	-	30
HN-706	Network Audits	-	13	71	0	30	56
HN-707	SHTs only Research	-	62	90	57	67	67
HN-708	Children's SHTs only Trans-cranial Doppler Quality Assurance	-	62	60	N/A	N/A	N/A

Ref	Quality Standard	% of compliant services					
		Children	Children	Children	Adults	Adults	Adults
		2010/11 (N = 8)	2014/16 (N = 15)	2019/20 (N = 15)	2012/13 (N = 9)	2014/16 (N = 10)	2019/20 (N = 10)
HN-798	Multi-disciplinary Review and Learning	-	93	67	56	100	70
HN-799	Document Control	-	60	87	56	70	90

Table 40: Comparison, for each 700 Standard, of compliance by haemoglobin disorder services that underwent physical visits in the 2019/20 programme and compliance by all the services reviewed in previous programmes

Ref	Quality Standard	% of compliant services					
		Children	Children	Children	Adults	Adults	Adults
		2010/11 (N = 17)	2014/16 (N = 33)	2019/20 (N = 15)	2012/13 (N = 34)	2014/16 (N = 33)	2019/20 (N = 10)
HN-701	National Haemoglobinopathy Registry	41	43	64	24	53	70
HN-702	Activity Data	-	67	60	32	64	70
HN-703	SHTs only Quality Dashboard (not comparable with previous version of the QS)	35	*	80	*	*	75
HN-704	Children's SHTs only Other Quality Data (not comparable with previous version of the QS)	*	*	100	N/A	N/A	N/A
HN-705	Other Audits (not comparable with previous version of the QS)	*	*	27	*	*	30
HN-706	Network Audits	-	36	71	15	30	56
HN-707	SHTs only Research	-	68	90	59	72	67
HN-708	Children's SHTs only Trans-cranial Doppler Quality Assurance	-	59	60	N/A	N/A	N/A
HN-798	Multi-disciplinary Review and Learning	-	88	67	71	97	70
HN-799	Document Control	-	73	87	59	73	90

Table 41: Graph showing compliance with the Quality Standards compared with previous programmes – Children and Young People (Note: comparison is only being made among services that were physically reviewed)

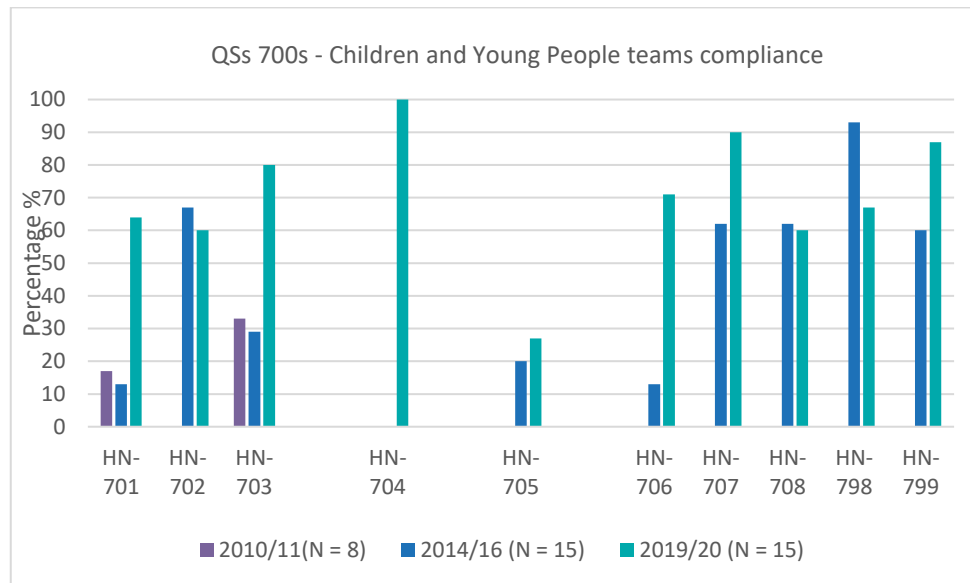
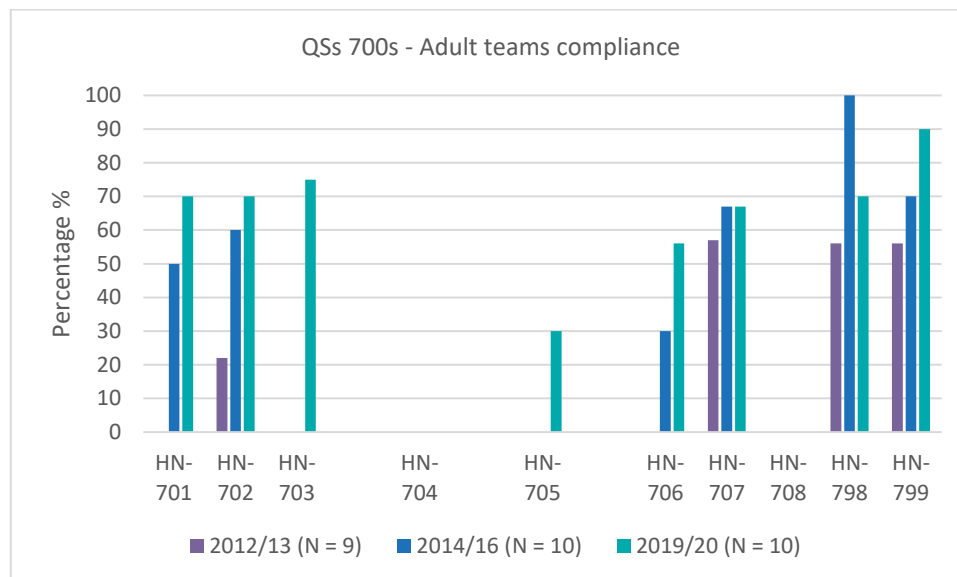


Table 42: Graph showing compliance with the Quality Standards compared with previous programmes – Adults (Note: comparison is only being made among services that were physically reviewed)



National Haemoglobinopathy Registry

123. The National Haemoglobinopathy Registry (NHR) provides a means of monitoring the number of patients being treated by a team or within a geographical area. At the time the review programme was taking place the NHR was in the process of being redeveloped, and it is anticipated that the revised version will have increased functionality as a clinical and research tool. The NHR also provides a means for demonstrating compliance with key standards of clinical care, and gives a denominator for clinical audits and service planning. It is also a tool for reviewing and learning from adverse events. Adult services demonstrated improved data entry into the NHR, with compliance with the relevant standard (HN-701) increasing from 50% to 70%, and compliance for children’s services increased from 13% to 64%. Most services that were non-compliant with this standard were using the NHR to register patients, but were not entering all their adverse events or annual reviews (C:2; FC:3). The main reason cited for incomplete entry was a lack of time for clinical and data administration staff.

Patient records

124. Implementation of electronic patient records in Trusts was better established than in the previous programmes, although for some services issues were raised by the reviewing team (C:2; FC:2) due to the governance issues of maintaining up to date patient records when using a combination of paper, electronic and service databases.

Audit and data

125. The Quality Standard (HN-702) required evidence of the ongoing monitoring of the service's activity. Such information can be used to benchmark care across and between geographical areas and provide information for local commissioners. In 2012/13 most teams had poor compliance with this standard (11% compliance). In 2014/16, data collection was divided into two standards, HN-702, which requested data on activity, and HN-703, which referred to the collection of additional data from the network. In 2014/16, activity data were available in 64% of services but some teams were still not monitoring basic activity data (hospital admissions, DNA rate). In 2019-20 the compliance with HN-702 was slightly lower for paediatric services (60%) than it was for adult services (70%).

126. Comments were received from three services who, because of the Trust systems in use, could not easily extract in-patient readmission data to show compliance with HN-702. The steering group was asked to consider the interpretation of the QS, but concluded that the collection of readmission data by services was important.

127. No evidence of audit or insufficient audit activity was an issue for six of the services reviewed (C:2; FC:6). Again, the main reason cited for the low number of audits undertaken was a lack of clinical staff time available, or a lack of support for data administration.

128. Services were asked to provide data on the numbers of transfused patients and the proportion of patients having annual reviews, as part the background information to the reviewing team. Data on waiting times for transfusion, the number of patients on hydroxycarbamide and the numbers of patients who are iron overloaded may be useful additional background information for any future peer review programmes or benchmarking processes.

129. The requirement to carry out other audits (HN-705) included auditing, in the previous two years, the availability of extended red cell phenotype in all patients, the proportion of patients who had developed antibodies, whether eligible patients on long-term transfusion had been offered automated exchange transfusion and the waiting times for elective care (phlebotomy, cannulation, setting up a blood transfusion). This QS was met by 27% of paediatric and 30% of adult services, and was raised as an issue for ten services (C:2; FC:8).

Recommendations

- 7a Audit can only occur when appropriate data support is provided. Trusts need to address this non-concordance and provide data manager support so that this information can be collected and quality improvement plans developed, leading to improved patient care and experience.
- 7b Service audit programmes should be supported by the HCCs and SHTs via an annual programme of work, and annual reports should be produced to show improvements and developments in the service.

GOOD PRACTICE

Audit

Barts Health NHS Trust – The Royal London Hospital

- The most recent 'time to analgesia' audit showed that 70% of children and young people received analgesia within 30 minutes of arrival. Reviewers were particularly impressed that the audit results showed that the longest time that a child had waited for analgesia was 38 minutes.

MDT working

Barking, Havering and Redbridge University Hospitals NHS Trust

- The frequency of the MDT meetings had been increased to weekly so that more timely decisions could be agreed. Telephone conference MDT meetings took place every month, and quarterly MDT meetings were held with the specialist haemoglobinopathy team based at the Royal London Hospital to discuss patients with more complex needs.

London North West University Healthcare NHS Trust

- Support from the SHT was provided for patients residing in the Bedford area and for the local team based at Bedford Hospital. Telephone conference calls were held on alternate months with the local team to discuss any patients, and eight outreach clinics were held, two of which were attended by the SHT consultant haematologists and consultant paediatrician.

