Central Manchester University Hospitals NHS
NHS Foundation Trust

Audit of Information provided to parents of carriers of abnormal haemoglobin variants

Audit Report

Date Undertaken: November 2014

Audit Lead: Helen Jopling

Person/s responsible for action plan: Beverly Hird

Person/s responsible for dissemination: Beverly Hird

Green	Amber	Red	Assurance Level	Risk Ref
			Very Limited	

Audit Outcomes Summary	
Audit Title	Audit of Information provided to parents of carriers of abnormal haemoglobin variants

Action Plan		
Key Action	Co-ordinator for action	Timescale
To disseminate findings to SLHV throughout the region via Screening and Immunisation Co-ordinators within the Local Area Teams	Bev Hird	Aug 2015
Share findings with the Manchester Sickle Cell and Thalassaemia Centre	Bev Hird	Aug 2015
Share findings with the North West Antenatal & Newborn Screening Quality Assurance Team	Bev Hird	Aug 2015
What was the main matter(s) of concern this audit identified?		
33% of audit forms for carriers of abnormal haemoglobin variants are not being returned to the NBS laboratory meaning there is no record as to whether these results have been communicated to parents during a face to face meeting.		
Please identify the main benefit(s) to our patient, or to hospital process that are expected to result from the action plan of this audit		
The NBS laboratory is responsible for reporting the carrier status of babies with abnormal haemoglobin variants. The completion of audit forms which are returned to the laboratory confirms that this information has been communicated with parents in a face to face meeting to avoid unnecessary anxiety.		
Will there be a re-audit?	*Yes*	When will the re-audit take place? *April 2016*

Background

Babies identified as carriers of abnormal haemoglobin variants through the newborn screening (NBS) programme, should ideally have their status reported to their parents as part of a face to face consultation[1]. Although there is no clinical impact from carrier status of an abnormal haemoglobin variant, it is important that the result is properly communicated, in order to avoid unnecessary anxiety or confusion if parents were to receive the report of their child's carrier status alone. In the northwest region, results of carrier status are reported by letter from the NBS laboratory to local screening link health visitors (SLHV) who are then responsible for communicating this information to parents. The information provided to the SLHV includes an audit form which should be returned to the NBS laboratory to confirm that the parents of the baby have been visited and had the result explained to them. The forms were introduced following several incidents, which came to light in 2013 (as a result of a research study), of parents being unaware of their child's carrier status, The audit form system has been in place since the start of April 2014, and it was therefore decided to review the return rate of these forms over a 6 month period.

Aim & Objectives

- To identify the return rate of haemoglobin carrier audit forms, from individual Child Health Records Departments (CHRDs),to the Manchester NBS lab, over the 6 month period from April to September 2014.

Standards

- NP2ii from Standards for the linked Antenatal and Newborn Screening Programme[1]

  Acceptable Standard: 80% of parents of carrier babies given written information ideally during a face-to-face discussion by trained healthcare professionals

  Achievable Standard: 90% of parents of carrier babies given written information ideally during a face-to-face discussion by trained healthcare professionals

Method

A list of babies with abnormal haemoglobin variants identified and reported was gathered from the NBS laboratory computer system Specimen Gate for the 6 month period from 1/04/14 to 30/09/14. All forms which have been returned to the NBS laboratory have been retained, and these were then matched with the sample numbers from the data collected from Specimen Gate.

Results

A total of 332 babies were reported to CHRDs as carriers of abnormal haemoglobin variants during the audit period. 223 completed audit forms were returned to the lab during this period, although 4 could not be matched with records due to missing patient demographics. This represents only 67% of the results reported. 216 of these audit forms reflected a conversation with parents where the result was given, entered in the baby's red book and explained, leaving patients with the screening programme information leaflet. 2 babies had left the area by the time the result was available; in one case the family returned to Nigeria and therefore the result could not be reported, in the other the family had moved within the UK and the result was passed onto the relevant screening lab for onward communication. The parents of a further baby refused a visit as the older sibling of their child is also a carrier and therefore they felt they knew enough about the status of their child. 109 babies (33%) did not have a returned audit form and therefore it is unclear whether the result has been communicated with the parents.

