

**DIVISION OF SPECIALISED SERVICES & WOMEN'S AND  
CHILDREN'S SERVICES**

**BRISTOL HAEMATOLOGY & ONCOLOGY CENTRE**

**BRISTOL ROYAL HOSPITAL FOR CHILDREN**

**ANNUAL REPORT**

**2024-2025**

South West Haemoglobinopathy Coordinating Centre for Sickle Cell and Specialist Haemoglobinopathy Team for Sickle Cell, Thalassaemia and Rare Inherited Anaemias

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## Summary

The annual report outlines the care provision our service offers patients with haemoglobinopathies and rare inherited anaemias at University Hospitals Bristol and Weston NHS Foundation Trust (UHBW).

In 2019, UHBW was awarded as Specialist Haemoglobinopathy Team (SHT) for haemoglobinopathies and rare inherited anaemias and granted a Haemoglobinopathy Coordinating Centre (HCC) status for Sickle Cell Disease. All relevant service specifications for both services are published by NHS England. [NHS England » Specialist haemoglobinopathy services \(adults and children\)](#).

The UHBW haemoglobinopathy team provides care for both Children, Young Adults and Adults. The paediatric service is based in the Bristol Royal Hospital for Children (BRHC). The adult service is based in the Bristol Haematology & Oncology Centre (BHOC).

As Haemoglobinopathy Coordinating Centre and Specialist Haemoglobinopathy Team, we oversee the care of haemoglobinopathy patients and rare inherited anaemia in the following hospital Trusts which include Royal United Hospital Bath NHS Foundation Trust, Dorset County Hospital NHS Foundation Trust (Adults only), Gloucestershire Hospitals NHS Foundation Trust, Royal Cornwall Hospital NHS Trust, Somerset NHS Foundation Trust, Royal Devon University Healthcare NHS Foundation Trust, University Hospitals Plymouth NHS Trust, Torbay and South Devon NHS Foundation Trust, North Bristol Trust (Adults only).

## Structural Organisation

POSITION	MEMBER OF STAFF	WTE or PA (not all HCC funded, some are existing posts)
HCC Clinical Lead	Dr Sanne Lugthart	1.25 PA
Deputy Clinical Lead	Dr Tom Latham	1 PA
Paediatric Clinical Lead	Dr Michelle Cummins	8 PA
Deputy Paediatric Clinical Lead	Dr Maria Pelidis	0.25 PA
Lead HCC Clinical Nurse Specialist	Prisca Lux	1 WTE
Adult Clinical Nurse Specialist	Eljil Joseph	0.7 WTE
Paediatric Clinical Nurse Specialist (Haemoglobinopathy Lead)	Sophie Smith	1 WTE
Paediatric Clinical Nurse Specialist	Helen O'Keefe	1 WTE
Paediatric Clinical Nurse Specialist	Katrina Riley	0.6 WTE
Quality Improvement Fellow	Dr Amy Cooper	1 WTE (contract until 02/09/2025)
Rotating Haematology Registrar (Adults)	4 monthly rotation	Variable with each rotation

Rotating Haematology Registrar (Paeds)	4 monthly rotation	Variable with each rotation
Practice Education Practitioner (Adults)	Charlotte Jones	0.2 WTE (Starting early June 2025)
Practice Education Practitioner (Paeds)	Currently vacant	0.2 WTE
Pharmacist (Adults)	Rachel Lloyd	0.4 WTE
Pharmacist (Paeds)	Vanessa Mclelland	0.2 WTE
Clinical Psychologist (Adults)	Dr Katie Wilkinson Dr Sarah Hellegren	0.55 WTE
Clinical Psychologist (Paeds)	Dr Sarah Muddle	0.4 WTE
Psychology Assistant (Paeds)	On rotation	0.2 WTE
Patient Support Worker (Adults)	Melanie Marsh	0.96 WTE
Family Support Worker (Paeds) (covers all benign haematology)	Hayley Wiles	1 WTE
Service Manager (Paeds & Adults)	Sandra Schneider	1 WTE
Data Manager (Paeds & Adults)	Rhyanna Britton	1 WTE

## Activities

See **appendix 1**

## SW HCC Meetings

We hold twice yearly business meetings as outlined in the service specifications. These take place in June and December.

