Health services for people with haemoglobin disorders

Homerton University Hospital NHS Foundation Trust – Adult Service

Visit Date: 20th November 2019

Report Date: March 2020

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Introduction

This report presents the findings of the peer review of health services for people with haemoglobin disorders in Homerton University Hospital NHS Foundation Trust that took place on 20th November 2019. The purpose of the visit was to review compliance with the Quality Standards for Health Services for People with Haemoglobin Disorders V4, 2018, which were developed by the UK Forum on Haemoglobin Disorders working with the Quality Review Service (QRS). The peer review visit was organised by QRS on behalf of the UK Forum on Haemoglobin Disorders. The Quality Standards refer to the following types of specialised service for people with haemoglobin disorders:

- Specialist Haemoglobinopathy Team (SHT)
- Local Haemoglobinopathy Teams (LHT) or linked providers

Haemoglobin Disorder Network and Commissioning Quality Standards were not reviewed as part of the 2019-20 review programme, although during the course of the review visit reviewers did enquire about the local network and commissioning arrangements.

The aim of the standards and the review programme is to help providers and commissioners of services to improve clinical outcomes and service users' and carers' experiences by improving the quality of services. The report also gives external assurance of the care, which can be used as part of organisations' Quality Accounts. For commissioners, the report gives assurance of the quality of services commissioned and identifies areas where developments may be needed.

The report reflects the situation at the time of the visit. The text of this report identifies the main issues raised during the course of the visit. Any immediate risk identified includes the Trust's proposed actions to mitigate the risk and QRS's response to those proposals. Appendix 1 lists the visiting team that reviewed the services at Homerton University Hospital NHS Foundation Trust. Appendix 2 contains the details of compliance with each of the standards and the percentage of standards met.

This report describes services provided or commissioned by the following organisations:

- Homerton University Hospital NHS Foundation Trust
- NHS England & NHS Improvement Specialised Commissioning – Haemoglobinopathies
- NHS City and Hackney Clinical Commissioning Group

Most of the issues identified by quality reviews can be resolved by providers' and commissioners' own governance arrangements. Many can be tackled by the use of appropriate service improvement approaches; some require commissioner input. Individual organisations are responsible for taking action and monitoring this through their usual governance mechanisms. The lead commissioner for the service concerned is responsible for ensuring action plans are in place and monitoring their implementation, liaising, as appropriate, with other commissioners, including commissioners of primary care. The lead commissioner in relation to this report is the NHS England & NHS Improvement Lead Commissioner for Haemoglobinopathies.

About the Quality Review Service

QRS is a collaborative venture between NHS organisations to help improve the quality of health services by developing evidence-based Quality Standards, carrying out developmental and supportive quality reviews (often through peer review visits), producing comparative information on the quality of services and providing development and learning for all involved.

Expected outcomes are better quality, safety and clinical outcomes, better patient and carer experience, organisations with better information about the quality of clinical services, and organisations with more

confidence and competence in reviewing the quality of clinical services. More detail about the work of QRS is available at www.qualityreviewservicewm.nhs.uk

Acknowledgments

We would like to thank the staff of Homerton University Hospital NHS Foundation Trust for their hard work in preparing for the review and for their kindness and helpfulness during the course of the visit. We are also grateful to the users and carers who took time to come and meet the review team. Thanks are also due to the visiting team and their employing organisations for the time and expertise they contributed to this review.

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Review Visit Findings

Trust-wide

General comments

This review looked at the health services provided for adults with haemoglobin disorders at Homerton University Hospital NHS Foundation Trust (HUH). Reviewers visited the emergency department, haematology medical day unit and in-patient wards during the course of the visit. Reviewers also met with patients and carers and with staff providing the services across the health economy.

HUH was a medium-sized local hospital providing acute and community health services for Hackney, the City and surrounding communities, and also a range of specialist services for a much wider population.

At the time of the visit the haemoglobinopathy services at the Trust were part of the East London and Essex Haemoglobin Disorders Network, which was formed with Barts Health NHS Trust, Barking, Havering and Redbridge University Hospitals NHS Trust, Basildon and Thurrock University Hospitals NHS Foundation Trust, Mid Essex Hospital Services NHS Trust, The Princess Alexandra Hospital NHS Trust, East Suffolk and North Essex NHS Foundation Trust, Southend University Hospital NHS Foundation Trust, the Sickle Cell and Thalassaemia Centres in Hackney (HUH) and Newham (East London NHS Foundation Trust), North East London NHS Foundation Trust, and the community service covering Essex.

As the SHT for the Homerton and Essex operational delivery network (ODN), the team provided support and advice to the adult LHTs within the area: Barking, Havering and Redbridge University Hospitals NHS Trust (BHR), Mid Essex Hospital Services NHS Trust, East Suffolk and North Essex NHS Foundation Trust, and Southend University Hospital NHS Foundation Trust. The team reported that, since the last visit, engagement with the local services within the ODN, apart from BHR, had continued to be limited, despite the team's efforts and offers to provide some outreach support.

All children resident in the London Borough of Hackney attended the paediatric specialist haemoglobinopathy service based at the Royal London Hospital (RLH, Barts Health NHS Trust), and transition arrangements were in place for ongoing care with the adult SHT team at HUH.

ADULTS

Trust	Reviewed as:	No. of adults with sickle cell disease	No. of adults with thalassaemia	No. of adults on long-term red cell transfusions
Homerton University Hospital NHS Foundation Trust	SHT	359	7	71

Support Groups	Yes /No
Sickle Cell Disease – Adults	Y
Thalassaemia – Adults	Y

Specialist Team (Adult Services): Homerton University Hospital NHS Foundation Trust

General Comments and Achievements

The team was enthusiastic, experienced and well-motivated, and was working hard to provide a patient-centred service; the team had good support from the senior management team at the Trust.

Multi-disciplinary team (MDT) meetings were held every fortnight, were well attended and included ED and ward staff. The meetings were well structured, with time allocated for review and learning.

The psychologist was fully integrated into the team, attending MDT meetings and actively following up patients who had been discharged from the hospital but who were not known to the psychology service, to offer support. All patients were contacted and offered an appointment within four weeks of the referral being received. This had resulted in a high DNA rate for psychology appointments, but plans were in place to address this.

