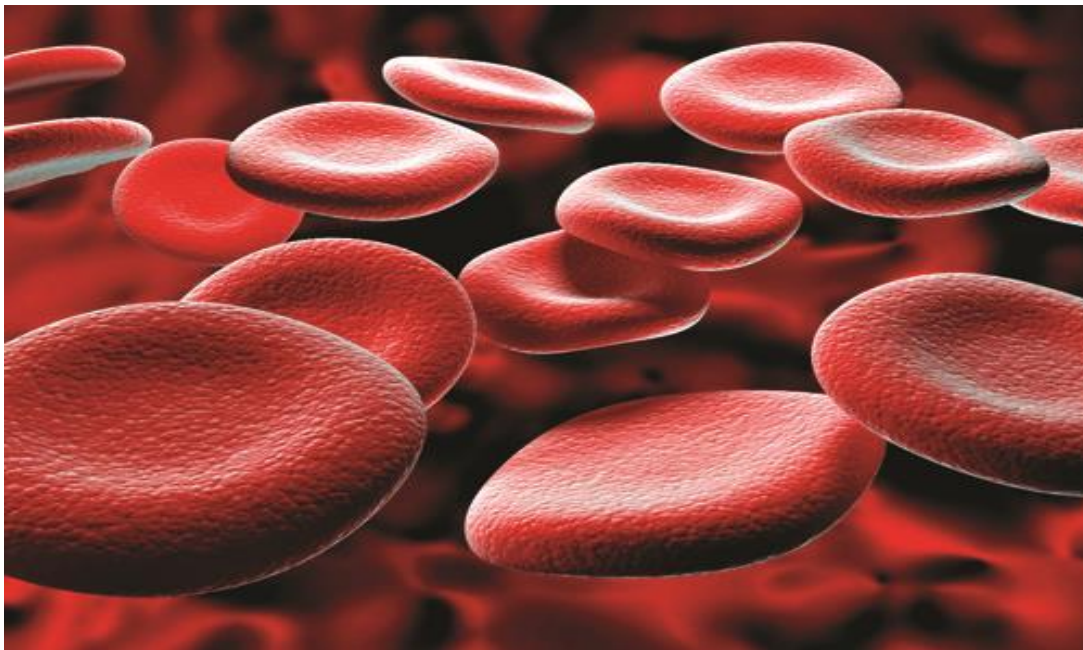


# WEST MIDLANDS PAEDIATRIC HAEMOGLOBINOPATHY NETWORK LAUNCH EVENT



**May 2016**

Birmingham has the highest concentration of patients with haemoglobin disorders outside London. The West Midlands Paediatric Haemoglobinopathy Network was launched 23<sup>rd</sup> May 2016. This report is a summary of event and discussions that took place during the launch.

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### **Authorship**

West Midlands Paediatric Haemoglobinopathy  
Network Launch led by:

Dr Mark Velangi  
*Consultant Paediatric Haematologist*  
*Birmingham Children’s Hospital*

Alison Davies  
*BCH Network Development Lead*  
*Birmingham Children’s Hospital*

Report and Evaluation compiled by Kingsley Idemudia  
Osarenren  
*West Midlands Haemoglobinopathy Network Co-ordinator*  
*Birmingham Children’s Hospital*

## Section 1: The Event

West Midlands Paediatric Haemoglobinopathy Network was launched on the 23<sup>rd</sup> of May 2016 at Maple House, Birmingham. A total of 45 delegates representing different Trusts and community services across the West Midlands, NHS England, voluntary organisations and two patients and their family attended. Also in attendance were representatives from South Thames Sickle Cell & Thalassemia Network.

The event commenced with an introductory presentation by Dr Mark Velangi, highlighting the Birmingham Children's Hospital Haemoglobinopathy team, clinical services provided, challenges and aspirations for the next year. The introduction also took a look at the demography of the West Midlands and Birmingham in terms of ethnicity, age, fertility rate, multiple deprivation and numbers of Haemoglobinopathy cases compared to other regions in England.