Historically, there has been low attendance from our LHT colleagues, therefore we have started to add our June business meeting to the start of our annual education day. On 6<sup>th</sup> June the attendance was 3 adult consultants from 3 LHTs, 3 CNS from 2 LHTs, 1 paediatric consultant from 1 LHTs.

## SW HCC MDT Meetings

We hold monthly regional multi-disciplinary team (MDT) meetings. These start off with a teaching session of about 15 minutes. Topics are suggested by the LHTs or HCCs staff members. We prioritise any teaching about any new treatment or research as they become available i.e. gene therapy. Further details on the teaching sessions can be found in the education and training activities section of this report (page 6).

Over the last 12 months we held 11 meetings and discussed a total of 32 cases. The breakdown of these is as follows: 20 adult cases (3 Bristol, 6 Bath, 6 Plymouth, 3 Gloucester, 1 Truro, 1 Taunton), 5 paedics case (5 Bristol), 7 transition cases (6 Bristol, 1 Gloucester).

## Education and training

We organise an annual education day for the South West region. This is a face-to-face event taking place in Bristol. This is aimed at all healthcare professionals in our region from consultants, registrars, nurses and many more. Please see **appendix 2** for the most recent agenda and topics that were covered.

We also offer various education sessions from shorter bitesize sessions to longer education sessions for various different staff groups. This includes Emergency department (ED) consultants, registrars and nurses, GP surgery staff members, BHOC nurses, Trustwide registrars, regional consultants, registrars, nurses, schools, universities, employers etc. Please see **appendix 3** for the up-to-date teaching spreadsheet for further details.

## Audits

All team members of the haemoglobinopathy team take part in audits. We hold twice yearly audit meetings where completed audits are presented and discussed.

Audits we have completed in the last 12 months are:

- Quality Improvement – reduce time spent in hospital for thalassaemia patient attending the outpatient department for routine transfusions (adults only)
- Time to transfusion (paeds only)

Audits we are planning to complete in the next 12 months are:

- Regional (HCC) pain audit – this will be a re-audit (paeds & adult)
- To assess sickle cell patients compliance with penicillin V prophylaxis (adult only)
- Incidence of new red cell alloantibodies in haemoglobinopathy patients on regular transfusion programme at UHBW (adult only)
- Antibiotic prophylaxis (paeds only)

## SW HCC Website

This year we were fortunate to get approval to create our own website. Our web address will be <https://www.southwesthcc.nhs.uk>. We aim to launch this at our next education day (June 2025). Creating a website and gathering all the information takes a lot of work and a huge thank you goes to Dr Amy Cooper, our Quality Improvement Fellow, who has designed the website and coordinated the content.

Once the website is live, we would welcome any feedback about our website and its content. We are aiming to update information regularly. If anyone identifies any missing information or has any novel ideas to share on our website, please do let us know.

## Memorandum of Agreements (Service Level Agreements)

We have memorandum of agreements (MoA) in place since 2023. See **appendix 4**. 8 out of the 9 LHTs have signed and returned the MoA to us, the only exception is Dorset County Hospital. We are currently reviewing our MoAs as we are in the process of introducing annual review clinics for adult patients and have changed a few processes. We will get in touch with our LHTs once the changes have been made.

## Shared care agreements/protocols

We have a shared care agreements in place with our LHTs about chelation therapy. See **appendix 5**. By April 2025:

- 3 have been signed and returned the agreement to us (Royal Devon University Healthcare NHS Foundation Trust, Torbay and South Devon NHS Foundation Trust, Royal Cornwall Hospital NHS Trust)
- 3 have been forwarded to other teams within their Trust (University Hospitals Plymouth NHS Trust, Royal United Hospital Bath NHS Foundation Trust, Gloucestershire Hospitals NHS Foundation Trust)
- 2 no reply yet (Dorset County Hospital NHS Foundation Trust, Somerset NHS Foundation Trust)
- 1 N/A (North Bristol Trust)

## Attendance of a SW HCC representative at the National Haemoglobinopathy Panel (NHP) business meetings and MDT meetings

The service managers attend all NHP business meetings. MDT meetings are attended by at least one of our consultants, registrars or clinical nurse specialists. Our adult haematology consultant is NHP lead for Adult Sickle Cell Disease cases discussed in the NHP.