Imperial College Healthcare NHS Trust

- A monthly apheresis MDT was in operation which enabled patient review to ensure that targets for HbS were met, treatments were reviewed and any issues with vascular access were resolved. The MDT included representation from a consultant haematologist, staff from both the adult and paediatric apheresis teams and the haemoglobinopathy and iron overload CNSs. Audits had shown that there had been improved engagement with patients, resulting in an increase in patients' compliance with iron chelation therapy, and that timely investigations and monitoring had taken place.

Nottingham University Hospitals NHS Trust

- Network-wide video conference linked MDT meetings were held every two months, and the minutes demonstrated that the process for the discussion of patients and actions following the MDT meetings were very comprehensive.

Oxford University Hospitals NHS Foundation Trust

- Reviewers were impressed by the outreach support and arrangements that were in place for obtaining specialist advice and support from the SHT lead clinician and specialist nurse, as well as the advice available to them out of hours from the on-call haematology team.
- The monthly network-wide MDT meetings were effective and were well attended by teams from across the network. Patients and staff had easy access to patient information and guidelines via the network website, and much of the information available had been co-produced with the adult and paediatric SHTs.

University Hospitals Bristol NHS Foundation Trust

- The structure of the weekly MDT meetings was good. The discussion of patients was subdivided into those who had attended clinics, those who had attended the day unit, and in-patients. Time was also allocated for general communication and information sharing.

Research

Barts Health NHS Trust – The Royal London Hospital

- Reviewers were impressed with the strong commitment to research into red cell disorders. Since the last visit in 2015, the team, with support from the research unit, had continued to expand their portfolio of prospective and observational research studies, with a good uptake in the number of patients who were willing to take part.

Imperial College Healthcare NHS Trust

- Reviewers were impressed with the strong commitment to research into red cell disorders. Since the last visits in 2015, the team had continued to expand their portfolio of prospective and observational research studies, with a good uptake in the number of patients who were willing to take part.

Sheffield Children's NHS Foundation Trust

- Clinical trial activity was good, despite this being a small service with a new consultant.

Data**Barts Health NHS Trust – The Royal London Hospital**

- The bespoke Trust haemoglobinopathy database had evolved further since the last visit and continued to provide comprehensive information for the clinical teams. It was also possible for the database to be synchronised with other Trust information systems. The SHT had plans to develop the database function further in order for the system to be web-based, which would enable the information to be available remotely and to be accessed by the LHTs.

Imperial College Healthcare NHS Trust

- The work of the quality team to support the clinical team for data collection, audit and research was excellent and unique.

Homerton University Hospital NHS Foundation Trust

- The service report included a wealth of information about the service, clinical and educational activity, service achievements and service developments. The report was also made publicly available.

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Commissioning

130. A number of issues were raised in relation to the reconfiguration and the progress of teams. The reviews were held at a time when NHSE commissioning for specialist haemoglobinopathy services was undergoing a radical restructuring. This resulted in some uncertainties about pathways and responsibilities. Some services were newly designated as SHTs and, rarely, SHT status was removed from some services, as was seen in Bradford.
131. Some SHTs with small patient numbers struggled to develop and maintain expertise, particularly in the management of complex organ failure needing expertise from other disciplines, such as orthopaedics, neurology, neurosurgery, endocrine, and renal.
132. In 2019 NHS England commissioned a 'hub-and-spoke' model of networked specialist care for people with haemoglobin disorders after extensive consultation. Services were invited to bid for designation as Haemoglobinopathy Coordinating Centres (HCC) and Specialist Haemoglobinopathy Teams (LHT). Additionally, a National Haemoglobinopathy Panel was established to provide specialist multi-disciplinary clinical advice. The current peer review programme was conducted at a time when such structures were in the process of being established and some of the newly designated teams had not yet formalised their pathways for delivering specialist care, including annual reviews and specialist investigations. The new commissioning and governance structure is expected to improve equity to access of care and future Quality Standards will reflect these structures.

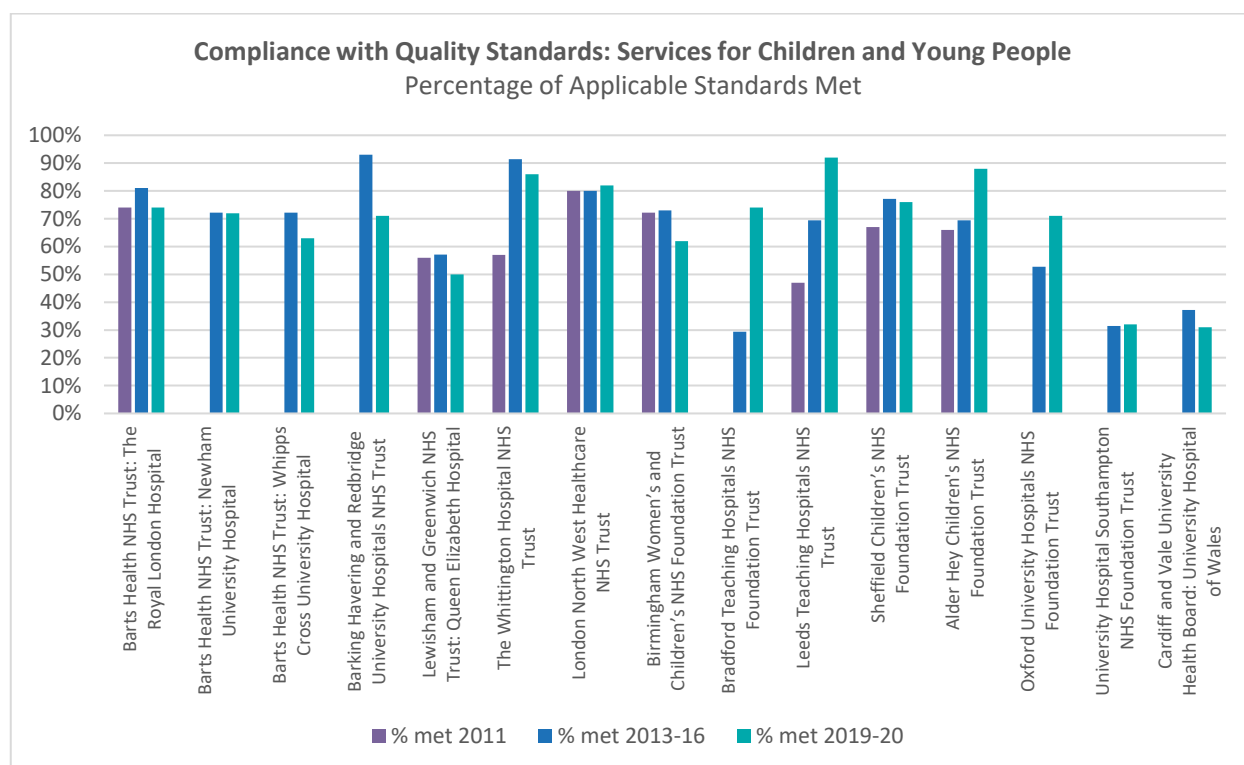
Recommendations

The new commissioning structure for haemoglobinopathy in England is likely to allow for more clinical networking, shared learning, equitable access to specialised services, unified protocols and collaborative research. It is therefore important to ensure that innovative commissioning and insightful self-assessment continue to remain a top priority for such services.

Compliance with Quality Standards

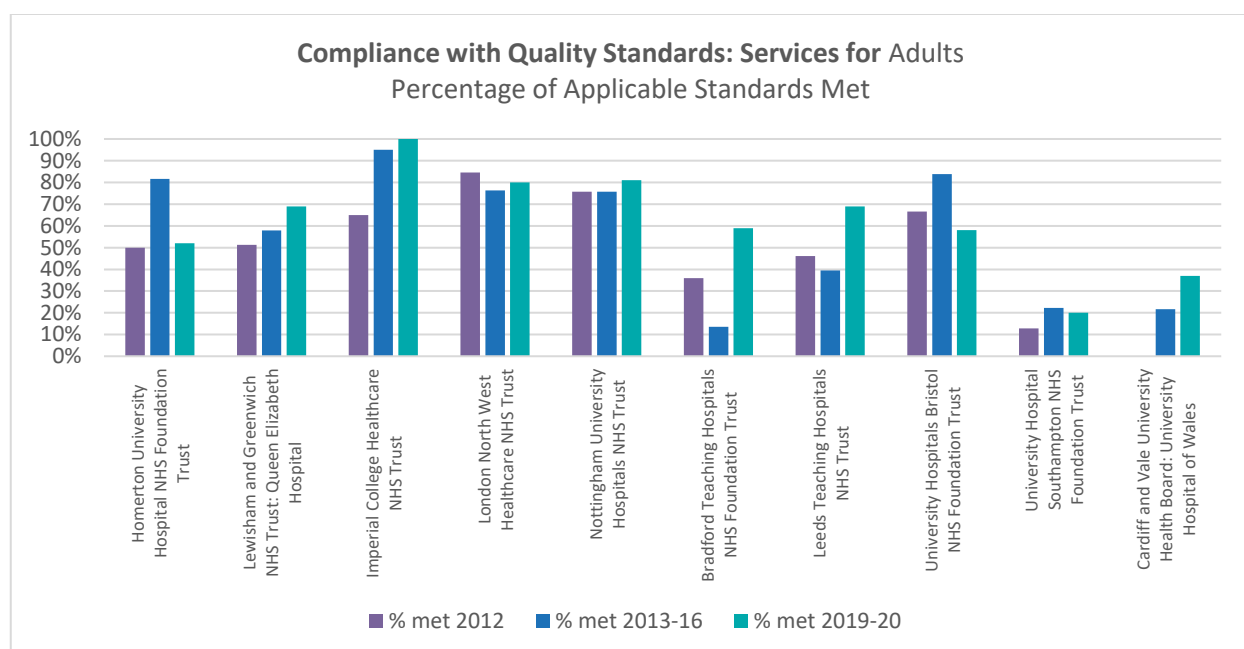
133. Comparisons of percentage compliance with Quality Standards should be interpreted with caution. The wording of the standards has changed over time. Reviewing teams are trained to be consistent, but the clinical environment within which the teams are working changes over time, which has an impact on their judgement of whether or not arrangements are satisfactory. Visit reports include comments on 'working towards' particular Quality Standards, but these are not reflected in the percentages of standards met. Reviewers often comment that it is better to have a 'No, but', where there is real commitment to achieving a particular standard, than a 'Yes, but' where a 'box has been ticked' but the commitment to implementation is lacking.
134. This second round of review visits with a very similar set of Quality Standards has provided the opportunity to compare performance against these standards. Tables 43 and 44 demonstrate the improvement in compliance with Quality Standards in some of the recent reviews. Although the standards have changed, these graphs show compliance against the standards expected at the time of the visit. Review visits that occur later in a review programme tend to have a higher percentage of standards met, although for this programme this did not appear to be the case, possibly because of the selection criteria used for undertaking a peer review visit.