The team had continued to provide an extensive range of training for different staff groups across the local health economy.

Progress since the Last Visit

Significant progress had been made since the last peer review visit:-

- A joint pain clinic had been established with the aim of improving the management of patients with complex pain.
- Access to automated red cell exchange had improved with the availability of a second machine. The service was available, depending on staffing, Monday to Friday, and had been able to treat patients from other areas.
- The Trust had been able to recruit a second haematologist to the team, although at the time of the visit the haematologist had left and recruitment for a replacement was in progress.
- During 2017/18 a data coordinator had been appointed to provide some data support as part of an NHS CQUIN. Funding for the post had since ceased and the post was no longer in place, so this work had now fallen to the clinical team.
- Participation in clinical trials had increased and the team had published a number of papers.
- A Trust-wide app had been developed so that staff could securely access all Trust-governed guidelines via mobile phone.
- Protocols for the use of analgesia had been revised and replacement patient controlled analgesia (PCA) pumps purchased.
- Senior psychologist time had been increased to 0.8 wte to reflect specialist clinical need and demand.

Specialist Haemoglobinopathy Centre	Local Haemoglobinopathy Teams
Homerton University Hospital NHS Foundation Trust	• Barking, Havering and Redbridge University Hospitals NHS Trust • Basildon and Thurrock University Hospitals NHS Foundation Trust • East Suffolk and North Essex NHS Foundation Trust • Mid Essex Hospital Services NHS Trust: Broomfield Hospital • Southend University Hospital NHS Foundation Trust

Staffing

Staffing for an Adult Specialist Haemoglobinopathy Team (SHT)[1]	Number of patients[2]	Actual wte (at time of the visit)	NHSE recommended staffing wte
Consultant haematologist with >0.6 wte per 150 patients dedicated to work with patients with haemoglobinopathies	366	1.0 0.75 (vacant)	1.46
At least 0.25 wte allocated to haemoglobinopathies CPD in the adult consultant job plan	366	yes	-
A clinical psychologist for adult patients who has >0.5 wte per 200 patients dedicated to work with patients with haemoglobinopathies	366	0.8	0.9

Emergency Care

Patients had direct access to the haematology medical day unit Monday to Friday between 9am and 5pm and were seen by members of the haematology team. Out of normal working hours, patients were asked to present to the Emergency Department (ED). Background information about the patient's illness and specific recommendations on their acute management were included in the patient's individual protocol in their electronic patient record, and this was available to the ED staff.

Inpatient Care

Patients were usually admitted from the haematology Medical Day Unit (MDU) or the ED to the acute care unit (ACU) under the care of the haematology team, and then transferred to one of the three wards that had been identified to care for patients with haemoglobinopathies: Lloyd, Edith Cavell and Lamb. Access to PCA was possible on these three designated wards.

Day Care

The MDU was open from 9am to 5pm (Monday to Friday), and patients attended for routine blood transfusions. Patients could also attend for analgesia, and patient group directions (PGDs) were in place to enable the nursing staff to administer specified analgesics. From the annual report, approximately seven patients attended the day unit each day, and day unit attendances for the management of acute sickle crises were 1,764 in 2017-18. Data for 2018-19 were not yet available.

Outpatient Care

Two consultant-led haemoglobinopathy clinics were held every week on Tuesday morning and Friday afternoon. A number of specialist clinics were also provided:

- A nurse-led hydroxycarbamide and iron chelation clinic was held weekly on the day unit. The clinic was led by the lead nurse who was also a nurse prescriber.
- A joint haemoglobinopathy–obstetric clinic attended by a consultant haematologist and consultant obstetrician was held every two weeks.

[1] *Recommended staffing: National NHS England compliance exercise for designation of SHTs 2019.*

[2] *Numbers exclude 14 patients with other conditions e.g. haemoglobin H.*

- A joint sickle cell and pain clinic was held every month and patients with complex pain were reviewed jointly by a consultant haematologist, a consultant anaesthetist with a special interest in pain management and the clinical psychologist.

Community-based Care

The sickle cell and thalassaemia at HUH was an integrated service covering both acute and community services. The community service was responsible for processing all affected or carrier new-born blood spot results in conjunction with Central Middlesex screening laboratory. The community centre was also responsible for routine and pre-conceptual screening.

The community service had two CNSs based in the community to provide support to patients, families and members of the primary health care team. The CNSs also followed up all patients who had been discharged from hospital, and liaised with other members of the primary care team.

A social liaison team was also part of the community service. The team included a social liaison officer and a welfare and benefits advisor. They provided support to patients and their families with education and employment issues as well as benefits and general advice. The social liaison team were active in raising awareness of sickle cell and thalassaemia within the local community and provided training and support for GPs, social care teams and housing services.

The paediatric CNS based in the community provided care for children and young people, who were seen at the RLH. The paediatric CNS organised transition workshops for young people in the holidays.

Staff rotated between in-patient and community services every three months.

Views of Service Users and Carers

The visiting team met with four service users and carers with sickle cell disease during the course of the visit. The visiting team did not meet any patients with thalassaemia, so their views are not represented. Overall, the patients and carers were highly complimentary about the care they received at the hospital, and they were particularly appreciative of the support from the haemoglobinopathy team. In addition:

- The service users considered that the services provided had improved. Access to appointments was well managed and they all had an individualised care plan.
- The process for 'stepping up and stepping down' from the day unit and wards was viewed as working well, and they felt well cared for by staff when they were in-patients.
- The support group was very active, with over 100 members, and the service users liked the 'What's App™' group that was used to provide additional communications. The service users commented that they would value a more collaborative relationship with the Trust team, saying that the support group would be willing to get more involved in service developments, and that more involvement from the Trust team in terms of links and education would be welcome.
- Concerns were raised by service users as to whether staff in the ED had sufficient knowledge of sickle cell disease; three patients explained that they had attended the ED and been sent away with a high temperature only to return acutely unwell, with one patient commenting that they had required emergency surgery.
- Parents whose children had been ready to transition to an adult service felt the process could be improved. The opportunities to discuss the transfer of care at a joint meeting with the paediatric and adult services were limited, with a comment being made that only an annual meeting with the cohort of young people ready to transition was offered. Young people were given the option to transition to the adult service at the RLH or HUH and, as they knew the staff better at the RLH, would often prefer to remain under their care. Those who met with the reviewing team also expressed a concern about young

people transitioning to the service because of the apparent risk of high opiate use, a view that they had heard repeated by other service users via their social networking groups.