## Annual review attendance (paeds & adults)

Regional paediatric patients are seen in Bristol for annual review.

Our Quality Improvement Fellow, Dr Amy Cooper, has worked in collaboration with our LHTs to set up outreach clinics for regional adult patients to have their annual review completed. The pilot clinic took place on 7<sup>th</sup> January 2025. Further annual review clinics with all LHTs are being set up to start from April 2025.

## Paediatrics:

ANNUAL REVIEWS 01/04/2024 - 31/03/2025		
Bristol Patients	Regional Patients	Total
65	60	125

## Adults:

ANNUAL REVIEWS 01/04/2024 - 31/03/2025			
Bristol Patients	Regional Clinics	Regional Patients	Total
124	0	8	132

## Transcranial Doppler (TCD)

All patients with a diagnosis of HbSS and HbS Beta Thalassaemia between the ages of 2 and 16 years are offered annual TCDs. This includes patients from our South West region. Patients with a diagnosis of HbSC are offered a TCD at age 2, 5 and 10 as long as the results are normal. Any abnormal, conditional or non-diagnostic scan results (for all patients) will be followed up as advised in the report.

In the last year we have performed 95 TCDs out of 102. 15 were conditional (9 patients) and 3 non-diagnostic.

## Patient support group meetings and patient events

We hold monthly virtual patient support group meetings. These usually take place on the first Wednesday of each month. Feedback is regularly collected to see how we can improve these sessions. The meetings are intended to be guided by patients and they are encouraged to make suggestions as to what topics should be covered.

We held our first face-to-face patient event on 6<sup>th</sup> March 2025. This was in collaboration with Primrose Granville who showed her film 'Sickle Cell Warrior'. We received great feedback and hope to hold further events in the near future.

Hayley Wiles (Paediatric Family Support Worker), Melanie Marsh (Adult Patient Support Worker) and Sarah Muddle (Paediatric Psychologist) are organising a teenage patient event for 13<sup>th</sup> August 2025.

We are now preparing for our first thalassaemia & rare inherited anaemia patient event which will be held on Saturday, 20<sup>th</sup> September. This event is being organised with the help of The Red Cell Network, our Thalassaemia & RIA HCC.

## Risks & Safety

There have been no incidents reported on Datix involving our patient cohort.

There are no staff safety concerns.

## Research and trials

Currently, we have IBHO ([Improving Black Health Outcomes \(IBHO\) BioResource](#)) and REDRESS trials ([Redress trial](#)) open. Our centre is a top recruiter for the IBHO trial. Unfortunately, no patients have been recruited to REDRESS, therefore this trial is being re-evaluated for our Trial Steering Group.

UHBW is Clinical Investigator (CI) for the DREAM trial, however this is put on hold due to Voxelator Food and Drug Administration (FDA – this is a U.S. federal agency) approval withdrawal. We hope to re-open DREAM in 2026. Once there is an update it will be shared with the wider team and patients.

## Guidelines

The paediatric sickle cell and thalassaemia guidelines are up-to-date. These are published on the Trusts 'MyStaff App' and a link for easy access will also be available on our website.

The adult thalassaemia guidelines are also up-to-date and published on the Trusts 'MyStaff App' and a link for easy access will also be available on our website.

The adult sickle cell guidelines are currently being updated and should be ready for publication by the end of August.

A new guideline for manual red cell exchanges for adult patients with a diagnosis of sickle cell in our South West regional hospitals is currently being developed. Once finalised and approved this will also be added to the Trusts 'MyStaff App' and a link for easy access will also be available on our website.