Table 43: Compliance with Quality Standards: Services for Children and Young People



Note: At the time of the 2011 review programme for CYP, there were no functioning specialist centres identified by the South Central Strategic Health Authorities. A large paediatric thalassaemia service in Bradford, previously linked with Leeds, was operating autonomously at this time, but a review of this service was not included in the 2011 programme of visits. Haemoglobinopathy services provided in Wales were not included in this programme.

Table 44: Compliance with Quality Standards: Adult Services



Note: Haemoglobinopathy services provided in Wales were not included in the 2012 programme of visits.

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Evaluation

Summary

Evaluations of the peer review programme give evidence of its impact, including the impact of the validation process and changes made before, during and after the review visits.

The validation process was considered to be a sensible approach, although there were some issues with the quality of evidence submitted and the interpretation of the evidence by the validation panel.

It is difficult to make comparisons with the overall evaluations from the three previous programmes, as not all services were reviewed. However, the peer review process overall continues to be a useful mechanism for helping services improve. The reviewers benefit from participating in the programme.

135. This was the first peer review programme to combine a peer-led electronic validation of self-assessments submitted by 64 haemoglobin disorder services in England, Wales and Eire, and then a subsequent peer review visits to a subset of 25 services for adults, children and young people in England and Wales.

136. [Appendix 5](#) summarises all the evaluations undertaken during the course of the 2019/20 peer review programme:

Types of evaluation

a. Validation Process

- i. Trust views – Not chosen for review
- ii. Trust views – Reviewed

b. Training

- i. Online training – Evaluation completed by reviewers after attending review visit

c. Review Process

- i. Trust views – Email evaluation from the Trust lead contact shortly after the review visit
- ii. Reviewers' views – Evaluation forms completed on the day of the review visit

d. Product

- i. Online evaluation forms completed by Trust lead contacts following the end of the programme

137. The response rate to the validation process for services who were not selected to have a peer review visit was very low, with only six responses (18%) received from the 34 services contacted. Apart from the responses about the evidence submitted, it was not really possible to derive any other conclusions from this low number of responses.

138. The response rate from the services who subsequently had a review visit to the survey about the validation process was 44% (11 out of the 25 teams (from 17 Trusts)). The majority of the respondents considered that the validation process was a sensible approach (90%).

139. All teams who took part in this programme (validation process and peer review visit) were asked whether the validation panel had reached a fair conclusion based on the evidence that the teams submitted. All six responding teams who did not subsequently have a peer review visit considered that the validation panel had reached a fair conclusion. As regards the responses from those teams who subsequently had a peer review visit, 73% considered that the panel had reached a 'fair' (55%) or 'very fair' (18%) conclusion based on the evidence they submitted. Teams that had a peer review visit were also asked if they considered that the outcome of the validation process gave a 'fair' (36%) or 'very fair' (45%) reflection of their services the time of the validation assessment.

140. Some of the comments raised about the validation process highlighted issues with insufficient evidence or concerns that the panel had misinterpreted the evidence submitted, and some referred to the complexity of some QS.

141. Many reviewers were very satisfied with the preparation, organisation and conduct of the visits. Some reviewers found the day was time pressured, however, and struggled with timekeeping. As with previous review programme evaluations, reviewers felt that the standard of the evidence presented for review was good on the whole, with some Trusts demonstrating a very good awareness of the requirements and preparing appropriately. This made the document reviews on the day run very smoothly. Other Trusts did not present their documentation clearly and did not relate it to the standards, so the reviewers found it difficult to find the appropriate information in the limited time available.
142. All the multiple rounds of peer review programmes have asked for volunteers to become involved, although the feedback from this programme suggests that some members of Trust teams did not have the opportunity to become involved.
143. It is difficult to make comparisons with the overall evaluations from the three previous programmes, as not all services were reviewed. However, the reviewers still considered that the experience of reviewing another service was useful in developing their own service (88%) and that the peer review process overall was useful in improving services (73%). These figures were consistent with the feedback from the previous three programmes.

Recommendations

UKFHD should consult with the wider haemoglobin disorder community about how any future review programmes should be developed.

The Quality Standards for Health Services for People with Haemoglobin Disorders should be updated to reflect the latest configuration of services. The information available from the NHR and NHSE quality dashboards should be considered so that the revised QS reflect a more outcomes-based approach.

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Summary of recommendations and responsibilities

The table below summarises the recommendations made in this report, with suggested responsibilities for action.

Key:

SHT/ LHT	Specialist or Local Haemoglobinopathy Team
NHP	National Haemoglobinopathy Panel
HCC	Haemoglobinopathy Coordinating Centres
NHSE	NHS England
NHS Health Boards	NHS Scotland
	NHS Wales
CRG	Clinical Reference Group – Haemoglobinopathies – NHSE Commissioning
SCS	Sickle Cell Society
UKTS	United Kingdom Thalassaemia Society
All	NHSE, NHP, HCCs, Trusts, SHTs and LHTs, Commissioners, SCS, UKTS and local patient groups

Responsibility	Recommendation
Executive Summary	
All	In future, every effort should be made to ensure that patients, regardless of their area of residence in England and Wales, receive equitable care. This will be done by standardising clinical pathways and guidelines, arranging joint specialist clinics, engaging with regional multi-disciplinary meetings, facilitating access to specialist investigations, conducting patient experience surveys and carrying out statutory audits.
NHP and HCCs	The NHP and the HCC MDTs should facilitate standardisation of care via peer review of decisions and discussions around complex patients and morbidity and mortality.
All	The Black Lives Matter movement has highlighted many deep inequities within society via lived experiences of individuals. It is important that haemoglobinopathy services are aware that systemic changes are required to ensure that healthcare provision is anti-racist and responsive to the needs of this marginalised and vulnerable group of people.
Validation	
UKFHD	If the process of validation is repeated, then further training and information should be provided for participants on how to provide good quality evidence. A template should be made available for evidence submission.
UKFHD	The UKFHD should consider whether the validation panel should have access to evidence prior to any validation panel meeting, and should review the criteria for selection of services for a peer review visit.
Information for patients and carers	
SHTs and LHTs	Teams need to ensure that service and condition-specific information is available in different formats and that it is routinely given to patients, particularly those who have attended the service for some time, so that they are fully aware of any changes in the service and treatments available and are able to make informed decisions about their care.
HCCs, UKTS and local patient groups	Information about thalassaemia should be available and consistent, regardless of the number of patients cared for by the service. Development of information should be overseen via the thalassaemia HCCs in conjunction with the UKTS and other patient representatives.
HCCs, SHTs and LHTs	Transition processes require further work to ensure patient outcomes and experience of care are regularly measured.

Responsibility	Recommendation
SHTs and LHTs	Access to personal clinical information, in particular, was raised by patients as an issue. It is important that individual clinic letters are shared with patients, together with clear updates and concise instructions to patients and their GPs.
SCS, UKTS and local patient groups	A central repository of patient information should be developed, identifying good quality, reliable information that already exists and allowing that to be shared with all providers and patients to reduce the variation in information. National patient organisations with local patient groups should lead on this work and this information should be available on their websites. The National Haemoglobinopathy Panel and/or National Haemoglobinopathy Registry could be utilised to ensure this information is made widely available.
Staffing	
All	Medical staffing: Trusts designated as providing specialist haemoglobinopathy care must have adequate medical staffing to provide this care safely and to a high standard. For every 150 patients, 0.6 wte of a consultant haematologist time must be job planned to manage patients safely.
All	Organisations such as Health Education England, the medical royal colleges, the Nursing and Midwifery Council, and the medical and nursing schools should engage with haemoglobinopathy specialist consultants and nurses to address current shortfalls and to carry out robust specialist workforce planning for the future.
HCCs and UKFHD	With the HCC arrangement and systems around this, including the NHP, now in place, it is essential that nursing competences specific to haemoglobinopathy specialist nurse practice are developed and agreed across HCCs. Additionally, agreement on the essential roles of a clinical nurse specialist in haemoglobinopathy, for practice both in the community and in hospitals, should be instituted either for each HCC or across all the HCCs.
HCCs	Each HCC must ensure there is adequate provision and access to psychology support for service users.
Support services	
Trusts, SHTs and LHTs	Training for ED Staff: service user reports and audit results confirm that the patient experience in ED departments remains unsatisfactory, especially when compared to haematology day unit or assessment units. This is contributed to by a high staff turnover, so regular and consistent teaching and training of staff in the ED departments must be instituted to ameliorate these issues.
Trusts, SHTs and LHTs	Haemoglobinopathy services should continue to engage with their emergency teams and any other emergency receiving teams to establish local processes that improve pain management.
HCCs	Virtual training modules should be instituted for areas with a high staff turnover or infrequent haemoglobinopathy in-patients to reduce the time spent by specialist nurses giving tutorials, and these tutorials should be developed by HCCs for their networks.
UKFHD	Consideration should be given to amending the QS that requires patients to receive analgesia within 30 minutes of arrival at the ED so that it applies to patients arriving at any area that has been designated to receive emergencies.
Facilities	
Trusts, SHTs and LHTs	Wherever possible, patients should have access to designated wards with staff who have appropriate training to care for patients with haemoglobin disorders.

