BMJ Outcomes

Implementation report: Peer review of Haemoglobinopathy Services in the UK 2010-2013

Howard J[1], Kaya B[2], Wright J[3], Chakravorty S[4], Ryan K[5], Yardumian A[6], Eminson J[7]

Jo Howard (corresponding author)
Consultant Haematologist
Honorary Reader in Haemoglobinopathies
Guy's and St Thomas' Hospital
Great Maze Pond
London
SE1 9RT

M: 0207 188 2741 E: jo.howard@gstt.nhs.uk

Step 1: Specify the measure you have implemented

Peer review of haemoglobinopathy services in the UK: Assessment of acute National Health Service (NHS) Trusts performance against Quality Standards – Health Services for People with Haemoglobin Disorders v2.3 12 May 2015 (wmqrs.nhs.uk)

Step 2: Background to your organisation

The peer review programme of services for patients with haemoglobin disorders was led by members of the UK Forum for Haemoglobin Disorders in collaboration with the West Midlands Quality Review Service (WMQRS). The services were reviewed against a comprehensive list of Quality Standards produced by a subgroup of these two organisations and trialled in a single acute NHS Trust to ensure their usability. The programme began with a review of paediatric services in England in 2010 and was followed by a review of adult services in 2012-3. This article will report the findings from these peer review programmes. A subsequent follow-up peer review programme of paediatric and adult services is ongoing (2014-6).

For the adult review, 32 services were reviewed over 29 visits and 19 services were visited as part of the paediatric review. The centres reviewed were either Specialist Centres or Local Centres with large numbers of patients.

Sickle cell and thalassaemia are recessively inherited disorders of haemoglobin. Sickle cell disease (SCD) is most common in people of African, Afro-Caribbean or Arab-Indian ethnic origin and worldwide over 250,000 are born with this condition annually. It affects 12,000-15,000 people in the UK and is characterised by a reduced life expectancy, haemolytic anaemia, intermittent episodes of severe pain and chronic complications including an increased risk of stroke, cardiorespiratory complications, renal failure, eye disease and chronic bony pain. Treatment is often supportive but disease modifying therapy includes transfusion therapy and hydroxycarbamide treatment. Thalassaemia is most common in those of Mediterranean origin or from the Asian sub-continent and there are over 800 patients with severe forms of thalassaemia in the UK. Thalassaemia Major causes lifelong severe anaemia and patients require frequent blood transfusion. This inevitably causes iron overload leading to organ damage, particularly affecting the liver and heart. To avoid these severe complications patients require treatment with iron chelation agents and monitoring for the effects of iron overload.

1. Guy's and St Thomas' NHS Foundation Trust/King's College, London
2. Barts Health NHS Trust
3. Sheffield Teaching Hospitals NHS Foundation Trust
4. King's College Hospital NHS Foundation Trust
5. Central Manchester University Hospitals NHS Foundation Trust
6. North Middlesex University Hospital NHS Trust
7. West Midlands Quality Review Service

There is considerable geographical variation in prevalence of these conditions across the UK with the majority of affected individuals being resident in Greater London or the other large conurbations. Patients require access to appropriate acute care for the management of acute disease complications but also access to long term care for monitoring and treatment of chronic complications and for transfusion therapy. The variation in prevalence has led to variability in service provision across the UK and concerns about the inconsistency of service provision were raised in several national reports in the 2000s and by patient organisations. Discussions between the Department of Health Clinical Development Group and UK Forum for Haemoglobin Disorders (a multidisciplinary professional organisation) led to the development of a peer review programme for Haemoglobin Disorders which was supported by the NHS sickle cell and thalassaemia screening programme.

Step 3: Record what is already known about this outcome measure

The outcome measure that was used to objectively determine the quality of service provided by the individual Trusts was the extent to which the Quality Standards were met in each of the categories outlined within the Standards. The Quality Standards for sickle cell disease were developed from the 'Standards for the Care of Children and Young People with Sickle Cell Disease' and the 'Standards for the Care of Adults with Sickle Cell Disease' and the Quality Standards for patients with thalassaemia were developed from the 'Standards for the Clinical Care of Children and Adults with Thalassaemia' by members of the UK Forum on Haemoglobin Disorders with representation from patient organisations (Sickle Cell Society and UK Thalassaemia Society). This is the first time a national overview of haemoglobinopathy disorders has been undertaken in the UK (or elsewhere) and there are no data with which to benchmark the findings.