Key speakers at the launch included Philippa Turner, Service Specialist within the Specialised Commissioning team at NHS England Midlands & East. Philippa spoke on 'Networking for a Sustainable Future: The Commissioner's Perspective'. She started her presentation with the prevalence of haemoglobin disorders, and then took a look at the longstanding service deficiencies, which include lack of specialist nurses, lack of robust data, patients being lost to follow-up, high outpatient DNA rates and poor arrangements for transition. She went further to talk about commissioning arrangements, service specification, the role of the clinical network and network configuration.

'A family experience' was presented by a family living with Haemoglobinopathy. This gave an insight into how families cope with the condition, how services

could be improved for the benefit of the patients and their families and also the social aspect of care. One key issue the family raised was around scheduling of appointments and a desire to bring together different appointments together to minimise hospital visits and time off work and school.

Dr Subarna Chakravorty, Consultant Paediatric Haematologist & Belle Kelly, Network Support Manager, both of South Thames Sickle Cell & Thalassemia Network, shared the success and benefits of their existing network.

Dr Shivan Pancham, Consultant Haematologist, Sandwell and West Birmingham Hospitals NHS Trust, gave an overview of the adult Haemoglobinopathy service.

## **Section 2: Discussion Feedback**

Series of table top discussions were held under three major groups – where delegates were asked to sit in one of three defined geographical areas of care; Shared Care/High Prevalence, Tertiary and DGH/Low Prevalence.

The topics for discussion were;

- What works well now within Paediatric HBO services?
- What are the greatest challenges across the region for HBO care?
- What are network-wide solutions to the challenges raised?
- Membership of the Network – who should be on the board?
- What meeting structure is required – where and how frequently?
- What education programme should the Network work towards?
- What are the data and governance needs of the Network?
- What are the Network priorities for the next 12 months?

## What works well now within Paediatric HBO services?

The three different discussion groups identified several areas they considered to be working well within the Paediatric HBO services.

### Specialist Haemoglobinopathy Centre (BCH)

1. The Haemoglobinopathy day transfusion service is nurse-led and is efficient
2. The innovative model of the hospital school available during transfusion. This ensures children don't have to miss school attendance during transfusion as they would be registered as present.
3. Crossmatching service is available on Thursday before/ after school.
4. Transition clinic is now in place with 8 weekly clinics with team from City hospital
5. Coordination of clinical review with TCD
6. Joint specialist clinics with neurology and endocrinology.
7. Outreach clinics in Coventry, Wolverhampton, Stoke and Sandwell.
8. BCH Hydroxycarbamide clinic.
9. There is a good link between hospitals and home with the placement of the community liaison roles although the capacity of this team is not currently adequate to cover these roles fully.
10. The group has been using 'healthy mind' as a way to fill the gap in psychology service

### Local Haemoglobinopathy Centre (Shared Care/High Prevalence group)

1. Informal network, with well-established relationship and communication within the community.
2. Wolverhampton schools and Walsall engagement with community support services is excellent.
3. There is good training and working relationships with women's refuge and smooth handover process between community services, to make sure families are not lost.

4. The voluntary sector (OSCAR) has a strong relationship with outreach team at BCH, the community and they are just phone call away.
5. Some health promotion and education taking place in schools.
6. Also established is the Social work student's drop-in voluntary service.

### Local Haemoglobinopathy Centre (DGH/Low Prevalence)

1. Ability to do cross –match out of hours in Stoke with most being done at home.
2. Combining patient review when they attend for transfusion in Telford.
3. Transfusion proforma in Telford
4. Worcester have alert attached to oncology patients on e-records and patients continue under care of one consultant as much as possible.

### What are the greatest challenges across the region for HBO care?

#### Specialist Haemoglobinopathy Centre (BCH)

In the Tertiary discussion group numerous challenges were identified, these include;

1. Current workforce capacity especially Consultant time and outreach nursing
2. The need for review patient need for out of hour transfusion services
3. Expansion of the red-cell exchange programme
4. Coordination of appointments to avoid repetition (outreach appointments especially)
5. Overview and follow-ups of DNA patients. There is an issue of geographical movement of families (coming into, moving around and moving out of the country) with no one following the family.