Responsibility	Recommendation
SHTs and LHTs with their local patient groups	Teams should work with their service users to understand their views about being cared for in other specialist areas.
Guidelines	
HCCs	The HCCs should aim to have standard guidelines across the UK that can be easily adapted by services for the local context.
Trusts, SHTs and LHTs	Guidelines should be reviewed and ratified according to standard Trust procedures and with appropriate version control to ensure that version control is maintained.
UKFHD	For the next version of the Quality Standards, the UK Forum should undertake a review of standards with regard to the appropriate information, particularly on complications, that is relevant to paediatric populations.
Organisation	
HCCs, Trusts, SHTs and LHTs	Many out-patient appointments, including annual reviews, have been converted to virtual appointments (telephone or video) during the pandemic. Anecdotally, this has resulted in fewer clinic non-attendances. Other innovative interventions, such as satellite phlebotomy clinics and the home delivery of goods and services, have also been beneficial to patients. It will be important for haemoglobin disorder teams to assess their own working patterns during the pandemic and to continue with pathways that provide high quality care while requiring less time and effort from users and providers alike.
CRG, NHSE, NHS Health Boards	A programme of external quality assurance for trans-cranial Doppler services should be established. This could utilize the new HCC structure.
Governance	
Trusts	Audit can only occur when appropriate data support is provided. Trusts need to address this non-concordance and provide data manager support so that this information can be collected and quality improvement plans developed leading to improved patient care and experience.
HCCs, SHTs and LHTs	Service audit programmes should be supported by the HCCs and SHTs via an annual programme of work, and annual reports should be produced to show improvements and developments in the service.
Commissioning	
NHSE specialist and local commissioners	The new commissioning structure for haemoglobinopathy in England is likely to allow for more clinical networking, shared learning, equitable access to specialised services, unified protocols and collaborative research. It is therefore important to ensure that innovative commissioning and insightful self-assessment continue to remain a top priority for such services.
Evaluation	
UKFHD	UKFHD should consult with the wider haemoglobin disorder community about how any future review programmes should be developed.
UKFHD	The Quality Standards for Health Services for People with Haemoglobin Disorders should be updated to reflect the latest configuration of services. The information available from the NHR and NHSE quality dashboards should be considered so that the revised QS reflect a more outcomes-based approach.

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Appendix 1: Summary of Compliance with Quality Standards (QS)

Grey-shaded Quality Standards denote the 17 key QS that were used as part of the validation process and the evidence requested. For the peer review visits, all QS were reviewed

**For the validation process, if the evidence was not clear or was ambiguous then the QS could be partially met. Only those QS that were fully met have been counted in the table below.

QS Ref. No	QS Short Title	Evidence requested for validation	Validation assessment % compliance (17 Key QS)**		Peer review visits % compliance (All QS)	
			Adult service (N=32)	CYP service (N=32)	Adult service (N=10)	CYP service (N=15)
HN-101	Haemoglobin Disorder Service Information		N/A	N/A	70	73
HN-102	Information about Haemoglobin Disorders		N/A	N/A	40	47
HN-103	Care Plan	Example of a care plan (anonymised) or templates.	94	76	70	73
HN-104	Information for Primary Health Care Team	Anonymised example of information sent to Primary Care team.	83	74	70	47
HN-105	Information about Trans-cranial Doppler Ultrasound (Children's Services Only)		N/A	N/A	N/A	85
HN-106	School Care Plan (Children's Services Only)		N/A	N/A	N/A	87
HN-194	Environment		N/A	N/A	100	100
HN-195	Transition to Adult Services		N/A	N/A	50	69
HN-199	Involving Patients and Carers	Examples of methods of receiving feedback. Examples of changes made as a result of feedback.	57	60	70	73
HN-201	Lead Consultant		N/A	N/A	70	40
HN-202	Lead Nurse		N/A	N/A	60	53

QS Ref. No	QS Short Title	Evidence requested for validation	Validation assessment % compliance (17 Key QS)**		Peer review visits % compliance (All QS)	
			Adult service (N=32)	CYP service (N=32)	Adult service (N=10)	CYP service (N=15)
HN-203	Medical Staffing and Competences	Evidence to show that staffing levels should be appropriate for the number of patients cared for by the service as defined in the QS.	53	43	20	40
HN-204	Nurse Staffing and Competences	Evidence to show that staffing levels should be appropriate for the number of patients cared for by the service as defined in the QS. Competence framework describing the competences expected for roles within the service.	50	32	40	33
HN-205	Psychology Staffing and Competences		N/A	N/A	10	7
HN-206	Training Plan		N/A	N/A	50	20
HN-207	Trans-cranial Doppler Ultrasound Competences (Children's Services Only)	Written confirmation of numbers of TCD undertaken per practitioner. Logbooks for individual practitioners will be reviewed during any peer review visit.	N/A	58	N/A	92
HN-299	Administrative, Clerical and Data Collection Support		N/A	N/A	50	60
HN-301	Support Services		N/A	N/A	70	73
HN-302	Emergency Department – Staff Competences	Documentation of training undertaken and discussion of audits of compliance with NICE Clinical Guideline on the management of acute pain could be used to demonstrate compliance with this QS.	60	33	50	47
HN-303	Specialist On-site Support	Access arrangements to be included in self-assessment.	88	86	89	100
HN-304	Specialist Services – Network	Provide detailed explanation in self-assessment.	77	70	56	80
HN-305	Laboratory Services		N/A	N/A	90	93
HN-401	Facilities and Equipment		N/A	N/A	100	100

QS Ref. No	QS Short Title	Evidence requested for validation	Validation assessment % compliance (17 Key QS)**		Peer review visits % compliance (All QS)	
			Adult service (N=32)	CYP service (N=32)	Adult service (N=10)	CYP service (N=15)
HN-501	Transition Guidelines		N/A	N/A	80	87
HN-502	Monitoring Protocols	Anonymised examples of monitoring to show protocols implemented.	81	92	70	87
HN-503	Clinical Guidelines: LHT Management and Referral		N/A	N/A	50	71
HN-504	Transfusion Guidelines		N/A	N/A	80	80
HN-505	Chelation Therapy		N/A	N/A	60	80
HN-506	Clinical Guidelines: Acute Complications	Clinical Guidelines.	80	75	60	73
HN-507	Specialist Management Guidelines		N/A	N/A	60	87
HN-508	Clinical Guidelines: Chronic Complications	Clinical Guidelines.	72	62	50	73
HN-509	Referral for Consideration of Bone Marrow Transplantation (Children's Services Only)		N/A	N/A	N/A	100%
HN-510	Non-Transfusion Dependent Thalassaemia (nTDT)		N/A	N/A	70	73
HN-599	Clinical Guideline Availability		N/A	N/A	90%	87
HN-601	Service Organisation	Service organisational policy.	55	42	60	53
HN-602	Multi-disciplinary Team Meetings	Anonymised examples of monitoring to show protocols implemented.	78	63	60	87
HN-603	Delegation of Annual Reviews		N/A	N/A	0 or N/A	57
HN-604	Out of Hours Elective Care		N/A	N/A	56	60
HN-605	Service Level Agreement with Community Services		N/A	N/A	25	22
HN-606	Trans-cranial Doppler Ultrasound Standard Operating Procedure (Children's Services Only)		N/A	N/A	N/A	60
HN-607	Network Review and Learning Meetings		N/A	N/A	78	93

QS Ref. No	QS Short Title	Evidence requested for validation	Validation assessment % compliance (17 Key QS)**		Peer review visits % compliance (All QS)	
			Adult service (N=32)	CYP service (N=32)	Adult service (N=10)	CYP service (N=15)
HN-608	Neonatal Screening Programme Review Meetings		N/A	N/A	N/A	82
HN-701	National Haemoglobinopathy Registry		N/A	N/A	70	64
HN-702	Activity Data	Examples of data showing compliance with QS.	73	63	70	60
HN-703	Quality Dashboard	Examples of data showing compliance with QS.	80	73	75	80
HN-704	Other Quality Data		N/A	N/A	N/A	100
HN-705	Other Audits		N/A	N/A	30	27
HN-706	Network Audits		N/A	N/A	56	71
HN-707	Research		N/A	N/A	67	90
HN-708	Trans-cranial Doppler Quality Assurance (Children's Services Only)		N/A	N/A	N/A	60
HN-798	Multi-disciplinary Review and Learning	Documentation depends on local arrangements, for example, minutes of review and learning meetings held within the service.	87	69	70	67
HN-799	Document Control		N/A	N/A	90	87

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Appendix 2: Services Reviewed

Key:

SHT: Specialist Haemoglobinopathy Team
 LHT: Local Haemoglobinopathy Team
 Days: The number of days over which the review took place
 Review Team Days: The number of review teams involved in each visit. For example, a one day visit with an adult and paediatric team would count as two 'review team days'

