



ARISE

African Research And Innovative  
Initiative For Sickle Cell Education

# Train-the-Trainer Workshop

## Abuja, Nigeria

### 11th – 13th September 2019

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Oxford University Hospitals, Oxford, UK

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# The UK National Haemoglobinopathy Registry and Dashboard



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## NATIONAL HAEMOGLOBINOPATHY REGISTRY

### WELCOME TO THE NHR

The National Haemoglobinopathy Registry (NHR) is a database of patients with red cell disorders (mainly Sickle Cell Disease and Thalassaemia Major) living in the UK. This new database collects data, which is required by the Department of Health from Haemoglobinopathy centres. The central aim of the registry is to improve patient care.



# The UK National Haemoglobinopathy Registry and Dashboard

## Established 2008

- Following commencement of National Antenatal and Neonatal Screening Programme in 2004

## What does it do?

- Data collection

**All UK patients with major haemoglobinopathies/rare anaemias**



# The UK National Haemoglobinopathy Registry and Dashboard

## What are the benefits of the NHR?

- Enhance monitoring of changing demographics
  - Enhance service delivery – Funding staff and infrastructure
  - Improves patient outcomes
  - Resource for research
  - Good practice – A template for limited resource countries
- 
- National Haemoglobinopathy Registry =NHR



# The UK National Haemoglobinopathy Registry and Dashboard



# The UK National Haemoglobinopathy Registry and Dashboard



**Commissioned by NHS England via the Haemoglobinopathies CRG**

## The NHR Steering Group

The NHR steering group oversee and guide all activities of the NHR. It has a broad membership giving all stakeholders an input into the running of the registry. Stakeholders include clinicians, commissioners, patient societies, patient representation and NHS England.

<b>Alison Thomas</b>	Consultant Haematologist
<b>Annette Wood</b>	Commissioner
<b>Cathy Coppinger</b>	Screening Programme
<b>Claire Foreman</b>	Commissioner
<b>Elaine Miller</b>	UK Thalassaemia Society Representative
<b>Farrukh Shah</b>	Consultant Haematologist and Interim Chair of NHR
<b>Jo Howard</b>	Consultant Haematologist
<b>John James</b>	Sickle Cell Society
<b>Marilyn Roberts Harewood</b>	Consultant Haematologist – Clinical Chair - On leave
<b>Mary Petrou</b>	UK Thalassaemia Society Representative
<b>Sara Trompeter</b>	Consultant Haematologist
<b>Shivan Pancham</b>	Consultant Haematologist
<b>Subarna Chakravorty</b>	Consultant Paediatric Haematologist
<b>Wale Atoyebi</b>	Consultant Haematologist
<b>Dr Robert Hollingsworth</b>	MDSAS



# The UK National Haemoglobinopathy Registry and Dashboard

## NHR Components

- Patient Registrations
- Serious Events
- Annual Review
- Patient Card
- National Information Service
- Public website and Annual Report
- **Newborn Outcomes Project**
- **NHS Blood Transfusion**