The number of returned audit forms was considered per Child Health district both as a percentage of the number of abnormal haemoglobin carriers reported (Figure 1), and the actual number of reported carriers versus the number of returned audit forms. SLHVs for the area covered by

Lancaster CHRD returned 100% of carrier audit forms, with Burnley performing the worst, returning less than 20% of those forms issued. Both these areas only had a few identified carriers of abnormal haemoglobin variants (Figure 2), with the vast majority being reported to Manchester CHRD, who returned 73% of their carrier audit forms.

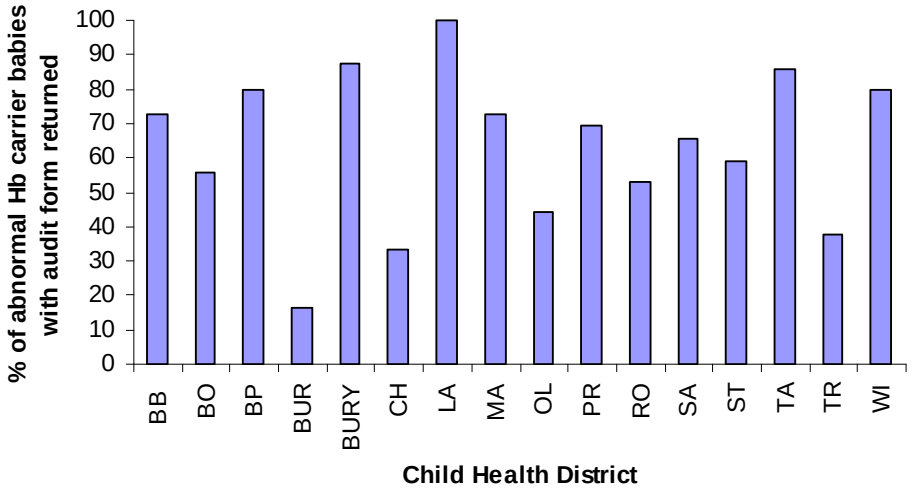

Figure 1. Percentage of Abnormal Haemoglobin carrier babies with an audit form returned to the NBS lab separated by CHRD. See Appendix 2 for Child Health abbreviations.

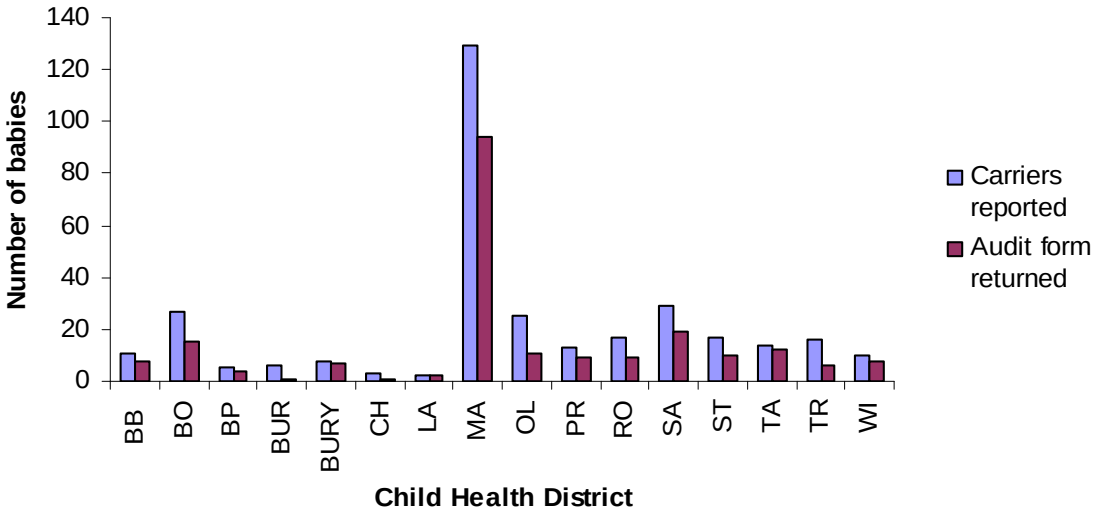

Figure 2. Number of babies reported as carriers of abnormal haemoglobin variants by CHRD and the number of audit forms returned to the NBS lab.