- Some patients commented that when the lead staff had been away for an extended period they had felt vulnerable and had been unable to get access to advice and support.
- Comments were also expressed that a number of patients with complex needs, who were more vocal, seemed to gain more attention than other patients.
- The service users accepted the rationale for the changes in access to the MDU, but considered that the reasons for the changes were not communicated properly; they had later understood that the changes had been made to manage those who 'abused' the system. The service users asked whether there could be some flexibility in the number of times they could attend the MDU or ED in one week if they rarely accessed the service.

Good Practice

1. Considerable work had been undertaken to improve the management of patients who attended the Trust on a frequent basis, usually with severe pain. The pathway had been revised since the last visit, and patients were restricted to attending the MDU or the ED as an out-patient twice in any week before they had to be reviewed by a senior decision-maker and, if appropriate, admitted for symptom management.

2. The CNS team rotated between the acute and community services every three months. Staff who met with the reviewing team commented how the process had improved and expanded their skills and knowledge to meet patient need, and had improved cross cover working. Feedback from patients was that they valued the continuity of care that this arrangement provided.

3. A good campaign had been led by the team with the staff working 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.

4. Reviewers were particularly impressed with the following information for patients:-

    a. Information covering the use of prophylactic antibiotics was well written and included clear advice about the importance and benefits of taking the prophylactic antibiotics regularly.

    b. The leaflet explaining the benefits of 'incentive spirometry' included the different techniques patients could use to help increase lung capacity and reduce the risk of ACS.

    c. Clear guidance was available about the risk of malaria, and preventative treatments when travelling. Reviewers considered that the advice was very well written and particularly useful because of the range of misinformation that is available via web-based information systems.

5. Collaborative working across the local health economy was impressive. 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. Reviewers were particularly impressed with the work undertaken by GPs to engage with patients with haemoglobin disorders registered at their practices so that they were highlighted as patients with a long-term condition, screened on a regular basis and encouraged to access help in primary care.

6. The team produced a service report every two years. This report was very comprehensive and included a wealth of information about the service, clinical and educational activity, service achievements and service developments. The report was also made publicly available.

Immediate Risk[3]

1. **Delay in recognising the deteriorating patient**[4]

   The clinical guidelines for the management of acute complications of sickle cell disease did not include sufficient detail to guide staff working in the ED about the assessment of patients with haemoglobin disorders who presented with a fever, infection or possible sepsis and the rationale for this assessment. Whilst this in itself does not constitute an immediate risk, two of the four patients selected to meet with the visiting team reported that they had been discharged from the ED with a pyrexia and feeling acutely unwell and had then returned to be admitted for urgent care. This, after extensive discussion among the reviewing team, including patient organisation representatives, elevated the concern to an immediate risk. At the time of the visit the Trust guidance on the management of sepsis was under review. Following discussions with the Trust team during the course of the visit, the team stated that they will ensure that specific reference to patients with haemoglobin disorders, who have a higher risk of developing sepsis and may attend with non-specific, non-localised presentations, is included in the revised Trust guidance. After the visit, the lead clinician contacted the reviewing team, and had already commenced work on a specific revised policy for the care of patients with haemoglobin disorders.

[3] **QRS definition of Immediate Risks**: An Immediate Risks is defined as a **potential** Serious Incident, that is, a situation where a Serious Incident **could occur** in the circumstances found by the reviewers (*QRS Principles and Approach V19 20190704).*

[4] **Trust response:** You stated that the clinical guidelines for the management of acute complications of sickle cell disease did not include sufficient detail to guide staff working in the Emergency Department (ED) about the rationale and assessment of patients with haemoglobin disorders who presented with a fever, infection or possible sepsis. You felt that this in itself didn't constitute an immediate risk however, the fact that two patients who were spoken to during the visit reported they had been discharged from our ED with a pyrexia then returned acutely unwell elevated the concern, in your view, to an immediate risk. I am aware that there has been an exchange of emails on this matter and it is unfortunate that the clinical team did not have the opportunity provide further details regarding the incidence and management of sepsis within the Trust. Prior to the peer review, we had produced a new policy for The Management for Acute Complications of Sickle Cell Disease: Acute Deterioration of Anaemia, Stroke, Priapism, Retinopathy. Following the visit and in light of your feedback, this has now been revised to include a specific section on infection and sepsis. The policy has been circulated to relevant clinicians for further comment and is due for ratification at a Divisional Governance Board meeting next month. I attach the revised version of the policy with the relevant section on page 6. In addition, the Trust sepsis leads have been informed that this risk was identified. The Trust sepsis policy is currently under review and it has been made clear that a specific reference to patients with haemoglobin disorders, who have a higher risk of developing sepsis and may attend with non-specific, non-localised presentations, should be referenced within the Trust policy.
QRS Response to Trust action: The reviewers have reviewed your response and the revised guideline covering acute complications of sickle cell disease. We note that the Trust sepsis policy will also be revised to include specific reference to patients with haemoglobin disorders and that your Trust sepsis leads have been informed of the risk identified. Patients reported being discharged from the Emergency Department with an existing pyrexia. Having reviewed the newly submitted policy covering acute complications of sickle cell disease, the reviewers considered that once both the policies (acute complications of sickle cell disease and the Trust sepsis policy) have been implemented, including dissemination and education with Trust staff groups, these actions will mitigate the risk that patients reported of being discharged with a fever.

Concerns

1. **Consultant staffing**

   The service had insufficient consultant medical staff with time for the care of people with haemoglobin disorders to provide staffing for regular reviews, emergency care, clinics, and support and oversight to other LHTs across the network. At the time of the visit there was one consultant haematologist (1.00 wte) for the SHT, with no cover for absences. The Trust was in the process of recruiting an additional consultant haematologist (0.75 wte) with time allocated for work with patients with haemoglobinopathies.