Trust: Hospital (where applicable)	Validation of self-assessment		Peer Review Visit					Organisation Abbreviation
	Adult service	CYP service	Review Date	Days	Review Team Days	Adult service	CYP service	
Alder Hey Children's NHS Foundation Trust	-	SHT	21.06.19	1.0	1.0	-	SHT	Alder Hey
Barking, Havering and Redbridge University Hospitals NHS Trust	LHT	LHT	26.09.19	1.0	1.0	-	LHT**	BHR
Barts Health NHS Trust: The Royal London Hospital	SHT	SHT	06.11.19	1.0	1.0	-	SHT	RLH
Barts Health NHS Trust: Newham University Hospital	LHT	LHT	07.11.19	0.5	1.0	-	LHT	NUH
Barts Health NHS Trust: Whipps Cross University Hospital	LHT	LHT	07.11.19	0.5	1.0	-	LHT	Whipps X
Birmingham Women's and Children's NHS Foundation Trust	-	SHT	19.12.19	1.0	1.0	-	SHT	BWCH
Bradford Teaching Hospitals NHS Foundation Trust	SHT	SHT	05.03.20	1.0	2.0	LHT	LHT	Bradford
Croydon Health Services NHS Trust	LHT	LHT	-	-	--	-	-	Croydon
Guy's and St Thomas' NHS Foundation Trust	SHT	SHT	23.04.20	-	-	-	C	GSTT
Homerton University Hospital NHS Foundation Trust	SHT	-	20.11.19	1.0	1.0	SHT		HUH
Imperial College Healthcare NHS Trust	SHT	SHT	27.09.19	-	-	SHT	-	IHC
King's College Hospital NHS Foundation Trust	SHT	SHT	-	-	-	-	-	KCH
Leeds Teaching Hospitals NHS Trust	SHT	SHT	09.07.20	1.0	2.0	SHT	SHT	Leeds

Trust: Hospital (where applicable)	Validation of self-assessment		Peer Review Visit					Organisation Abbreviation
	Adult service	CYP service	Review Date	Days	Review Team Days	Adult service	CYP service	
Lewisham and Greenwich NHS Trust: University Hospital Lewisham	LHT*	LHT*	-	-	-	-	-	LGT
Lewisham and Greenwich NHS Trust: Queen Elizabeth Hospital, Greenwich	LHT*	LHT*	09.10.19		2.0	SHT	LHT**	QEH
Liverpool University Hospitals NHS Foundation Trust – previously The Royal Liverpool and Broadgreen University Hospitals NHS Trust and Aintree University Hospitals NHS Foundation Trust	SHT	-	-	-	-	-	-	LUHT
London North West University Healthcare NHS Trust	SHT	SHT	22.01.20	1.0	2.0	SHT	SHT	LNWUH
Manchester University NHS Foundation Trust	SHT	SHT	26.03.20	-	-	-	C	MUH
North Middlesex University Hospital NHS Trust	SHT	SHT	-	-	-	-	-	NMH
Nottingham University Hospitals NHS Trust	SHT	SHT	05.02.20	1.0	1.0	SHT	-	NUHT
Oxford University Hospitals NHS Foundation Trust	SHT	SHT	04.02.20	1.0	1.0	-	SHT	OUH
Sandwell and West Birmingham Hospitals NHS Trust	SHT	-	-	-	-	-	-	SWBH
Sheffield Children’s NHS Foundation Trust	-	SHT	16.10.19	1.0	1.0	-	SHT	Sheffield CH
Sheffield Teaching Hospitals NHS Foundation Trust	SHT	-	-	-	-	-	-	Sheffield TH
South Tees Hospitals NHS Foundation Trust	SHT	SHT	-	-	-	-	-	South Tees
St George’s University Hospitals NHS Foundation Trust	SHT	SHT	28.04.20	-	-	c	-	St Georges
The Newcastle upon Tyne Hospitals NHS Foundation Trust	SHT	SHT	-	-	-	-	-	Newcastle
The Royal Wolverhampton NHS Trust	LHT	LHT	-	-	-	-	-	RWH
University College London Hospitals NHS Foundation Trust	SHT	SHT	-	-	-	-	-	UCLH
University Hospital Southampton NHS Foundation Trust	SHT	SHT	28.06.20	1.0	2.0	SHT	SHT	UHS
University Hospitals Bristol NHS Foundation Trust	LHT*	LHT*	13.11.19	1.0	1.0	SHT	-	UHBT
University Hospitals Coventry and Warwickshire NHS Trust	LHT	LHT	-	-	-	-	-	UHCW
University Hospitals of Leicester NHS Trust	SHT	SHT	-	-	-	-	-	UHL

Trust: Hospital (where applicable)	Validation of self-assessment		Peer Review Visit					Organisation Abbreviation
	Adult service	CYP service	Review Date	Days	Review Team Days	Adult service	CYP service	
Whittington Health NHS Trust	SHT	SHT	04.07.19	1.0	1.0	-	SHT	WHC
Cardiff and Vale University Health Board: University Hospital of Wales	SHT	SHT	01.10.19	1.0	2.0	SHT	SHT	Cardiff
Our Lady's Children's Hospital, Crumlin	-	SHT	-	-	-	-	-	Dublin
NHS Greater Glasgow and Clyde: Glasgow Royal Infirmary and Royal Hospital for Children	Invited but did not submit – SHT at Edinburgh was not invited as not included on initial list but would take part in future programmes			-	-	-	-	Glasgow

*Services self-assessed at the time of the validation exercise as an LHT, while awaiting formal designation as an SHT

**Services reviewed as an LHT at the organisation's request because they were in the process of transitioning to an SHT

^c Visit to service cancelled because of Covid-19 pandemic

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Appendix 3: UKFHD Peer Review Steering Group Membership

Name	Position	Organisation
Dr Subarna Chakravorty (Chair)	Consultant Paediatric Haematologist	King's College Hospital NHS Foundation Trust
Helen De Marco	Consultant Clinical & Health Psychologist in Haematology	University College London Hospitals NHS Foundation Trust
Dr Emma Drasar	Consultant Haematologist	Whittington Health NHS Trust
Sandy Hayes	Adult Haemoglobinopathy Senior Specialist Nurse and Thames Valley Network Lead Nurse	Oxford University Hospitals NHS Foundation Trust
Prof Jo Howard	Consultant Haematologist / Honorary Professor in Haemoglobinopathies	Guy's and St Thomas' NHS Foundation Trust
John James	Chief Executive	Sickle Cell Society
Dr Banu Kaya	Consultant Haematologist	Barts Health NHS Trust
Dr Rachel Kesse-Adu	Consultant Haematology and Sickle Cell Disease	Guy's and St Thomas' NHS Foundation Trust
Roanna Maharaj	Public Health & Patient Advocacy Lead	UK Thalassaemia Society
Heather Rawle	Consultant Clinical and Health Psychologist	Guy's and St Thomas' NHS Foundation Trust
Maureen Scarlett	Community Nurse Specialist Haemoglobinopathies	Cambridgeshire Community Services NHS Trust
Louise Smith	Sickle Cell CNS	Alder Hey Children's NHS Foundation Trust
Dr Mark Velangi	Consultant Paediatric Haematologist	Birmingham Women's and Children's NHS Foundation Trust
Dr Josh Wright	Consultant Haematologist	Sheffield Teaching Hospitals NHS Foundation Trust
Sarah Broomhead	Assistant Director	Quality Review Service

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Appendix 4: UKFHD Peer Review Validation Panel Members

Name	Position	Organisation
Dr Subarna Chakravorty	Consultant Paediatric Haematologist	King's College Hospital NHS Foundation Trust
Helen De Marco	Consultant Clinical & Health Psychologist in Haematology	University College London Hospitals NHS Foundation Trust
Dr Emma Drasar	Consultant Haematologist	Whittington Health NHS Trust
Sandy Hayes	Adult Haemoglobinopathy Senior Specialist Nurse and Thames Valley Network Lead Nurse	Oxford University Hospitals NHS Foundation Trust
John James	Chief Executive	Sickle Cell Society
Dr Banu Kaya	Consultant Haematologist	Barts Health NHS Trust
Dr Rachel Kesse-Adu	Consultant Haematology and Sickle Cell Disease	Guy's and St Thomas' NHS Foundation Trust
Roanna Maharaj	Public Health & Patient Advocacy Lead	UK Thalassaemia Society
Heather Rawle	Consultant Clinical and Health Psychologist	Guy's and St Thomas' NHS Foundation Trust
Dr Kate Ryan	Consultant Haematologist	Manchester University NHS Foundation Trust
Maureen Scarlett	Community Nurse Specialist Haemoglobinopathies	Cambridgeshire Community Services NHS Trust
Louise Smith	Sickle Cell CNS	Alder Hey Children's NHS Foundation Trust
Dr Mark Velangi	Consultant Paediatric Haematologist	Birmingham Women's and Children's NHS Foundation Trust
Tim Cooper	Director	Quality Review Service
Sarah Broomhead	Assistant Director	Quality Review Service

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Appendix 5: Evaluation Summary

In the following tables the number of comments on any issue is given in brackets alongside the comment made. There was only one such comment unless otherwise stated.