# The UK National Haemoglobinopathy Registry and Dashboard

## Registration Status

### Active Registrations

13,357

Increasing number of patients  
Registered at more than 1 centre

Flag patients when no  
longer active





# The UK National Haemoglobinopathy Registry and Dashboard

2018 /2019 Report

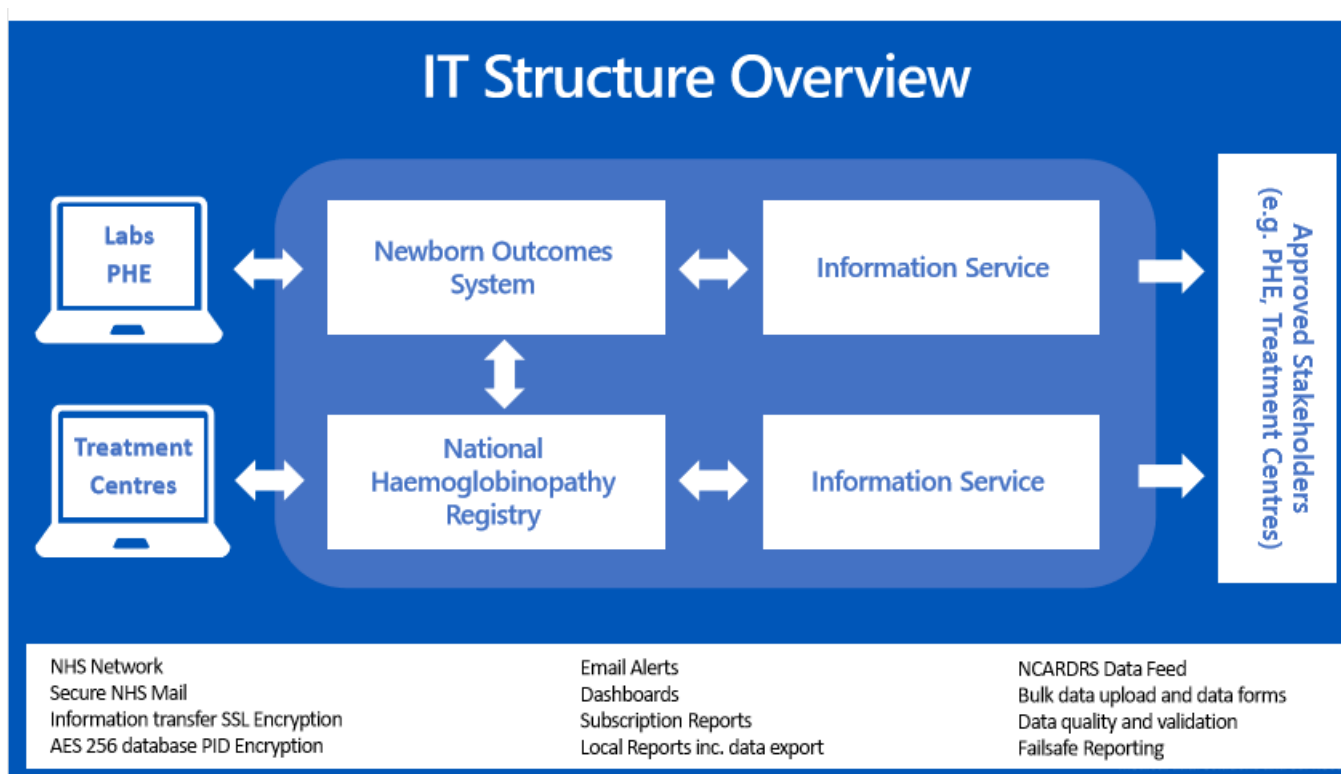


## Total Diagnosis by Gender

Name	Male	Female	Not Specified	Total
Thalassaemia	973	942	0	1915
Sickle Cell	6353	7251	3	13607
Other	221	239	0	460
<b>Total</b>	<b>7547</b>	<b>8432</b>	<b>3</b>	<b>15982</b>



# The UK National Haemoglobinopathy Registry and Dashboard



E.g. In Kaduna State

**Laboratory** = Patrick Yakowa Hospital, Kafanchan

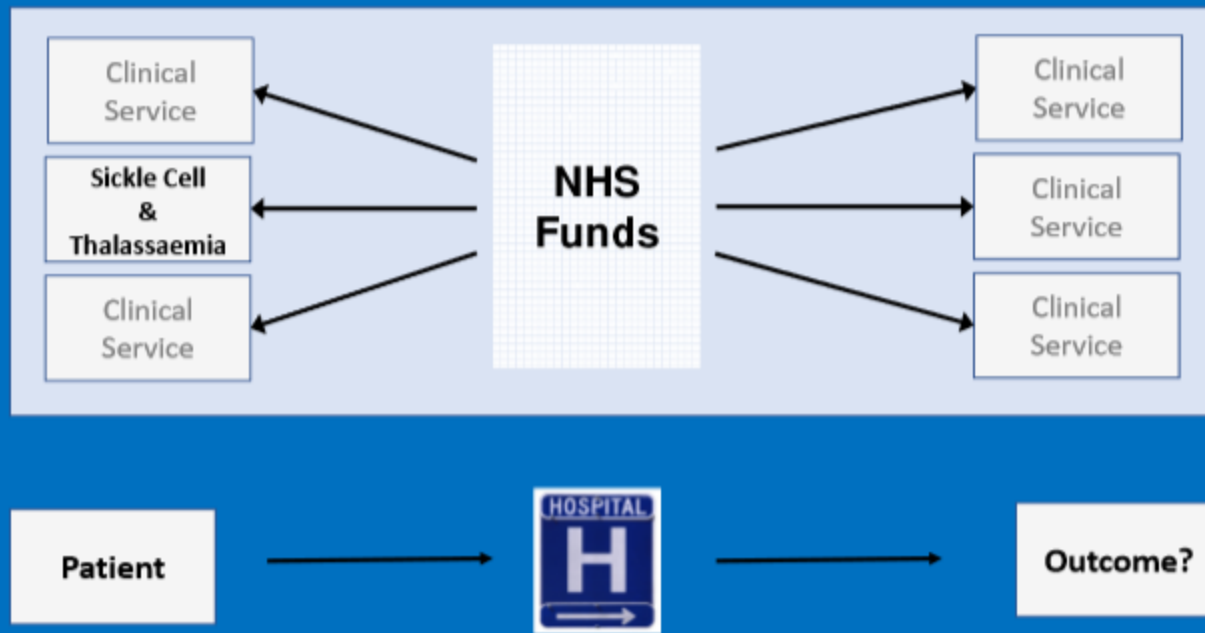
**PHE** = Primary Health Care Development Agency