2. **Clinical guidelines – sickle cell disease**

   Guidance for staff on the management of acute and chronic complications was incomplete. Some guidance was available as separate documents with no document control, while for other guidance staff would refer to the national sickle cell guidelines, which had not been adapted for use locally. Reviewers were told that guidelines for the management of sickle cell disease had previously been in a compendium (red book) but that once the guidelines had exceeded their review date, the team had made a conscious decision not to update the compendium for non-haematology staff. Reviewers considered that the governance process for the development of clinical guidelines would benefit from being strengthened to ensure that guidance is appropriately governed and referenced.

3. **In-patient activity**

   The policy of actively admitting to a ward patients who attended from the ED or the MDU more than twice in a week had had an impact on the number of patients who were being admitted for an overnight stay or discharged very quickly. In-patient attendances had doubled from 408 in 2013 to 830 in 2019. The mean length of stay, however, had reduced from 4.6 days in 2018 to 3.7 days in 2019, indicating that the overall length of stay was reducing. From discussions with staff at the time of the visit, it was clear that the team were aware of the challenges they were encountering to provide care for patients who attended the hospital on a frequent basis, and were actively working to reduce in-patient activity.

4. **Patient review**

   Patients with haemoglobinopathies were not always reviewed by a senior haematology decision-maker within 14 hours of admission, because of staffing constraints.

Further Consideration

1. At the time of the visit the percentage of patients who had an annual review performed was 75%. Reviewers were told that annual reviews were only undertaken in the out-patient clinical setting, and therefore those patients who were frequent attenders at the MDU and who then did not attend for their clinic appointments would not have a timely annual review performed. Reviewers considered that this patient group would benefit from an annual review, and were at risk of chronic complications if they were not receiving comprehensive reviews.
2. The number of patients on hydroxycarbamide appeared low for the patient population for by the SHT.
3. Patients had no access to an out-of-hours service for routine blood transfusions.
4. The transition process was not yet fully implemented to ensure that all young people would be given the appropriate information and support to transition to adult care at HUH. Service users who met with the reviewing team said that a transition meeting with young people, the HUH adult team and the paediatric team at the RLH was held once a year, which they considered did not give them enough time to meet with the team at HUH. The paediatric CNS held three workshops during the school holidays but these were not always well attended. Reviewers considered that, as a result of the changes in service

configuration across the network, it would be timely to include a review of the pathway for young people transitioning to adult services.

5. Trust and commissioner support will be required once the reorganisation of haemoglobinopathy services by NHS England (NHSE) has been completed, to review local and network pathways, develop the network, and support the SHT to provide a comprehensive service for local referring teams. At the time of the visit, only BHR were engaged with the team (and were likely to become an SHT in the future). Reviewers were told that, despite discussions with local teams based in Essex, engagement with the SHT at HUH had not improved.
6. The psychology service was working well, but reviewers considered that the workload should be kept under review to ensure that the psychologist had sufficient capacity for the complexity and numbers of patients accessing the service, given that the psychology provision was slightly below the recommended levels for the number of patients actively cared for by the service.
7. In the light of other feedback from patients at the time of the visit, it may be helpful to undertake further work with the support group to understand more about their concerns, perceptions and expectations, and how best to meet their needs.

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Commissioning

Reviewers met with a representative from NHS City and Hackney Clinical Commissioning Group.

Several of the issues in this report will require active involvement of the Trust with local and NHSE specialist commissioners in order to ensure that progress is made.

Further Consideration

1. As identified at the last visit in 2015, the SHT had limited engagement with local referring teams (see table on page 9) within the Homerton and Essex ODN, apart from BHR who, at the time of the visit, had applied to become an SHT. Reviewers suggested that some support to develop the network would be needed from both commissioners and the Trust, to formalise network arrangements and ensure that patients residing in the Essex area were referred for specialist care, such as antenatal care, specialist MDT discussion and completion of annual reviews. The ongoing lack of clarity around access to specialist care meant there was potential for patients to receive suboptimal treatment.

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APPENDIX 1 Membership of Visiting Team

Clinical Lead		
Dr Emma Drasar	Consultant Haematologist	Whittington Health NHS Trust

Visiting Team		
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 Jenna Love	Clinical Psychologist	St George's University Hospitals NHS Foundation Trust
Karen Madgwick	Deputy Clinical Lead for Blood Transfusion	North Middlesex University Hospital NHS Trust
Roanna Maharaj	Patient Representative	UK Thalassaemia Society
Katherine Stevenson	Haemoglobinopathy Specialist Nurse	Manchester University NHS Foundation Trust
Joan Walters	Senior Practitioner Lecturer (Children and Young People / Haemoglobinopathies)	King's College Hospital NHS Foundation Trust

Quality Review Service		
Sarah Broomhead	Assistant Director	Quality Review Service

Observers from the UK Accreditation Service (UKAS)		
Rebecca Gibbons	Senior Assessment Manager	UKAS
Gail Partridge	Technical Advisor	UKAS

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APPENDIX 2 Compliance with the Quality Standards

Analyses of percentage compliance with the Quality Standards should be viewed with caution as they give the same weight to each of the Quality Standards. Also, the number of Quality Standards applicable to each service varies depending on the nature of the service provided. Percentage compliance also takes no account of 'working towards' a particular Quality Standard. 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. With these caveats, table 1 summarises the percentage compliance for each of the services reviewed.

Table 1 - Percentage of Quality Standards met

Details of compliance with individual Quality Standards can be found below.