The time taken for parents to be contacted with their child's diagnosis was also considered. The acceptable standard for the haemoglobinopathy programme is for 95% of screen negative results, including haemoglobinopathy carriers, to have results available by 6 weeks of age[1]. Whilst this reflects the time required to report results to the CHRD, rather than to the parents, it would be expected that the carrier status of the child should be reported in a timely manner to the baby's parents. The shortest turnaround time from a result being issued to a visit with the parents was 3 days during the audit period, with the longest length of time 65 days. The spread of time taken was

quite varied and is illustrated in figure 3. There was no clear pattern for variation in time taken for the result to be reported and CHRD.

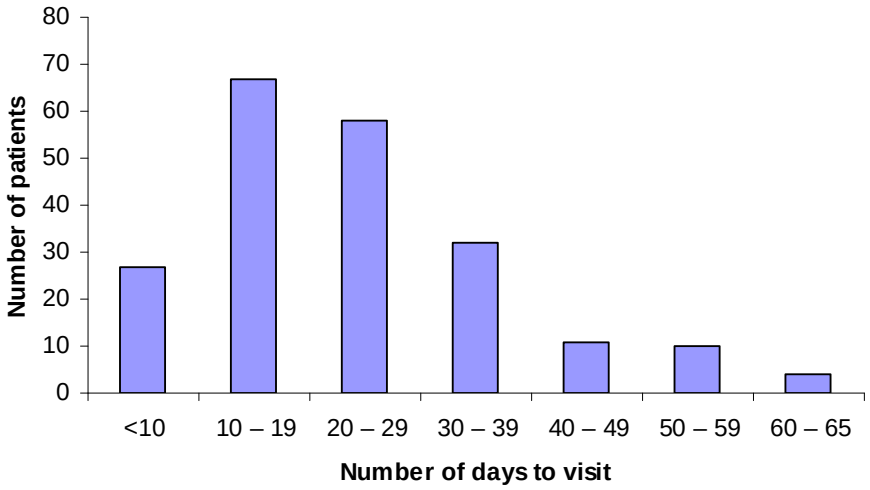

Figure 3. Time taken for parents to be informed of their child's status as a carrier of an abnormal haemoglobin variant.

Key:

Compliance ≥ 95%	Compliance 75% - 94%	Compliance ≤ 74%

Standard	Compliance (%)
80% of parents of carrier babies given written information ideally during a face-to-face discussion by trained healthcare professionals	67%

Conclusions

Only 67% of babies who were reported to be carriers of an abnormal haemoglobin variant during the audit period were clearly identified as having their result reported to their parents as part of a face to face consultation. Whilst the other 33% of babies may also have had this information reported, the lack of receipt of a carrier audit form by the NBS laboratory means that we have no way of identifying if the result has been passed on.

References

1. Standards for the linked Antenatal and Newborn Screening Programme. NHS Sickle Cell and Thalassaemia Programme. 2nd Edition. October 2011

Action Plan

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Appendix 1 – Assurance levels for Clinical Audit

For each clinical audit undertaken, an assurance rating is reported for each standard measured.

Step 1:
Each standard is given a rating of red, amber or green depending on how high, or low, it measured.

Calculation of individual ratings against standard	
Colour	Standard % measure
	95% and above
	75% to 94%
	74% and below

Step 2:
Once each standard has been rated an overall level of assurance for the audit project can be determined using the matrix below.

Assurance Level	Calculation of assurance
Full	To be used when each standard has achieved a score of 95% or above and is rated Green
Significant	To be used when there are only Green and Amber rated findings (although where there are a significant number of Amber rated findings, consideration will be given as to whether in aggregate the effect is to reduce the assurance level given)
Limited	To be used when there is a small ratio of Red and Amber to Green rated findings
Very Limited	To be used when the ratio of Red rated findings are greater than the Amber and Green

The appropriate level of assurance will be decided following a discussion between the clinical audit lead, or leads, and the clinical audit department.

In the event that a decision cannot be reached, the Trust Clinical Audit Committee has the final word.

The assurance level and a summary of the how the standards were rated then sits on the front page of the report, as can be seen above on Page 1.

Appendix 2

Key to Child Health District Abbreviations

BB	Blackburn
BO	Bolton
BP	Blackpool
BUR	Burnley
CH	Central Lancs/Chorley
LA	Lancaster
MA	Manchester
OL	Oldham
PR	Preston
RO	Rochdale
SA	Salford
ST	Stockport
TA	Tameside
TR	Trafford
WI	Wigan