6. Capacity of specialist clinic which currently has limited slots
7. Capacity for increase in the hydroxycarbamide clinic caseload.
8. Support for developing local database and input into the national HBO Registry
9. Inadequate psychological support as the gap is being filled through nurses. There is poor medication compliance, thus having impact on outcome and cost and getting parents on board is also challenging
10. Inadequate social care support as the gap is being filled through nurses eg. Caseload on child protection cases
11. There is also the need for more school liaison or community support in BCH and the establishment of school care plans.

#### Local Haemoglobinopathy Centre (Shared Care/High Prevalence group)

The group identified several challenges which include;

1. Lack of CNS in Wolverhampton/Walsall
2. Language barriers leading to medication problems
3. Need for improved knowledge in primary care.
4. Difficulty in accessing psychological services for HBO caseload.
5. Community support services currently providing support beyond expertise
6. OSCAR Sandwell identified its limitations as a challenge
7. Transition of acute care from child to adulthood
8. Ambulance referrals to centres with little specialist expertise
9. Shortage of work force and patient population increase
10. Challenges in the voluntary sector include limited resources and the postcode lottery for provision

#### Local Haemoglobinopathy Centre (DGH/Low Prevalence)

1. Peer group support is challenging as there is difficulty in reaching out to patients.
2. There is also lack of consistent guidelines.
3. Invisibility of children's issues in primary care commissioning.

4. Difficulties with long term prescribing in primary care.
5. Need for psychological services for the families in Stoke.
6. There are no dedicated named HBO nurses in Stoke and Worcester, even as the nursing team roles need definition.
7. Nursing education in form of study days, and e-learning needed. There is also need to link GP PLT with nurses' education.

### **What are network-wide solutions to the challenges raised?**

Again the solutions proffered for the challenges raised will be reported under the three major discussion groups.

#### **Specialist Haemoglobinopathy Centre (BCH)**

1. Network support/local funding
2. Mapping of current population and HBO services
3. Work force gap analysis
4. Increase in Consultant sessions. Large gap when benchmarked with other centres and non-compliant with recent review of workforce requirements.
5. Review of capacity of current outreach nursing support
6. Gather evidence/ research to justify need for psychologist employment
7. Collective resourcing for key points
  - a. E.g. psychology/ community services
  - b. spreading equity of access of care
8. Review capacity for community nursing provision outside of Birmingham
9. Regional HBO forum (used to exist) and network events
  - a. Education
  - b. Data reporting
  - c. Learning
  - d. Guidelines
10. Peer-2-peer support
11. Ongoing data support to
  - a. Comply with the mandatory reporting outcomes to national and regional bodies
  - b. Report regional data to network group
12. Education



### Local Haemoglobinopathy Centre (Shared Care/High Prevalence group)

1. For acute care referrals
  - a. Review of protocols & training /education for local trusts/teams by consultants in specialist hospitals
  - b. Liaise with ambulance services
  - c. To ensure appropriate delivery of patients Care plan teams involving GPs, schools and specialists
  
2. Educational tools:
  - a. Setting up educational programs/meetings
    - i. Organising educational events for peer groups
    - ii. Videos/Podcasts in different languages
    - iii. E-learning Module adoption (Developed by Dr Pancham-Sandwell)
    - iv. Mailing list sent to network members to capture who is interested in hosting and coordinating events
    - v. To provide training to local district centres.
    - vi. Buddy/mentoring system between similar parents who have experience of overcoming challenges, run at district level
    - vii. Public health link-health prevention (Need to show sustainability)
  
3. Clinical psychological needs/referrals
  - a. Dedicated psychology sessions
  
4. Staffing
  - a. Development of specialist social work post (West midlands). Someone with HBO interest
  - b. Review of frequency and staffing of dedicated HBO Clinics (including review of frequency of outreach from SHC)
  
5. Support
  - a. voluntary sector grant application
  - b. CCGs-engagement and multi-agency approach

### Local Haemoglobinopathy Centre (DGH/Low Prevalence)

1. Each hospital establish a lead or named clinician and lead nurse for HBO
2. Establish a cross boundary outreach service from SHC
3. Develop network guidelines

4. Regional presentation of outcomes
5. Develop robust interactive network website

### **Membership of the Network – who should be on the board?**

Everyone present at the launch was given the opportunity to air their views as to membership of the network; including who can be clinical lead and board members.