Service	Number of applicable QS	Number of QS met	% met
Specialist Haemoglobinopathy Team – Homerton University Hospital NHS Foundation Trust	42	22	52
Total	**42**	**22**	**52**

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Specialist Services for People with Haemoglobin Disorders

Ref	Standard	Met?	Comments
HN-101	**Haemoglobin Disorder Service Information** Written information should be offered to patients and, where appropriate, their carers covering at least: a. Brief description of the service, including times of phlebotomy, transfusion and psychological support services b. Clinic times and how to change an appointment c. Ward usually admitted to and its visiting times d. Staff of the service e. Community services and their contact numbers f. Relevant national organisations and local support groups g. Where to go in an emergency h. How to: i. Contact the service for help and advice, including out of hours ii. Access social services iii. Access benefits and immigration advice iv. Interpreter and advocacy services, PALS, spiritual support and HealthWatch (or equivalent) v. Give feedback on the service, including how to make a complaint vi. Get involved in improving services (QS HN-199)	N	The description of services did not include the times when the services were available (a). Written information for patients with thalassaemia covering what to do when unwell and where to access help was not in place (g). Information did not cover how to access interpreter services, although in practice staff could contact 'Language Line' if patients needed access to interpreter services (h(iv)). All other aspects of the QS were met.
HN-102	**Information about Haemoglobin Disorders** Written information should be offered to patients and, where appropriate, their carers covering at least: a. A description of their condition (SC or T), how it might affect them and treatment available b. Problems, symptoms and signs for which emergency advice should be sought c. How to manage pain at home (SC only) d. Splenic palpation and Trans-Cranial Doppler scanning (children only) e. Transfusion and iron chelation f. Possible complications, including priapism and complications during pregnancy g. Health promotion, including: i. Travel advice ii. Vaccination advice h. National Haemoglobinopathy Registry, its purpose and benefits i. Self-administration of medications and infusions	N	Written information for patients with thalassaemia did not cover (b), (e), (f), (g), or (h). The information for patients with sickle cell disease was descriptive, but did not include advice and strategies to help them deal with priapism or possible complications during pregnancy. Information from Public Health England covering antenatal and new-born screening was available to patients. The information covering malaria, use of prophylactic antibiotics and incentive spirometry was very good (see Good Practice section of the main report).

Ref	Standard	Met?	Comments
HN-103	**Care Plan** All patients should be offered: a. An individual care plan or written summary of their annual review including: i. Information about their condition ii. Plan for management in the Emergency Department iii. Planned acute and long-term management of their condition, including medication iv. Named contact for queries and advice b. A permanent record of consultations at which changes to their care are discussed The care plan and details of any changes should be copied to the patients' GP and their local / specialist team consultant (if applicable).	Y	
HN-104	**Information for Primary Health Care Team** Written information should be sent to the patient's primary health care team covering available local services and: a. The need for regular prescriptions including penicillin or alternative (SC and splenectomised T) and analgesia (SC) b. Side effects of medication, including chelator agents [SC and T] c. Guidance for GPs on: i. Hydroxycarbamide and iron chelation therapy (if being prescribed by GPs) ii. Immunisations iii. Contraception and sexual health d. Indications and arrangements for seeking advice from the specialist service	Y	
HN-105	**Information about Trans-Cranial Doppler Ultrasound (Children's Services Only)** Written information should be offered to patients and their carers covering: a. Reason for the scan and information about the procedure b. Details of where and when the scan will take place and how to change an appointment c. Any side effects d. Informing staff if the child is unwell or has been unwell in the last week e. How, when and by whom results will be communicated	N/A	

Ref	Standard	Met?	Comments
HN-106	**School Care Plan (Children's Services Only)** A School Care Plan should be agreed for each child or young person covering, at least: a. School attended b. Medication, including arrangements for giving / supervising medication by school staff c. What to do in an emergency whilst in school d. Arrangements for liaison with the school e. Specific health or education need (if any)	N/A	
HN-194	**Environment** The environment and facilities in phlebotomy, out-patient clinics, wards and day units should be appropriate for the usual number of patients with haemoglobin disorders. Services for children and young people should be provided in a child friendly environment, including toys and books / magazines for children and young people of all ages.	Y	Facilities were bright, with ample space around the beds. Cubicles were also modern, with glass doors for patient privacy and easy observation by staff.
HN-195	**Transition to Adult Services** Young people approaching the time when their care will transfer to adult services should be offered: a. The opportunity to discuss the transfer of care at a joint meeting with paediatric and adult services b. A named coordinator for the transfer of care c. A preparation period prior to transfer d. Written information about the transfer of care including arrangements for monitoring during the time immediately afterwards	N	Meetings with young people transitioning to adult services were only held annually with the paediatric team at the Royal London Hospital. Some workshops were held during school holidays by the local CNS for paediatrics.
HN-199	**Involving Patients and Carers** The service's involvement of patients and carers should include: a. Mechanisms for receiving feedback from patients and carers b. An annual patient survey (or equivalent) c. Mechanisms for involving patients and, where appropriate, their carers in decisions about the organisation of the service d. Examples of changes made as a result of feedback and involvement of patients and carers	N	Limited involvement had taken place with users and carers in decisions about the organisation of the service (see patient feedback). Evidence of the service's involvement with patients with thalassaemia was not seen at the time of the visit.

Ref	Standard	Met?	Comments
HN-201	**Lead Consultant** A nominated lead consultant with an interest in the care of patients with haemoglobin disorders should have responsibility for guidelines, protocols, training and audit relating to haemoglobin disorders, and overall responsibility for liaison with other services within the network. The lead consultant should undertake Continuing Professional Development of relevance to this role and should have an appropriate number of session/s identified for this role within their job plan and cover for absences should be available.	Y	
HN-202	**Lead Nurse** A lead nurse should be available with: a. Responsibility, with the lead consultant, for guidelines, protocols, training and audit relating to haemoglobin disorders b. Responsibility for liaison with other services within the network c. Competences in caring for people with haemoglobin disorders d. Competences in the care of children and young people (children's services only) The lead nurse should have appropriate time for their leadership role and cover for absences should be available.	Y	

Ref	Standard	Met?	Comments
HN-203	**Medical Staffing and Competences** The service should have sufficient medical staff with appropriate competences in the care of people with haemoglobin disorders, including: **All services:** a. Haematology or paediatric medical staffing for clinics and regular reviews b. 24/7 consultant and junior staffing for emergency care **SHCs only:** c. A consultant specialising in the care of people with haemoglobin disorders on call and available to see patients during normal working hours d. If doctors in training are part of achieving 'a' or 'b' then they should have the opportunity to gain competences in all aspects of the care of people with haemoglobin disorders Staffing levels should be appropriate for the number of patients cared for by the service and its role in the network (SHC/LHT). Staff working with children and young people should have competences in caring for children as well as in haemoglobin disorders. Cover for absences should be available.	N	Only one consultant haematologist was available for clinics and regular reviews, and there was no cover for absence. The Trust was in the process of recruiting an additional haematologist whose job plan would stipulate that 75% of their time would be spent working with patients with haemoglobinopathies.
HN-204	**Nurse Staffing and Competences** The service should have sufficient nursing staff with appropriate competences in the care of people with haemoglobin disorders, including: a. Clinical nurse specialist/s with responsibility for the acute service b. Clinical nurse specialist/s with responsibility for the community service c. Ward-based nursing staff d. Day unit (or equivalent) nursing staff e. Nurses with competences in cannulation and transfusion available at all times patients attend for transfusion Staffing levels should be appropriate for the number of patients cared for by the service and its role in the network (SHC/LHT). Staff working with children and young people should have competences in caring for children as well as in haemoglobin disorders. Cover for absences should be available.	Y	