Response rate

Response	Number	% Response	Notes
Validation Process			
• Trusts – not reviewed	34 services	18	Issues with online evaluation. Data not reliable and therefore not included.
• Trusts – reviewed	25 visits	44	
Review Process			
• Reviewers	113	82	
• Trusts	25 visits	48	
Product	25 visits	44	

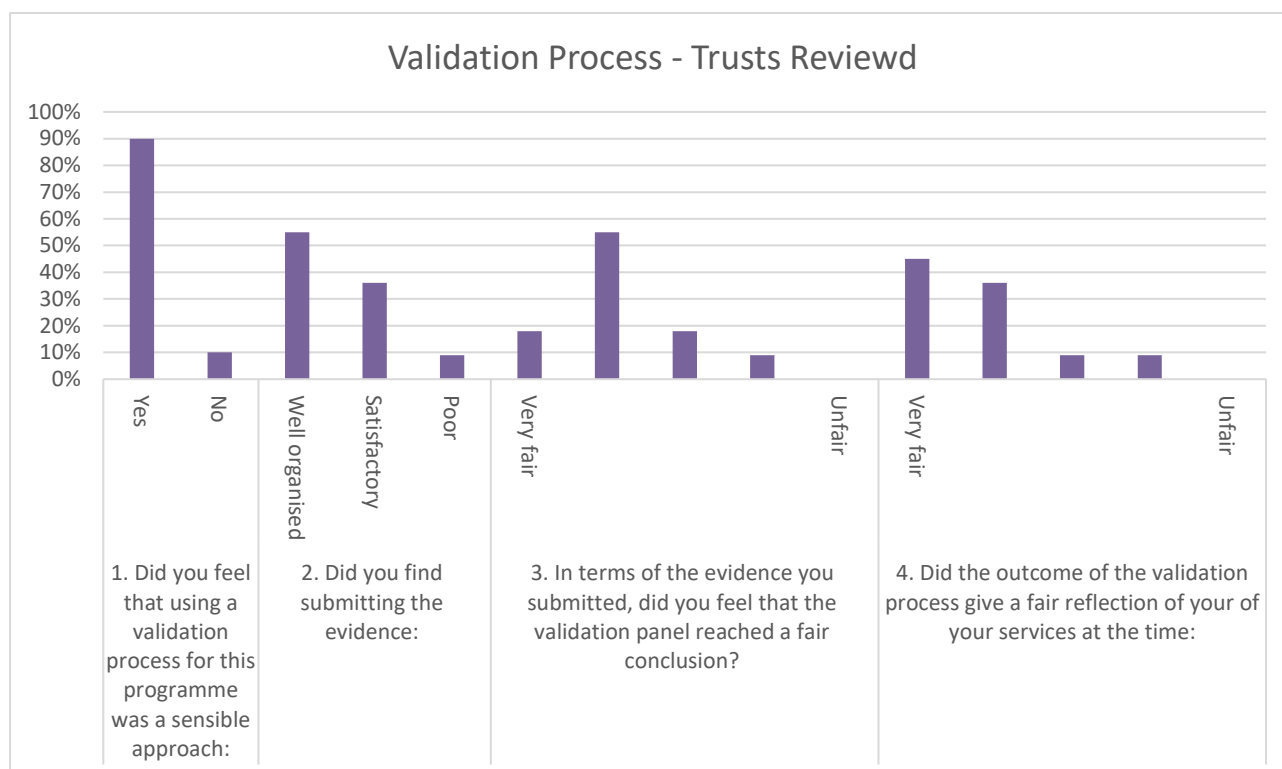
Validation Process

1. Trusts not chosen for review: Comments received

Trust comments	
Comments or suggestions you feel would help improve the process:	<ul style="list-style-type: none"> • Earlier advice on how to handle file size for transmission and surprise that Trust assessed as 2 separate services (1 per site) when data submitted for whole Trust. Probably helpful in the end however. • Difficulty in submitting evidence and no response about disagreement of one of the QS.

2. Trusts reviewed:

N = 11 (Response rate: 44%; 11 responses relating to 25 visits; responses from 10 Trusts out of 17 Trusts contacted)

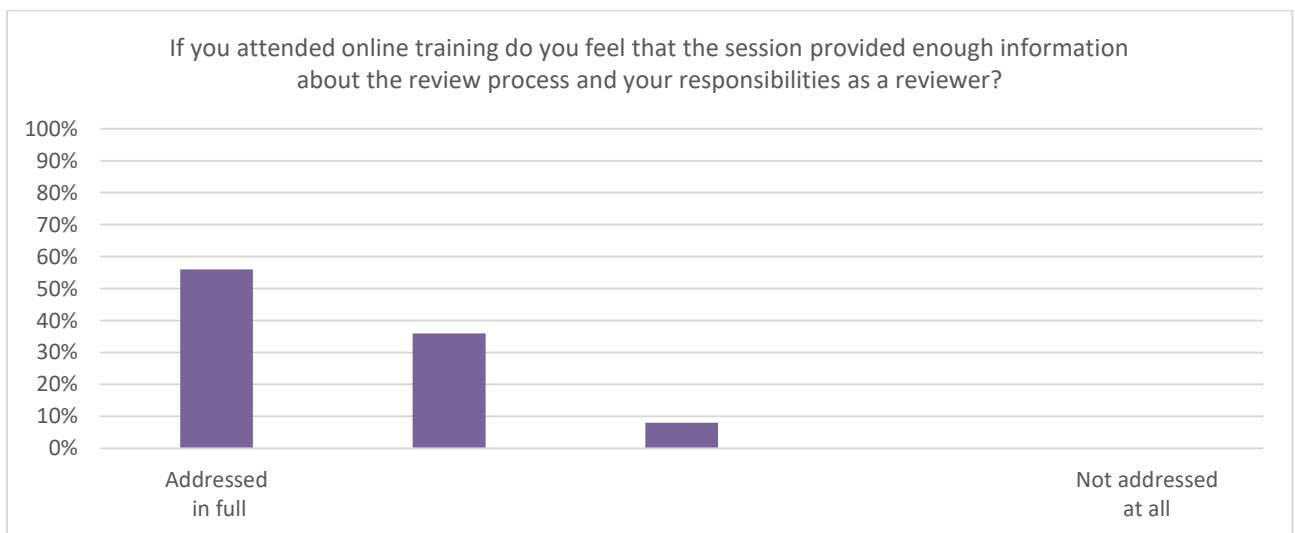


	Trust comments
1. Did you feel that using a validation process for this programme was a sensible approach	<ul style="list-style-type: none"> No, it is a huge amount of work and there should be other ways of showing a service is meeting standards (dashboard/ MDT data)
3. In terms of the evidence you submitted, did you feel that the validation panel reached a fair conclusion?	<ul style="list-style-type: none"> Did not mark us consistently against the standard. It was fair for paediatrics but some of the comments directed towards the adult service were not reflective, possibly due to misunderstanding/misinterpretation of some of the information. Where we got marked down it was mainly our own fault for not being clear on evidence. I was taken aback, even thinking there was error with the paperwork, when our split site Trust was evaluated as 2 different services, although could subsequently see the rationale behind it. Many of the Key Performance Indicators are composite and so one can have met most criteria, but still fail the standard. It might be better to have separate point for each. Also, the upload process was difficult and time-consuming, requiring multiple zip files to be uploaded individually. Had I been able to review another service prior to our review, I feel that I would have submitted more evidence. Having reviewed another centre now, that team did really well, partly because they were doing some really good things, but also because they had the advantage of reviewing many other services prior to their review.

	<ul style="list-style-type: none"> • Internal intelligence was sometimes used to determine specific visits. This was particularly felt to be the case in the London hospitals. • We appreciate the feedback since this helps us in pushing forward our case for bringing about service improvements.
4. Did the outcome of the validation process give a fair reflection of your of your services at the time	<ul style="list-style-type: none"> • It was fair for paediatrics but some of the comments directed towards the adult service were not reflective, possibly due to misunderstanding/misinterpretation of some of the information. • The visit was much better than the paper assessment done in advance.
5. Comments or suggestions you feel would help improve the process	<ul style="list-style-type: none"> • Be consistent in the approach. • Perhaps a discussion with the team before an unexpected evaluation goes out. • Separate rather than composite standards allowing easier identification of short-comings and a fairer reflection of what has already been achieved. • I found the QRS team really helpful and supportive, but I do think it would be beneficial to take part in reviewing a service prior to your service being reviewed. • I feel centres would benefit from examples of near perfect reports of other centres in guiding them about how to improve their own evidence base.

Training

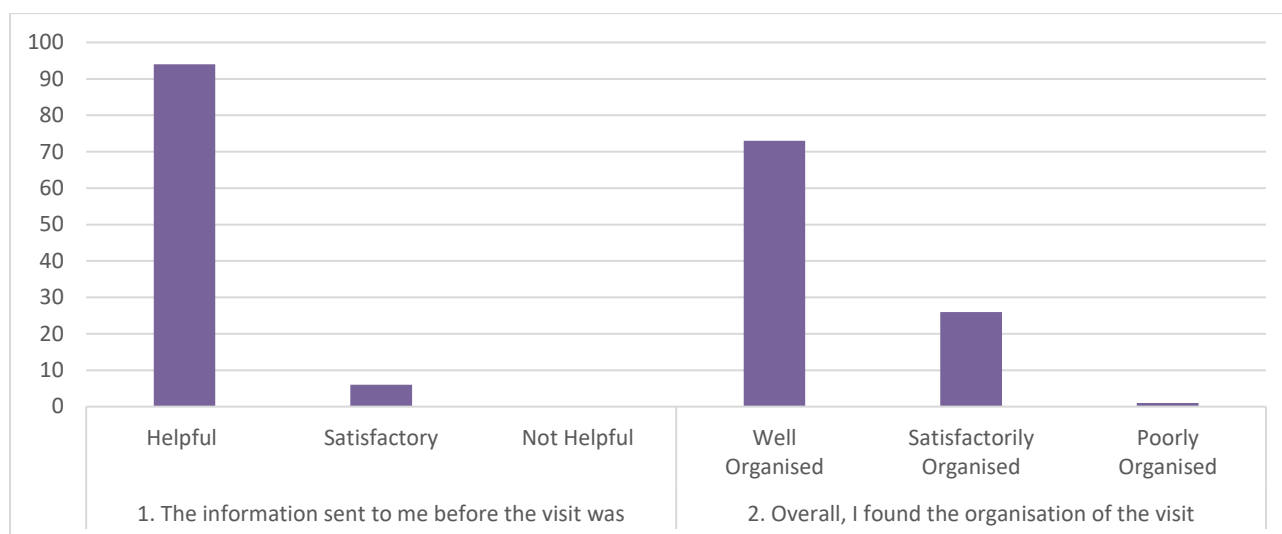
N = 25



Review Process

3. Reviewers

Evaluations issued to 113 reviewers. 93 responses. Response rate 82%.



“The team was cohesive and shared an agenda to improve service and give constructive feedback.”

“Very interesting review – as always very helpful lessons learnt and good networking opportunities.”

“The entire day was well organised, the visiting team and Trust worked well together.”