## Patient feedback

Patient feedback is collected via an online survey once a year. The last survey took place Jan/Feb 2024. Due to staff changes, this has not yet been repeated in the last year but will be done do so very soon.

We also ask for patients to attend our annual service review meeting to give feedback. For our meeting scheduled for 16<sup>th</sup> June 2025 we have invited 1 adult patient with sickle cell, 1 adult patient with beta thal major and 1 parent of a paediatric sickle cell patient.

The feedback collected in Jan/Feb 2024 was overall good, but some suggestions were made where we have room for improvement. The suggestions were taken into consideration not only by the haemoglobinopathy team but also shared with other teams such as Same Day Emergency Care Unit (SDEC), ward staff and ED staff. Changes were put into place and a letter/email with a description of the changes was sent to all patients in July 2024. See **appendix 6**.

## Statistics (patient numbers, mortality)

We only recently started to keep track of our total patient numbers. In early September 2024 we had a total of 433 patients. This includes all paediatric and adult patients both Bristol and regional.

On the 1<sup>st</sup> April 2025 the total number increased to 460.

In the last financial year, we had one bereavement of an adult patient. The cause is still unknown as the case is with the coroner.

There was also one paediatric death, however the baby was too young to get a clear picture of the diagnosis, too young for genetic testing. The report reveals that the baby passed away in a hospice with sepsis.

## Support services (Psychology, support worker)

Psychology: With the additional funding we have received in 2024 as outcome of a compliance exercise back in 2022, we have increased the adult psychology PAs to be able to cover regional patients as well. Due to staff turnover the set-up has been slightly delayed. The psychology team are working on creating a regional referral form and updating the guidelines and patient information leaflets.

Patient support workers: Both (Paeds & adult support workers) are helping our patients with benefit applications, housing requests, food vouchers, teaching to schools/colleges/universities and employers as well as setting up a TYA patient event.

## Transition pathway

Hayley Wiles (Paediatric Family Support Worker) and Melanie Marsh (Adult Patient Support Worker) have been working hard over the last few years to improve the transition pathway. This included creating guideline, SOP, education and patient feedback. They meet regularly to update guidance with patients aged 11 to 17.

## Achievements

- We had our peer review on 12<sup>th</sup> September 2024 which found no major concerns or immediate risks.
- We held our first successful face to face patient event on 6<sup>th</sup> of March 2025.

## Challenges

Our main challenges as HCC are:

- Staff shortages in psychology department delaying the regional psychology set-up.
- Engagement with LHTs, especially clinical nurse specialists.
- Teaching attendance from nursing staff at BHOC and other specialities within the Trust i.e. ED.
- Limited financial oversight/involvement of our HCC and SHT funding due to fractured communication with finance department.



## Appendix 1 – Activities

### Paediatric Service:

<b>TIMEFRAME 01/04/2024 - 31/03/2025</b>	
New Referrals	41
Discharges	11
Outpatient appointments	204
Day Unit/ED attendances	118
Admissions	66

### Adult Service:

<b>TIMEFRAME 01/04/2024 - 31/03/2025</b>	
New Referrals	45
Discharges	6
Outpatient appointments	521
Day Unit/ED attendances	143 (SDEC) 22 (ED)

Admissions	104
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## Appendix 2 – South West Education Day Agenda

### Southwest HCC Education Day

Wednesday 12<sup>th</sup> June 2024

Location: Radisson Blu Hotel, Broad Quay, Bristol BS1 4BY

09:00 – 09:25	Registration	All
09:25 – 09:30	Welcome and Housekeeping	Sandra Schneider
09:30 – 10:00	HCC Business Meeting	Sanne Lugthart & Sandra Schneider
10:00 – 10:30	No one's listening report - improvement since then. What we would like to focus on going forward.	Sanne Lugthart
10:30 – 11:00	Coffee/Tea break	
11:00 – 11:45	Acute/chronic complications on SCD	Sanne Lugthart
11:45 – 12:30	Voxelator/Oxbryta	External speaker from Pfizer
12:30 – 13:15	Lunch break	
13:15 – 13:45	Transition	Hayley Wiles, Melanie Marsh, CNS paed & adult
13:45 – 14:15	CNS perspective	Nicole Paterson & Helen O'Keefe
14:15 – 15:00	Thalassaemia updates	Tom Latham
15:00 – 16:00	Treatment updates SCD (trials, transplant, gene therapy)	Sanne Lugthart & Rachel Lloyd