Ref	Standard	Met?	Comments
HN-205	**Psychology Staffing and Competences** The service should have sufficient psychology staff with appropriate competences in the care of people with haemoglobin disorders, including: a. An appropriate number of regular clinical session/s for work with people with haemoglobin disorders and for liaison with other services about their care b. Time for input to the service's multi-disciplinary discussions and governance activities c. Provision of, or arrangements for liaison with and referral to, neuro-psychology Staffing levels should be appropriate for the number of patients cared for by the service and its role in the network (SHC/LHT). Staff working with children and young people should have competences in caring for children as well as in haemoglobin disorders. Cover for absences should be available.	N	Psychological support for people with haemoglobin disorders was available (0.8 wte), but the psychologist did not have cover for absences. Reviewers considered that the time available was insufficient for the number of patients cared for by the service (British Psychology Society Special Interest Group for Psychologists working in Sickle cell and Thalassaemia (2017) suggests 1 wte for 300 patients). Access to neuropsychology was in place.
HN-206	**Training Plan** A training plan should ensure that all staff are developing and maintaining appropriate competences for their roles in the care of patients with haemoglobin disorders.	Y	A comprehensive training programme for staff was delivered by all members of the SHT.
HN-207	**Trans-Cranial Doppler Ultrasound Competences (Children's Services Only)** Sufficient staff with appropriate competences for Trans-Cranial Doppler ultrasound should be available. Staff should undertake at least 40 scans per annum and complete an annual assessment of competence. Cover for absences should be available.	N/A	
HN-299	**Administrative, Clerical and Data Collection Support** Administrative, clerical and data collection support should be appropriate for the number of patients cared for by the service.	N	Since the loss of the data management post, staff were spending time collecting data, which reviewers considered was not a good use of clinical time.

Ref	Standard	Met?	Comments
HN-301	**Support Services** Timely access to the following services should be available. In Specialist Centres staff should have specific competences in the care of people with haemoglobin disorders and sufficient time for patient care and for attending multi-disciplinary meetings (HN-602) as required. a. Social worker/ benefits adviser b. Leg ulcer service c. Play specialist (children's services only) d. Chronic pain team (adult services only) e. Dietetics f. Physiotherapy (in-patient and community-based) g. Occupational therapy h. Mental health services (adult and CAMHS) i. DNA studies j. Polysomnography	Y	
HN-302	**Emergency Department – Staff Competences** Medical and nursing staff working in the Emergency Department/s should have competences in urgent care of people with haemoglobin disorders.	Y	The time to analgesia had improved, with the proportion of patients receiving analgesia within 30 minutes of arrival having increased from 30% to 50%. See also the Good Practice section of the main report about the acute chest syndrome campaign.
HN-303	**Specialist On-site Support** Access to the following specialist staff and services should be easily available on the same hospital site as the specialist team: a. Manual exchange transfusion (24/7) b. Erythrocytapheresis c. Acute pain team including specialist monitoring of patients with complex analgesia needs d. High dependency care, including non-invasive ventilation e. Level 2 and 3 critical care	Y	Two machines were available for automated red cell exchanges. The service could undertake two exchanges per day and had capacity to provide a service for patients who presented acutely unwell.

Ref	Standard	Met?	Comments
HN-304	**Specialist Services - Network** Access to the following specialist staff and services with an appropriate level of specialist expertise in the care of people with haemoglobin disorders should be available: a. Pulmonary hypertension team (adults) b. Consultant obstetrician with an interest in care of people with haemoglobin disorders and specialist high risk anaesthetics (adults) c. Respiratory physician with interest in acute/chronic sickle lung disease and obstructive sleep apnoea (adults & children) d. Fertility, including pre-implantation genetic diagnosis and sperm storage (adults) e. Consultant cardiologist with interest in sickle cardiomyopathy, iron overload related heart disease (adults) f. Consultant endocrinologist with interest in thalassaemia related endocrinopathy and osteoporosis (adults) g. Consultant paediatric endocrinologist with interest in growth problems related to haemoglobinopathies and thalassaemia related endocrinopathy (children) h. Hepatobiliary team with an interest in sickle hepatopathy, viral liver disease, iron overload-related liver disease (adults & children) i. Consultant neurologist and neurosurgeon with an interest in sickle vasculopathy (adults & children) j. Hyperacute stroke service (adults) k. Consultant ophthalmologist with an expertise in sickle retinopathy and chelation related eye disease (adults & children) l. Consultant nephrologist with expertise in sickle nephropathy (adults & children) m. Consultant urologist with expertise in managing priapism and erectile dysfunction (adults & children) n. Orthopaedic service with expertise in managing sickle and thalassaemia related bone disease (adults & children) o. Specialist imaging, including i. MRI tissue iron quantification of the heart and liver ii. Trans-Cranial Doppler ultrasonography (children) p. Bone marrow transplantation services (children only) q. Physiotherapy services (in patient and community based) r. Interventional and neuroradiology for neurovascular complications	N	The specialist services to which patients were referred for acute / chronic sickle lung disease and obstructive sleep apnoea and fertility, including pre-implantation genetic diagnosis and sperm storage, and access to a consultant neurologist and neurosurgeon with an interest in sickle vasculopathy, were not clear from the evidence provided.