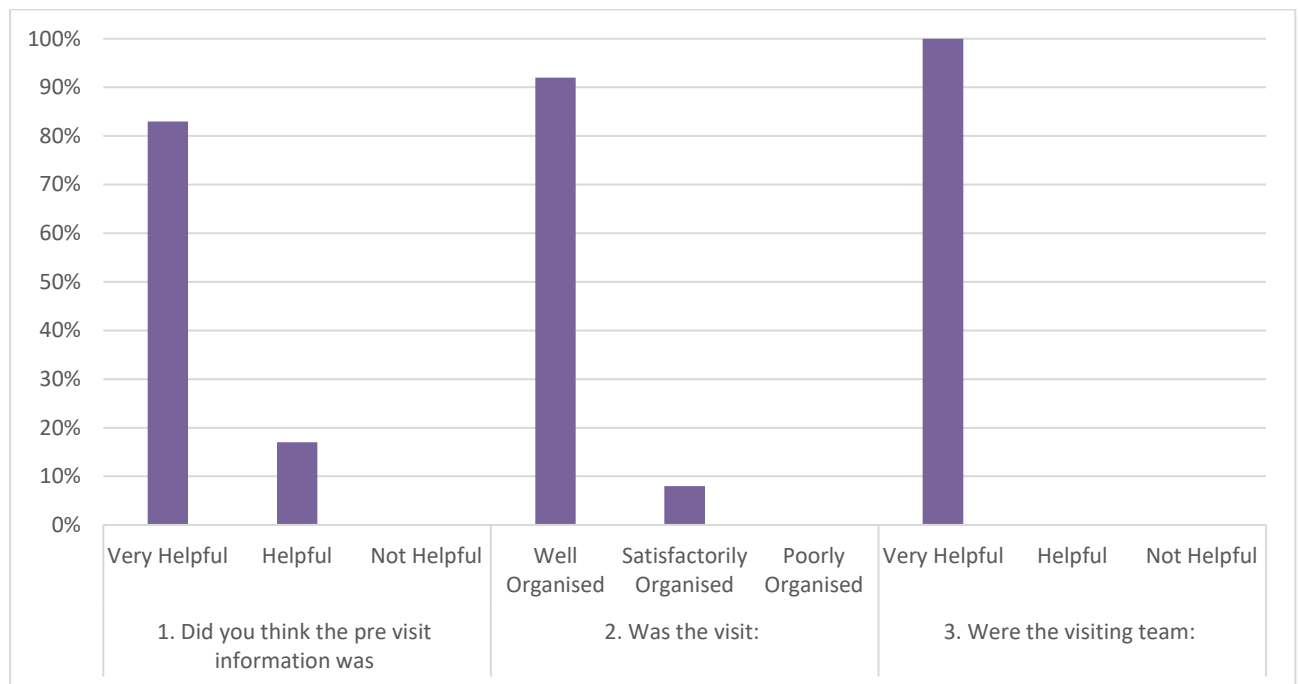
Reviewer comments on Review process

Reviewer comments	
What went well?	<ul style="list-style-type: none"> Good pre-visit information and travel/accommodation provided (12) Good overall leadership and coordination of the reviewing team (6) Timing – kept to programme (7) Flow of the day (3) Good breakdown of the day with clear instructions and guidance (3) Team very welcoming, informative (33) Evidence - Well organised (5) Organised & professional (18) Walkabout of facilities (8) Teamwork of review team (24) Networking opportunities (2) Very interesting to learn from another centre and meet others working in the area (1) Meeting patients and carers (15) Good, positive process (3) Fantastic opportunity (1)

What didn't go so well?	Arrival arrangements (5) Time available (3) Time management (2) Information provided by site (14) Site including signage, traffic and parking (4) Base room (4) Visiting review team (4) Meeting more patients (7) Organisation of service (7) Catering (1)
Comments and suggestions?	Visit timings (1) Guidelines/recommendations provided for review centres on how to provide evidence (1) Meeting more patients (1) Having done it once has prepared me how to do it better next time (1) Interesting / helpful lessons learnt (1) Good networking opportunities (2) Good accommodation/transport arrangements (1) Well organised/ planned (6) Good visit / Enjoyable / rewarding process (6) Venue / catering (1) Interpretation, understanding and repetitiveness of some Standards (2)

4. Trusts

N = 12 (Evaluations issued to 17 Trusts relating to 25 visits. 12 responses received (relating to 10 visits). Response rate 48%).



“Whilst having your service reviewed is a stressful process the team made this much more enjoyable and relaxed than anticipated.”

“I was particularly grateful to the Team for reinforcing the size and importance of the service to the Trust.”

“The team were very pleasant, open and understanding to hearing how the service is delivered at our hospital.”

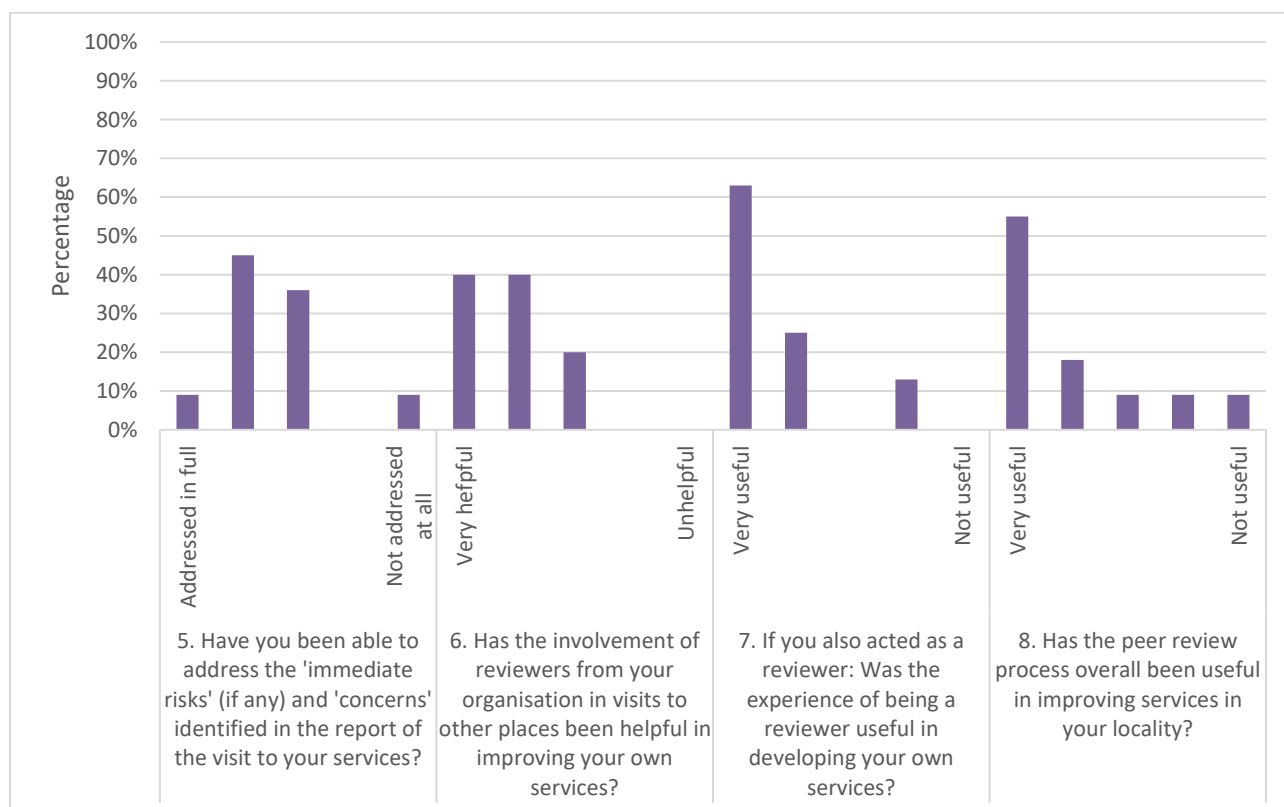
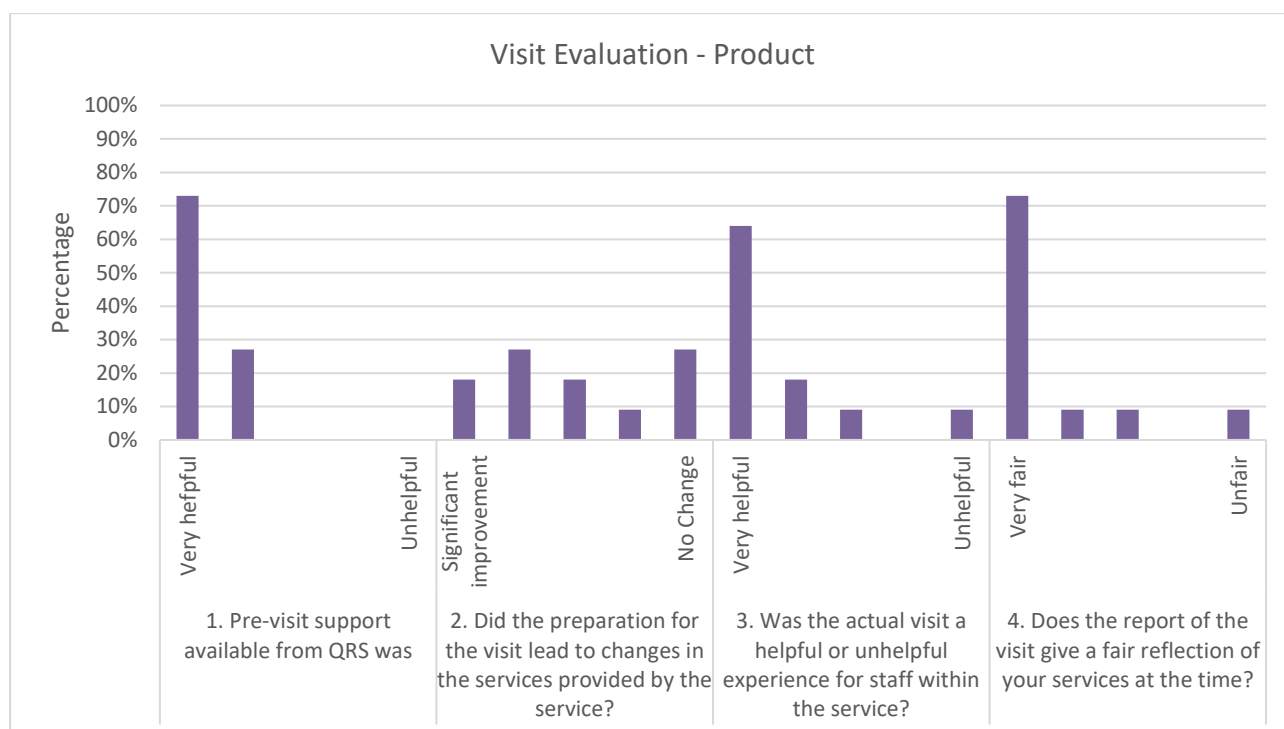
Trust comments on Review process