## Appendix 3 – Teaching Spreadsheet

We provide teaching to various staff groups both within UHBW and regionally to our LHTs. Topics vary depending on requirements of the staff group as well as topics being chosen by staff members receiving education. A full list of all teaching provided by one of our staff members can be found on our spreadsheet:

[Teaching Spreadsheet 2024-2025](#)

## Appendix 4 – Memorandum of Agreements (Service Level Agreements)

See separate documents of [Memorandum of Agreements](#) and [Data Sharing Agreements](#)

## Appendix 5 – Shared care protocol chelation

Deferiprone, deferasirox and desferrioxamine shared care NHSE approved – please see [separate document](#).

## Appendix 6 – Patient Feedback Outcome Letter



Dr Sanne Lugthart  
Consultant Haematologist

Dr Tom Latham  
Consultant Haematologist

Nicole Paterson  
Clinical Nurse Coordinator / Specialist

Prisca Lux  
Clinical Nurse Specialist

Our Ref: NP/ss



University Hospitals  
Bristol and Weston  
NHS Foundation Trust

Bristol Haemoglobinopathy Service (Adult Service)  
The Bristol Haematology Unit  
Bristol Haematology and Oncology Centre  
Horfield Road  
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Haemoglobinopathy Team:  
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HaemoglobinopathyBristol@uhbwt.nhs.uk

Typed: 11/07/2024

Dear Patients,

Many thanks to everyone who took the time to complete our patient feedback survey in January/February 2024.

We are writing to respond to some of the comments raised.

### Outpatient appointments:

There were a few comments regarding having appointments face to face, via video or via telephone.

We prefer to review our patients face to face at least once a year, but appreciate this is not always possible. Therefore, each patient can request the type of appointment they prefer. If this needs changing, please contact our team on 0117 342 2774 or 07825 948 038.

We have no influence over appointments with other specialities (ie, respiratory, cardiology, ophthalmology etc) or how they conduct their appointments. You will need to contact that speciality directly to see if it can be changed to face to face or virtual as you prefer.

### Ward / staffing on ward:

Patient feedback highlighted experiences, where staff on wards had little knowledge about haemoglobinopathies (sickle cell, thalassaemia and rare anaemia)

We have increased our teaching for staff to every other week and spoken to the matron and ward sisters to ensure all nurses will attend one of the teaching sessions.

We also give regular teaching session to ED staff and junior doctors.

The room temperatures on wards have been highlighted as an item for improvement. Please note, if you are hot or cold always mention this to a staff member, who can supply you with

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respectful  
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extra blankets and a heater or fan. We have recently received funding from the BHOC [charity](#) and we have purchased some fans. Please ask a member of staff for one if needed.

Treatment options:

Our Pharmacist Rachel recently gave a talk on a new treatment (Voxelotor) which was recently approved by NICE. We have also asked her to give another talk on analgesia options, we will inform you in due course of the date and time.

Other NHS services:

Some of you mentioned issues with accessing other NHS services whether GPs, other hospitals or other services at our Trust. Please note that this is unfortunately outside of our remit.

If you are unhappy with a service at UHBW you can contact the Patient Advice and Liaison Service (PALS) and Complaints team on 0117 342 1050 or visit this website <https://www.uhbristol.nhs.uk/patients-and-visitors/support-for-patients/patient-support-and-complaints/> , where you can find more information or scan this QR code.



Other hospitals will have a similar PALS service so you will need to contact them. Each GP surgery operates slightly differently so it would be best to contact the practice manager at your GP surgery to find out how you can raise a concern.

Many thanks again for taking your time to complete our survey.

Please do contact us if you have any questions.

Haemoglobinopathy Team