**Treatment Centre** = Barau Dikko Teaching Hospital (BDTH)



# The UK National Haemoglobinopathy Registry and Dashboard

## Service Reorganisation – NHR is a central part



The NHR Dataset is broken down into three main data collection types:

# Datasets

## 1. Patient Data

Consent Obtained	Yes / No
NHS number	Unique patient identifier
Title	Patient title e.g. Mr, Mrs etc
Forename	Patient Forename
Surname	Patient Surname
Gender	Male / Female
Date of Birth	Date of Birth of the Patient
Ethnicity	NHS standard list of ethnicities
Post code	Patient post code
GP practice code	Code to identify location of GP Practice
Year of diagnosis	When patient was diagnosed
Diagnosis	Patient diagnosis
Therapy	Treatment method patient receiving e.g Iron Chelation
Therapy type	Specific details of treatment method e.g Deferiprone
Transfusion frequency	If applicable how many transfusions given e.g 0-20, >20-50 etc.
Year of first transfusion	Year first transfusion given to patient
Bone marrow transplant	Yes / No
Receives regular penicillin usage	Yes / No
TCD monitoring	Yes / No
Regular Transfusion	Yes / No
Other Comments	Other Comments

## 2. Adverse Events

NHR Patient Consent Obtained	Yes / No
NHS Number	Unique Patient Identifier
Gender	Male / Female
Diagnosis	Patient diagnosis
Event Type	The type of event e.g. death
Date of event	The date which the event took place
Age of patient	The patients age in months (up to 1 <sup>st</sup> year), or years
Other Information	Any other relevant information