Trust comments	
What went well?	Organisation (QRS) – (5) Timetable and logistics (time keeping) – (8) Feedback – (5) Review Team (Supportive, open) – (9)
What didn't go so well?	Engaging Senior management Teams – (1) Meeting point for Reviewers – (3) Venue and refreshments – (2) Time restraints – (3)
Comments and suggestions?	<ul style="list-style-type: none"> Phone call the day before as a last minute check on arrangements Example Self-Assessment and Evidence Allow more time for tour of facilities <p>“I think it is a very well informed process and there is plenty of communication leading up to the review day. The reviewing team make it as easy a process as possible and are extremely professional.”</p>

Product Evaluation

N = 11

Response Rate: 44% (11 responses relating to 25 visits; Responses from 10 Trusts. 17 Trusts contacted).



“Excellent, must continue in order to drive progress in what is unfortunately not yet a high priority service.”

“Well run and brings the whole service together nationally.”

“Good to get some benchmarking and very good to be part of network.”

Trust comments on Review process

Comments	
1. The pre-visit support available from QRS	<ul style="list-style-type: none"> • .. was so helpful to me, especially as this was my first time being peer reviewed as a new Consultant for my service. She also allowed me to do peer reviewer training myself and participate in a visit which helped my own preparations. • Excellent opportunity to ask questions/seek clarification. • We were able to update some of our SOPs ahead of the meeting and to organise our SOPs better. • The QRS team were very approachable and helpful. • Team requested the info well in advance and kept in touch. Good organisation. • Pre-visit support gave us a clear picture of what to expect on the day of the visit.
2. Did the preparation for the visit lead to changes in the services provided by the service?	<ul style="list-style-type: none"> • Peer Reviews are always an incentive to tidy up things, which invariably leads to improvements. • Too soon. • Two new paediatric consultants have been recruited, but by the time they had settled in, Covid 19 has come in to play and put changes on hold. • Large injection of funding to address the shortfalls in staffing. • I wish I had more support from the management.
3. Was the actual visit a helpful or unhelpful experience for staff within the service?	<ul style="list-style-type: none"> • Excellent, very supportive. • Excellent visit. • It remains very difficult in a low prevalence area to free up Consultant time to be dedicated to Haemoglobinopathy. • Very positive experience for the team here. • Didn't tell us things we didn't know but hopefully may help to get services we don't have! • Everyone from the Trust present at the review valued the feedback given.
4. Does the report of the visit give a fair reflection of your services at the time?	<ul style="list-style-type: none"> • Again, supportive and developmental, gives a strong basis for additional commissioning support. • It was fair for paediatrics but some of the comments directed towards the adult service were not reflective, possibly due to misunderstanding/misinterpretation of some of the information.
5. Have you been able to address the 'immediate risks' (if any) and	<ul style="list-style-type: none"> • Yes – the fact that the report goes to Chief Executive etc makes it high profile and triggers action via governance structures.

<p>'concerns' identified in the report of the visit to your services?</p>	<ul style="list-style-type: none"> • No immediate risks, still working on concerns. Intervening COVID pandemic has not helped with commissioning aspect. • Too soon. • No immediate concerns were identified. • This is still in progress, but has been delayed with Covid 19. • Funding available but staffing not yet complete. • Medical staffing – still under review. TCD – proposed changes currently work in progress with radiology. • Work in progress but unfortunately not at a speed I'm happy with.
<p>6. Has the involvement of reviewers from your organisation in visits to other places been helpful in improving your own services?</p>	<ul style="list-style-type: none"> • Always great to see how things are done elsewhere. • I have gained some ideas, particularly around school visits, that I can use. Unfortunately, I am unable to do this at the moment. • So useful to see how other teams operate and literature that they are using. • Good to see standards elsewhere. • I've been a reviewer myself once and picked up useful hints – so should be able to incorporate examples of good practice into my own service.
<p>7. If you also acted as a reviewer: Was the experience of being a reviewer useful in developing your own services?</p>	<ul style="list-style-type: none"> • The process uses the same quality standards for areas of high prevalence as low prevalence areas, where it is more difficult to find specialists with expertise in haemoglobinopathy. • Excellent opportunity to support colleagues in different units.
<p>8. Has the peer review process overall been useful in improving services in your service?</p>	<ul style="list-style-type: none"> • External reviews and benchmarking always very helpful/useful in escalating a service up the Trust financial priorities. • The most recent visit has provided the support that has led to a funding increase of over £300,000 to the HBO service which will allow the service to finally operate to its full potential. • Good to get some benchmarking and very good to be part of network.
<p>9. Any other comments</p>	<ul style="list-style-type: none"> • Excellent, must continue in order to drive progress in what is unfortunately not yet a high priority service. • The team were all very supportive and wanted to do their best to help develop the service, offered lots of advice and were understanding. • Well run and brings the whole service together nationally. • Lack of consistency disappointing. • Thank you very much.

Overall Evaluation

2019-20 Haemoglobin Disorders Programme: Overall evaluations issued for 25 visits. 11 responses. Response rate 44 %.

Question	Response	2003 CIC %	2005 Cancer %	2006 CIC %	2009 Renal %	2010- 11 Haem %	WMQRS 2010-11 %	WMQRS 2011-12 %	WMQRS 2012-13 %	2012- 13 Haem %	WMQRS 2013-14 %	WMQRS 2014-15 %	2014- 16 Haem %	WMQRS 2015-16 %	2016 Renal %	2013- 16 CIC %	QRS IABD %	QRS Haem %
Did the preparation for the visit to your own organisation lead to changes in the services provided?	Improvement or Significant Improvement	34	41	71	14	50	33	32	0	56	20	33	45	43	83	38	44	44
Was the peer review visit to your own organisation a helpful or unhelpful experience?	Helpful or Very Helpful	72	47	78	80	100	73	74	79	100	100	94	86	86	100	100	100	82
Did the report of the visit give a fair reflection of the services at your own organisation at the time of the visit?	Fair or Very Fair	83	58	65	66	100	73	68	84	88	40	73	76	71	100	88	100	82
Was the experience of being a reviewer useful in developing your own services?	Useful or Very Useful	81	74	89	91	92	88	80	88	89	100	100	80	100	100	100	79	88
Has your organisation been able to address the 'immediate risks' (if any) and 'concerns' identified in the visit report?	Addressed in full or nearly addressed		43		48	23	56	60	58	35	50	88	39	33	100	63	44	55

Question	Response	2003 CIC %	2005 Cancer %	2006 CIC %	2009 Renal %	2010- 11 Haem %	WMQRS 2010-11 %	WMQRS 2011-12 %	WMQRS 2012-13 %	2012- 13 Haem %	WMQRS 2013-14 %	WMQRS 2014-15 %	2014- 16 Haem %	WMQRS 2015-16 %	2016 Renal %	2013- 16 CIC %	QRS IABD %	QRS Haem %
Has the peer review process overall been useful to your organisation in improving services?	Useful or Very Useful	67	45	61	52	73	73	71	60	75	75	73	71	83	50	86	88	73

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Appendix 6: Glossary of Terms and Abbreviations

Glossary of terms and abbreviations	
C	Concerns.
CNS	Clinical Nurse Specialist who has specialist skills, knowledge and experience in a particular aspect of nursing.
CCG	Clinical Commissioning Group.
Commissioner	A commissioner decides how NHS and / or social care resources are spent, with the aim of improving health, reducing inequalities, and enhancing patient experience.
CYP	Children and Young People.
FC	Further Consideration.
GPs/ GP	General Practitioner/s.
GP	Good Practice.
IR	Immediate Risk.
HCC	Haemoglobinopathy Coordinating Centre: responsible for coordinating, supporting and promoting a system-wide networked approach to the delivery of haemoglobinopathy services across a defined geographical area.
LHT	Local Haemoglobinopathy Team.
NHP	National Haemoglobinopathy Panel: Provides expert and evidence-based advice on the management of adults and children with Sickle Cell Disease, Thalassaemia and Rare Inherited Anaemias.
NICE	National Institute for Health and Care Excellence.
NHS England (NHSE) NHS Improvement (NHSI)	These two organisations work together and are at the head of the NHS in England.
Non-specialist ward	Wards which do not care for patients solely with a particular condition.
MDT	Multi-disciplinary Team.
MRI	Magnetic Resonance Imaging.
NHR	National Haemoglobinopathy Registry.
PCA	Patient Controlled Analgesia.
QRS	Quality Review Service.
QS	Quality Standard.
SCD	Sickle Cell Disease.
SCS	Sickle Cell Society.
SHT	Specialist Haemoglobinopathy Team.
SOP	Standard Operating Procedure.
T / Thal	Thalassaemia.
TCD	Trans-cranial Doppler Ultrasound.
Trust	An NHS Trust, NHS Foundation Trust or other organisation with management responsibility for the service.
UKTS	United Kingdom Thalassaemia Society

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