Ref	Standard	Met?	Comments
HN-305	**Laboratory Services** UKAS / CPA accredited laboratory services with satisfactory performance in the NEQAS haemoglobinopathy scheme and MHRA compliance for transfusion should be available.	Y	
HN-401	**Facilities and Equipment** Facilities and equipment should be appropriate for the usual number and case mix of patients. Equipment should be appropriately maintained.	Y	
HN-501	**Transition Guidelines** Guidelines on transition to adult care should be in use covering at least: a. Age guidelines for timing of the transfer b. Involvement of the young person, their carer, paediatric services, primary health care, social care and Local Haemoglobinopathy Team (if applicable) in planning the transfer c. Allocation of a named coordinator for the transfer of care d. A preparation period and education programme relating to transfer to adult care e. Communication of clinical information from paediatric to adult services f. Arrangements for monitoring during the time immediately after transfer to adult care g. Arrangements for communication between the Specialist Haemoglobinopathy Centres and Local Haemoglobinopathy Teams	Y	
HN-502	**Monitoring Protocols** Protocols should be in use covering the monitoring expected at: a. First out-patient appointment (SHC only) b. Routine monitoring c. Annual review (SHC & any LHTs to which annual reviews are delegated) Protocols should cover both clinical practice and information for patients and families.	N	Written monitoring protocols covering both clinical practice and information for patients and families were not in place. In practice, new patients were reviewed and some patients had annual reviews undertaken.
HN-503	**Clinical Guidelines: LHT Management and Referral** Guidelines on routine out-patient monitoring and management between annual reviews should be in use which specify the indications for telephone advice, early referral and immediate transfer to the Specialist Centre.	N/A	

Ref	Standard	Met?	Comments
HN-504	**Transfusion Guidelines** Transfusion guidelines should be in use covering: a. Indications for: i. emergency and regular transfusion ii. use of simple or exchange transfusion iii. offering access to automated exchange transfusion to patients on long-term transfusions b. Protocol for carrying out a manual and automated exchange transfusion c. Investigations and vaccinations prior to first transfusion d. Recommended number of cannulation attempts	N	The guidelines did not include (c) or (d).
HN-505	**Chelation Therapy** Guidelines on chelation therapy should be in use covering: a. Indications for chelation therapy b. Choice of chelation drug/s, dosage and dosage adjustment c. Monitoring of haemoglobin levels prior to transfusion d. Management and monitoring of iron overload, including management of chelator side effects e. Use of non-invasive estimation of organ-specific iron overloading heart and liver by T2*/R2 f. Where prescribing is undertaken through shared care arrangements with GPs, guidelines for GPs on prescribing, monitoring and indications for seeking advice from and referral back to the LHT/SHC. g. Self-administration of medications and infusions and encouraging patient and family involvement in monitoring wherever possible.	N	Monitoring of haemoglobin levels prior to transfusion was not included in the chelation guidelines (some reference was included in the thalassaemia guidelines). The guidelines did not cover self administration (g). (f) was not applicable as there were no shared care arrangements in place with local GPs.

Ref	Standard	Met?	Comments
HN-506	**Clinical Guidelines: Acute Complications** Guidelines on the management of acute complications should be in use covering at least: **For patients with sickle cell disease:** a. Acute pain b. Fever, infection and overwhelming sepsis c. Acute chest syndrome d. Abdominal pain and jaundice e. Acute anaemia f. Stroke and other acute neurological events g. Priapism h. Acute renal failure i. Haematuria j. Acute changes in vision k. Acute splenic sequestration (children only) **For patients with thalassaemia:** l. Fever, infection and overwhelming sepsis m. Cardiac, hepatic or endocrine decompensation	N	Guidelines for the management of patients with sickle cell disease covering (b), (d), (h) and (l) were not in place. Guidance covering acute complications for patients with thalassaemia were agreed.
HN-507	**Specialist Management Guidelines** Guidelines should be in use covering the care of patients with sickle cell disease and thalassaemia: a. During anaesthesia and surgery b. Who are pregnant c. Receiving hydroxycarbamide therapy	N	Guidelines did not cover the care of patients with sickle cell disease and thalassaemia during anaesthesia and surgery.
HN-508	**Clinical Guidelines: Chronic complications** Guidelines on the management of chronic complications should be in use covering at least: a. Renal disease b. Orthopaedic problems c. Retinopathy d. Cardiological complications / pulmonary hypertension e. Chronic respiratory disease f. Endocrinopathies g. Neurological complications h. Chronic pain i. Liver disease j. Growth delay / delayed puberty (children only) k. Enuresis (children only)	N	The service referred to the national guidelines which had not been adapted for use locally.
HN-509	**Referral for Consideration of Bone Marrow Transplantation (Children's Services Only)** Guidelines for referral for consideration of bone marrow transplantation should be in use.	N/A	

Ref	Standard	Met?	Comments
HN-510	**Non-Transfusion Dependent Thalassaemia (nTDT)** Network-agreed clinical guidelines for the management of Non-Transfusion Dependent Thalassaemia should be in use, covering: a. Indications for transfusion b. Monitoring iron loading c. Indications for splenectomy	N	Indications for splenectomy were not included in the guidance seen by the reviewers.
HN-599	**Clinical Guideline Availability** Clinical guidelines for the monitoring and management of acute and chronic complications should be available and in use in appropriate areas including the Emergency Department, clinic and ward areas.	Y	Guidelines that were agreed were available in the clinical areas.
HN-601	**Service Organisation** A service organisation policy should be in use covering arrangements for: a. 'Fail-safe' arrangements for ensuring all children with significant haemoglobinopathy disorders who have been identified through screening programmes are followed up by a SHC (Children's SHC only) b. Ensuring all patients are reviewed by a senior haematology decision-maker within 14 hours of acute admission c. Patient discussion at multi-disciplinary team meetings (QS HN-602) d. Arrangements for liaison with community paediatricians and with schools (children's services only) e. 'Fail-safe' arrangements for ensuring all children and young people have Trans-Cranial Doppler ultrasound when indicated (children's services only) f. Follow up of patients who do not attend g. Transfer of care of patients who move to another area, including communication with all SHC, LHTs and community services involved with their care before the move and communication and transfer of clinical information to the SHC, LHT and community services who will be taking over their care. h. Accessing specialist advice (QS HN-304) i. Two-way communication of patient information between SHC and LHTs j. If applicable, arrangements for coordination of care across hospital sites where key specialties are not located together	N	The annual report did not cover arrangements for (h), (i), or (j). Because of the consultant haematologist vacancy, it was not always possible for patients to be reviewed by a senior haematology decision-maker within 14 hours of acute admission.