For the initial paediatric visits the Quality Standards (2010) were divided into subsections which covered:

- Information and support for patients and their carers
- Staffing and support services
- Clinical and referral guidelines
- Service organisation and liaison with other services
- Governance

The complete Quality Standards included 51 standards, two advditional standards for commissioning of services and five standards for the newborn screening programme.

Following the completion of the paediatric reviews the Quality Standards were adapted for the adult visits by a sub-group of the UK Forum of Haemoglobin Disorders and the West Midlands Quality Review Service (WMQRS). The resulting adult Quality Standards (2012) were divided into similar subsections to the previous standards with additional subsections covering:

- Facilities and Equipment
- Guidelines and Protocols
- Network: the network standards were added because of increasing evidence of the importance of networks of care as a method of improving quality and equity of care. The development of networks was becoming a key requirement of Specialist commissioning of services.

The complete Quality Standards included 51 standards of which 41 were service standards, 10 were network standards and two were commissioning standards. The service being reviewed was marked as compliant or non-compliant to each standard.

Examples of standards included:

- 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 session/s identified for this role within their job plan
- HN- 402 **Facilities for Out of Hours Care.** Facilities should be available for out of hours transfusion, phlebotomy and out-patient clinics appropriate to the needs of the local population
- HN-511 **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
- HN-602 **Multi-disciplinary Meetings.** Multi-disciplinary team meetings should be held regularly involving at least the lead consultant, lead nurse, nurse specialist or counsellor who provides support for patients in the community, other members of the service team and representatives of the support services
- 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 patients with a serious adverse event or who died

b) Review of any patients requiring admission to a critical care facility

- HY -701 **Ongoing Monitoring.** The network should monitor on a regular basis

  a) Submission of data on all patients to the National Haemoglobinopathy Registry

  b) Proportion of patient who have had their comprehensive annual review undertaken and documented in the last year

Step 4: Numerator

Data were collected in two ways. Firstly for each unit visited, the denominator was the total number of Quality Standards. The unit was assessed as compliant or non-compliant for each standard. For the adult standards, the numerator was the number of Quality Standards where the unit was compliant. For example if the unit was assessed for all 51 standards and was compliant for 41 of these, the denominator was 51 and the numerator was 41. This provided a useful overview of a particular unit's performance. In addition at the end of the review process, the total number of units compliant with any particular standard was calculated. Here the denominator was the number of units inspected and the numerator was the number of units compliant with the standard. This provided an overview of how well haemoglobinopathy services around the country performed against a certain standard. For example:

- HN-201 **Lead consultant:** In 31 centres, out of 34 visited, there was a named consultant undertaking appropriate personal development so 31/34 centres were compliant.
- HN-402 **Facilities for Out of Hours care:** 17 centres provided appropriate out of hours facilities so 17/34 centres were compliant with this standard.

It should be noted that not all standards had equal 'weight' or importance so that the percentage compliance is not an accurate 'score' but more a guide to the general quality of service and it should not be used to directly compare services.

Step 5: Denominator

Compliance with each Quality Standard

Step 6: Implementation of the outcome

Both the adult and paediatric programmes were co-ordinated by the WMQRS. The paediatric programme was led by a consultant haematologist, who was supported by a steering group, and 19 centres were visited as part of the paediatric peer review between March 2010 and January 2011. Trusts were invited to participate in the programme with at least three months notice and were asked to complete a background report and self-assessment against the Quality Standards before the visit. The peer review visit lasted one day and included a Trust introduction, review of written documentation, a meeting with patients and carers, a tour of facilities and and discussions with the clinical team, managers and commissioners. The visiting team included the lead clinician, paediatricians, paediatric haematologists, haematologists, specialist nurses, managers, psychologists and lay members. They assessed the centre against the Quality Standards and provided verbal feedback on the day of the visit and a written report after the visit, which was sent to the Hospital Trust. The report included a description of the hospital services, findings of the review visit (including good practice, concerns and further considerations) and listed compliance with all the standards. Any Immediate Risks were reported to the Trust on the day or within five working days.

The adult programme was run in a similar way; it was co-chaired by two haematologists who were supported by a steering group and completed 32 visits between March 2012 and April 2013.

All review reports are available on the WMQRS website (wmqrs.nhs.uk). At the end of the programme overview reports were produced which included detailed summary reports of findings and recommendations. These reports are also available on the WMQRS website and were circulated widely to NHS England (Specialised Commissioning Team), NHS Health Education England and to the All Party Parliamentary Group for Sickle Cell and Thalassaemia. In addition to the compliance data, examples of good practice were collected from across all services. Subsequent good practice events have been held to disseminate lessons learnt from the reviews more widely.