#### **For Network Steering Group, the following were suggested:**

- Specialised commissioning rep (NHSE). CHAIR PERSON
- Consultants from each main provider (Coventry, Wolverhampton, Sandwell, City)
- Invitations to all low prevalence regional DGHs to provide a Consultant/Nurse Lead representative if they wish
- Network pharmacist (from BCH)
- Psychologist
- Network coordinator
- Data management
- Patient/family representative
- Support Groups representative

#### **For clinical lead, the following were suggested:**

- 1 x BCH Consultant
- 1 x DGH/ co-clinical lead (from either Coventry or Wolverhampton)
- Board to be chaired by NHSE Service Specialist

Other organisations to be considered for membership at a later stage (or as a one-off invitation):

- Health watch
- Discuss the attendance of rep from CCG, Public health
- Research groups
- Maternity /newborn services
- Local authorities

- Social care/social workers
- Health visiting

### **What meeting structure is required – where and how frequently?**

Suggestions made for content of the meetings include governance issues/practicalities, updates, pain management, transition, A&E and community. Others suggested the need to have sub group meeting e.g. nurses, clinicians, research and patient/parents.

As for frequency of meetings, majority of people suggested 3-4 times a year. In terms of location, there were suggestions for rotation between different Trusts and high prevalence area. Others suggested volunteering centres, Maple House (if fund is available) and university lecture hall.

### **What education programme should the Network work towards?**

Several suggestions made include:

- Embedded education programme for all staff coming into nursing and social workers
- Annual conference for nursing students from Birmingham city, Wolverhampton, Staffordshire and Worcester University.
- Unified management guidelines for routine and emergency care, recent advancement and research.
- Educating parents for buddying schemes
- Raising awareness involving care plans within schools
- E-learning modules, taught sessions to assist with sharing ideas and networking
- Patient information sessions

### **What are the data and governance needs of the Network?**

1. Development of regional database for audit and research. It was suggested that the regional data base be updated monthly.
  - a. post code mapping
2. Data entry compliance with the National HBO Registry
3. Publication with local contacts.
4. Admission notification
5. Terms of reference and engagement
6. Policies for monitoring, evaluation and risk assessment
7. Need to establish ways to ensure equity of services across the region and the sharing of good practice.
8. Regional guidelines to be communicated via the network group
9. Audits/ Surveys
  - a. Determination of ratio of patients per specialist nurses,
  - b. Patient survey to improve care
  - c. Time and analgesia in A&E.

### **What are the Network priorities for the next 12 months?**

After a full day of presentations and deliberations by different stakeholders present at the launch, six main network priorities were agreed upon for the next 12 months.

These are:

- Regular network meeting every 4 months
- Mapping of current services and gap analysis against service specifications
- Dissemination of shared consistent protocols/management of patients across the network
- Development of the regional and national database with data collection/sharing
- Audit programme for 2016/2017
- Regional patient/family experience survey

### Section 3: Event Evaluation

At the end of the event, 31 evaluation forms were received after being shared out to everyone present.

The event was evaluated positively, with delegates demonstrating that they had found the day to be worthwhile.

Session	Evaluation result
Introduction to Paediatric HBO Network Dr Mark Velangi	57% of the delegates found this session extremely useful and 43% found it useful
Networking for a sustainable future: The commissioners perspective Phillipa Turner	45% of the delegates found this session extremely useful ,48% found it useful and 7% found it fairly useful
A family experience	44% of the delegates found this session extremely useful ,40% found it useful, 13% found it fairly useful, while 3% found it not useful
Table top discussions:  What works well now within Paediatric HBO services?  What are the greatest challenges across the region for HBO care?  What areas were highlighted at the recent Peer Review visit for further	42% of the delegates found this session extremely useful ,55% found it useful and 3% found it fairly useful

work?	
Sharing success and benefits of existing Networks Dr Subarna Chakravorty & Belle Kelly	64% of the delegates found this session extremely useful ,33% found it useful and 3% found it fairly useful
Table Top discussions:  What does the West Midlands need from a HBO Network?  What are network-wide solutions to the challenges raised?	28% of the delegates found this session extremely useful, 66% found it useful and 6% found it fairly useful
An overview of the adult HBO service Dr Pancham	26% of the delegates found this session extremely useful, 55% found it useful and 19% found it fairly useful
Table Top Discussions  Membership of the Network-who should be on the board?  What meeting structure is required- where and how frequently?  What education programme should the Network work towards?  What are the data and governance	45% of the delegates found this session extremely useful, 52% found it useful and 3% found it fairly useful