Ref	Standard	Met?	Comments
HN-602	**Multi-Disciplinary Meetings** Multi-disciplinary team meetings to discuss and review patient care should be held regularly, involving at least the lead consultant, lead nurse, nurse specialist or counsellor who provides support for patients in the community, psychology staff and representatives of support services (QS HN-301).	Y	
HN-603	**Delegation of Annual Reviews** If annual reviews are undertaken by LHT/s on behalf of the SHC, a written agreement should be in place covering: a. Monitoring protocols (QS HN-502) b. LHT management and referral guidelines (QS HN-503) c. National Haemoglobinopathy Registry data collection (QS HN-701)	N	Agreements with LHTs covering arrangements for ongoing monitoring, referral and delegation of annual reviews were not seen.
HN-604	**Out of Hours Elective Care** Arrangements should be in place for out of hour's transfusion, phlebotomy and out-patient clinics appropriate to the needs of the local population.	N	Access to out-of-hours elective care as defined by the QS was not in place.
HN-605	**Service Level Agreement with Community Services** A service level agreement for support from community services should be in place covering, at least: a. Role of community service in the care of patients with haemoglobin disorders b. Two-way exchange of information between hospital and community services.	N/A	Acute and community services were integrated.

Ref	Standard	Met?	Comments
HN-606	**Trans-Cranial Doppler Ultrasound Standard Operating Procedure (Children's Services Only)** A Standard Operating Procedure for Trans-Cranial Doppler ultrasound should be in use covering at least: a. Trans-Cranial Doppler modality used b. Identification of ultrasound equipment and maintenance arrangements c. Identification of staff performing Trans-Cranial Doppler ultrasound (QS HN-207) d. Arrangements for ensuring staff performing Trans-Cranial Doppler ultrasound have and maintain competences for this procedure, including action to be taken if a member of staff performs less than 40 scans per year e. Arrangements for recording and storing images and ensuring availability of images for subsequent review f. Reporting format g. Arrangements for documentation and communication of results h. Internal systems to assure quality, accuracy and verification of results	N/A	
HN-607	**Network Review and Learning Meetings** At least one representative of the team should attend each Network Review and Learning Meeting (QS HY-798).	Y	
HN-608	**Neonatal Screening Programme Review Meetings** The SHC should meet at least annually with representatives of the neonatal screening programme to review progress, discuss audit results (QS HN-703), identify issues of mutual concern and agree action.	N/A	
HN-701	**National Haemoglobinopathy Registry** Data on all patients, following patient or parental consent, should be entered into the National Haemoglobinopathy Registry. Data should include annual updates, serious adverse events, pregnancies and patients lost to follow up.	Y	75% of patients cared for by the service had consented to their details and annual reviews being submitted on the NHR.
HN-702	**Activity Data** The service should monitor on an annual basis: a. Number of acute admissions, day unit admissions, Emergency Department attendances and out-patient attendances b. Length of in-patient stays c. Re-admission rate d. 'Did not attend' rate for out-patient appointments	Y	However, the overall acute admissions data were not clear about the number of patients admitted via the ED.

Ref	Standard	Met?	Comments
HN-703	**Quality Dashboard** The service should monitor Quality Dashboard data including the number and percentage of: a. Adverse events reported on the NHR for which a mortality or serious case review has taken place b. Children who have had Trans-Cranial Doppler screening undertaken within national guidelines c. Patients given pain relief within half an hour of presentation with sickle crisis d. Patients with possible sickle disorders identified by neonatal screening who have been entered on a care pathway e. Eligible children beginning penicillin at or before three months of age f. Patients registered on the National Haemoglobinopathy Registry who had an annual review undertaken within the last year g. Patients on long-term transfusion who received cardiac MRI, and the proportion of those receiving a cardiac MRI who achieved a figure of less than 20ms h. Eligible patients with sickle cell disease who received an MRI for liver iron, and the proportion of those who received an MRI for liver iron who achieved more than 7 mg/gm/DW (sickle cell and thalassaemia separately)	Y	
HN-704	**Other Quality Data** The service should monitor on an annual basis: a. Proportion of children who have been offered treatment following Trans-Cranial Doppler Screening	N/A	
HN-705	**Other Audits** Clinical audits covering the following areas should have been undertaken within the last two years: a. Availability of extended red cell phenotype in all patients and the proportion of patients who have developed antibodies b. Whether all eligible patients on long term transfusion have been offered automated exchange transfusion c. Waiting times for elective: i. Phlebotomy ii. Cannulation iii. Setting up of the blood transfusion (for pre-ordered blood)	N	Audits covering time to analgesia and acute chest syndrome had been completed, but not the other audits as defined by the QS.

Ref	Standard	Met?	Comments
HN-706	**Network Audits** The service should participate in agreed network-wide audits.	N	This was not clear from the evidence of the agreed network audit programme. Some network audits had been completed but there was no evidence of 'closing the loop'.
HN-707	**Research** The SHC should actively participate in research relating to the care of patients with haemoglobin disorders.	Y	The team were actively engaged with research.
HN-708	**Trans-Cranial Doppler Quality Assurance (Children's Services Only)** The service should monitor and review at least annually: a. Whether all staff performing Trans-Cranial Doppler ultrasound have undertaken 40 procedures in the last year (QS HN-207) b. Results of internal quality assurance systems (QS HN-606) c. Results of National Quality Assurance Scheme (NQAS) for Trans-Cranial Doppler Ultrasound (when established) or local peer review arrangements (until NQAS established)	N/A	
HN-798	**Review and Learning** The service should have appropriate multi-disciplinary arrangements for review of, and implementing learning from, positive feedback, complaints, outcomes, audit results, incidents and 'near misses'. This should include: a. Review of any patient with a serious adverse event or who died b. Review of any patients requiring admission to a critical care facility c. Annual review of trends in National Haemoglobinopathy Registry data, activity data, Quality Dashboard, other quality data and other audits (QSs HN-701 to HN-705)	Y	
HN-799	**Document Control** All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	Y	Trust-wide documents were controlled. The Trust also allowed services to develop local guidance that was not required to be submitted for Trust approval.

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