Step 7: Changes made to improve this outcome

The Quality Standards (outcome measures) were reviewed after the paediatric peer reviews by a sub-group of the UK Forum for Haemoglobin Disorders. They were reviewed again by the Peer Review steering group after the adult peer reviews before the subsequent second round of peer reviews which commenced in 2014. As part of each review each standard was reviewed for usefulness, relevance and ability to discriminate between services. Standards were re-worded, removed or replaced as appropriate. In addition the 2012/13 peer reviews were externally evaluated and the Evaluation Report is available on the WMQRS website.

Step 8: Implications of this outcome measure

Overview of the paediatric programme and the evaluation exercise of the adult peer review showed that the majority of participants felt that preparation for the visit had lead to changes in their services, that the peer review process had been useful to their organisation in improving services and all participants found it had been a helpful experience. However only 35% of participants felt that their organisation had been able to address the immediate risks or concerns identified in the report and this compared unfavourably with other peer reviews carried out by the WMRQS. The full impact of the peer review will only be realised when the second round of peer reviews is completed allowing comparison of the results from the successive peer reviews and measurement of any improvements in service.

Step 9: Related outcomes

Additional outcomes from the peer review visits include recommendations for service improvement which were produced for the overview reports. Summarized recommendations are listed below:

- NHS England should ensure that all patients with haemoglobin disorders have access to a Specialist Haemoglobinopathy Centre. Each Specialist Haemoglobinopathy Centre should have a geographic region across which it has responsibility for all patients with haemoglobin disorders
- NHS England should work with Clinical Commissioning Groups to ensure that all patients with haemoglobin disorders have access to local hospital care, community care, social work support and benefits advice.
- NHS England should ensure that commissioning of Specialist Haemoglobinopathy Centres includes provision of all relevant data to the National Haemoglobinopathy Registry, access to automated erythrocytopheresis, access to cardiac T2* and Liver R2 MRI monitoring, access to experienced psychology support and provision of training and support to local hospitals.
- NHS England should commission an ongoing programme of joint peer review of services for children and adults with haemoglobin disorders.
- Specialist Haemoglobinopathy Centres should pay particular attention to ensuring they have adequate medical and nurse staffing levels, training of junior medical staff, provision of out of hours transfusion, provision of neuropsychology assessments and provision of data to the National Haemoglobinopathy Registry.
- NHS Health Education England should review the workforce plan for staff specialising in the care of people with haemoglobin disorders to ensure an adequate supply of consultants and nurses.

The peer review process began its second visits in 2014 and whilst excellent progress has been made in some centres, the overall impression is that the majority of Trusts have not responded to concerns raised in the original peer review process. Services for patients with Haemoglobinopathies in England remain inadequate and inequitable and whilst there are many examples of units providing high quality care these excellent services are exceptions rather than the norm. Haemoglobinopathies are now a Specialist Commissioned service and Trusts should work collaboratively with NHS England and the Specialist Commissioning Teams to invest in a sustained improvement in service provision for haemoglobin disorders.

Step 10: Ratings

Please rate 1-5 (1 being the lowest and 5 being the highest) for the following measures of your outcome:

Ease of implementation (1, 2, 3, 4, 5): **2** – whilst the standards were easy to produce, the peer review process is time consuming and costly and needs to be resourced

Ease of data collection (1, 2, 3, 4, 5): **2** – again there is a lot of information to be collected and this needs to be resourced

Sustainability of outcome (1, 2, 3, 4, 5): **5**

Evidence base for outcome (1, 2, 3, 4, 5): **4** - based on expert consensus and published guidance

Reliability of outcome (1, 2, 3, 4, 5): **5** (as shown by evaluation report)

References:

Standards for the Clinical Care of Children and Adults with Thalassaemia in the UK. Second edition 2008. UK Thalassaemia Society (www.hbinfo.com/ukts-standards-2008.pdf)

Sickle Cell Disease in Childhood. Standards and Guidelines for Clinical Care. 2nd edition October 2010. NHS Screening Programmes Sickle and Thalassaemia www.gov.uk/government/uploads/system/uploads/attachment_data/file/408961/1332-SC-Clinical-Standards-WEB.pdf

Standards for the Clinical Care of Adults with Sickle Cell Disease in the UK (sicklecellsociety.org/wp-content/uploads/2016/02/Standards-for-the-Clinical-Care-of-Adults-with-Sickle-Cell-Disease-in-the-UK.pdf)

Overview Report – 2012/13 Adults with Haemoglobin Disorders reviews. Sept 2013. wmqrs.nhs.uk

Overview Report – SC&T 2010/11 Peer Review Programme. Sept 2011. wmqrs.nhs.uk