<p>needs of the Network?</p> <p>What are the Network priorities for the next 12 months?</p>	
<p>Closing remarks and agree onwards plan Mark Velangi</p>	<p>35% of the delegates found this session extremely useful, 58% found it useful and 7% found it fairly useful</p>

## ATTENDANCE LIST

Name	Organisation	Position
Abdul Alim	OSCAR Sandwell	
Alexandra Birch	NHS Stafford CCG	Snr Comm Mgr for Maternity and Children's Services
Ally Davies	Birmingham Children Hospital	BCH Networks Lead
Amanda Cope	Birmingham Children Hospital	Advanced nurse practitoner HBO
Annie Cheatham	Birmingham Children Hospital	Associate Service director Haem/Oncology
Aswath Kumar	Stoke	Consultant Paediatrician
Barbara Bailey	Community HBO team - Birmingham	Adult HBO CNS
Baylon Kamalarajan	Worcestershire Acute Hospitals NHS Trust	Consultant Paediatrician
Beccy Heath	BCH	Psychology
Belle KELLY	South Thames HBO Network	HBO network manager
Beryl Douglas-Green	University Hospitals of Coventry and Warwickshire	Paed HBO CNS
Carl Tiivas	University Hospitals of Coventry and	Head of Vascular Lab / provider

	Warwickshire	of TCD services
Deepak Kalra	Sickle Cell & Thalassaemia Support Project	Director
Edel Robinson	BCH/ South Birmingham CCG	Paed HBO CNS (outreach)
Elaine Carrolan	Birmingham Children Hospital	Quality,Accreditation & Data Manager
Family rep	Wolverhampton	Marho Fovie and family
Gill Taylor	Birmingham Children Hospital	HBO Unit Manager
Gillian Lowe	University Hospital Birmingham	Consultant Haematologist
Hobby Rahman	OSCAR Birmingham	Youth Development Manager
Isabel Adams	BCH/ South Birmingham CCG	Paed HBO CNS (outreach)
Janice Llewellyn	Shrewsbury & Telford NHS Trust	Paed HaemOnc CNS
Julie Brent	Royal Wolverhampton Hospital Trust	Consultant Paediatrician
Juliet Brown	Birmingham Children Hospital	Coordinator Patient Pathways
Kingsley Idemudia Osarenren	Birmingham Children Hospital	West Midlands Paediatric HBO Network Coordinator
Leon Small	OSCAR Birmingham	Client Support Officer
Lucy Jennings	Birmingham Children Hospital	Project Assistant patient pathway
Luriteen Miller	Community HBO team - Birmingham	Service Co – ordinator
Mark Velangi	Birmingham Children Hospital	Paediatric Consultant Haematologist
Maserat Lal	Uk Thalassaemia Society	Administrator and patient advocate
Paminder Kaur Lakhpuri	HBO Support Project (Wolverhampton & Walsall Community Services)	HBO Community Counsellor
Phillipa Turner	NHSE	Service Specialist
Rachel McFee	Oscar Sandwell	Centre Manager
Ronald Walker	OSCAR Birmingham	Volunteer
Sammy Sharp	Birmingham Children Hospital	Administrative assistant patient pathways
San Pandya	Birmingham Children Hospital	Project Assistant patient pathways
Sarah Lawson	Birmingham Children Hospital	Paediatric Consultant Haematologist
Shivan Pancham	City Hospital	Consultant Haematologist (Adult)
Simon Dyson	Unit for the Social Study of Sickle Cell, De Montfort University	Professor of Applied Sociology
Subarna Chakravorty	South Thames HBO Network	Paediatric Consultant Haematologist



**West Midlands Paediatric Haemoglobinopathy Network Launch Event**

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Sutinder Herian	HBO Support Project, Wolverhampton,	Project Co-ordinator
Suzi Crawford	Community HBO team - Birmingham	Paed HBO CNS (community)
Tabitha Parsons	Shrewsbury and Telford NHS Trust	Consultant Paediatrician