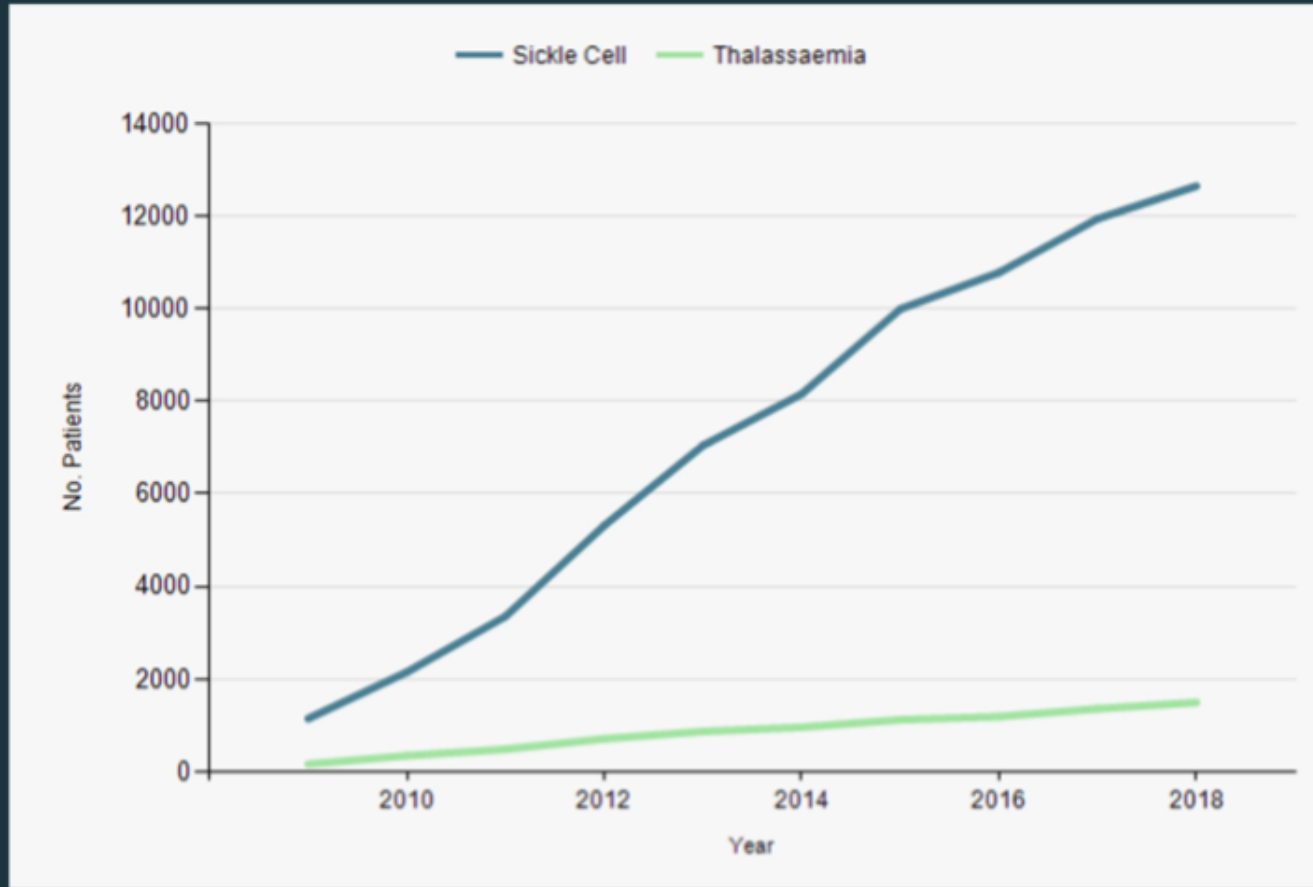
## 3. Annual Review

<b>Management Plan</b>	
Date Set	Date when management plan was set
Date Completed	Date when management plan was completed
Todo Action	The action required to be undertaken within the management plan
<b>About the patient</b>	
Date of Annual Review	The date when the annual review was due for completion
Patient failed to attend	Whether the patient attended or not
Height (cm)	The patients height in cm
Weight (kg)	The patients weight in kg
Spleen Size (cm)	The patients spleen size in cm
Centre change in this review period	Yes / No
Patient Status	The patients status e.g. active, no longer seen etc
Date of no longer seen	The date when the patient was no longer seen
Date of death	The date of the patients death
Transferred to	Which centre the patient was transferred to
Date transferred to	The date of when the patient transfer took place
Centre type	Specialist Haemoglobinopathy Team (SHTC) or Secondary Care Centre - Local (LHT)
Number of hospital admissions in this review period	The number of times the patient has been admitted during the review period
Have they had a transfusion in this review period	Yes / No
Has there been a pregnancy in this review period	Yes / No
Outcome of pregnancy	e.g. C section, live birth etc
<b>Complications</b>	
Hepatitis C Status	Whether the patient has Hepatitis C
Date of Hepatitis C status	The date of when the status was diagnosed
HIV Status	Whether the patient has HIV
Date of HIV status	The date of when the status was diagnosed
<b>Therapy initiated or continued in this review period</b>	
Therapy	Treatment method patient receiving e.g Iron Chelation
Therapy type	Specific details of treatment method e.g Deferiprone
Transfusion frequency	If applicable how many transfusions given e.g 0-20, >20-50 etc.
Therapy start / end date	When therapy was started and completed

Date of Vaccination	The date of when the vaccination took place
Expiry of vaccination	When the vaccination expires
Comments	Any comments related to the vaccination
<b>Serious adverse events in this review period</b>	
Serious Adverse Event	Additional adverse events during the review period not already reported
Reason for ITU admission	Why the patient was admitted
Pulmonary Hypertension Proof	How pulmonary hypertension was proved
Date of serious adverse event	The date of when the serious event took place
Comments	Any further comments relating to the event
<b>Other Complications</b>	
Bone Problems	Whether the patient has had any bone problems e.g. fracture
Endocrinopathy Detail	Detail of endocrinopathy reported e.g. diabetes
Endocrinopathy start date	When the patient was diagnosed with the endocrinopathy
Endocrinopathy continued	Whether the endocrinopathy has still present
Comments	Any further comments relating to the endocrinopathy
<b>Investigations in this Review Period</b>	
Investigation details	What investigation have occurred during the review period e.g. audiometry, blood pressure etc.
<b>Results</b>	
Myocardial	Myocardial test score
Hepatic	Hepatic test score
Liver Iron Concentration	Liver Iron Concentration test score
<b>Medications in this review period</b>	
Medication	Medication that the patient has use during the review period
Medication start date	When the medication was started
Medication end date	When the medication was finished
Medication continued	Whether any further medication is required
Comments	Any comments relating to medications taken

# The UK National Haemoglobinopathy Registry and Dashboard

## Registration History



# The UK National Haemoglobinopathy Registry and Dashboard

NHR Information Service



## Number of Patients by Diagnosis

Condition	Diagnosis	Patients
Sickle Cell		<b>12,191</b>
	HbSS	8,174
	HbSC	3,192
	SickleB+ thal	456
	SickleB0thal	202
	HbS/HPFH	93
	HbS /D Punjab	26
	HbS/E	19
	HbS beta +	10
	HbS beta0 thal	8





# The UK National Haemoglobinopathy Registry and Dashboard

NHR Information Service

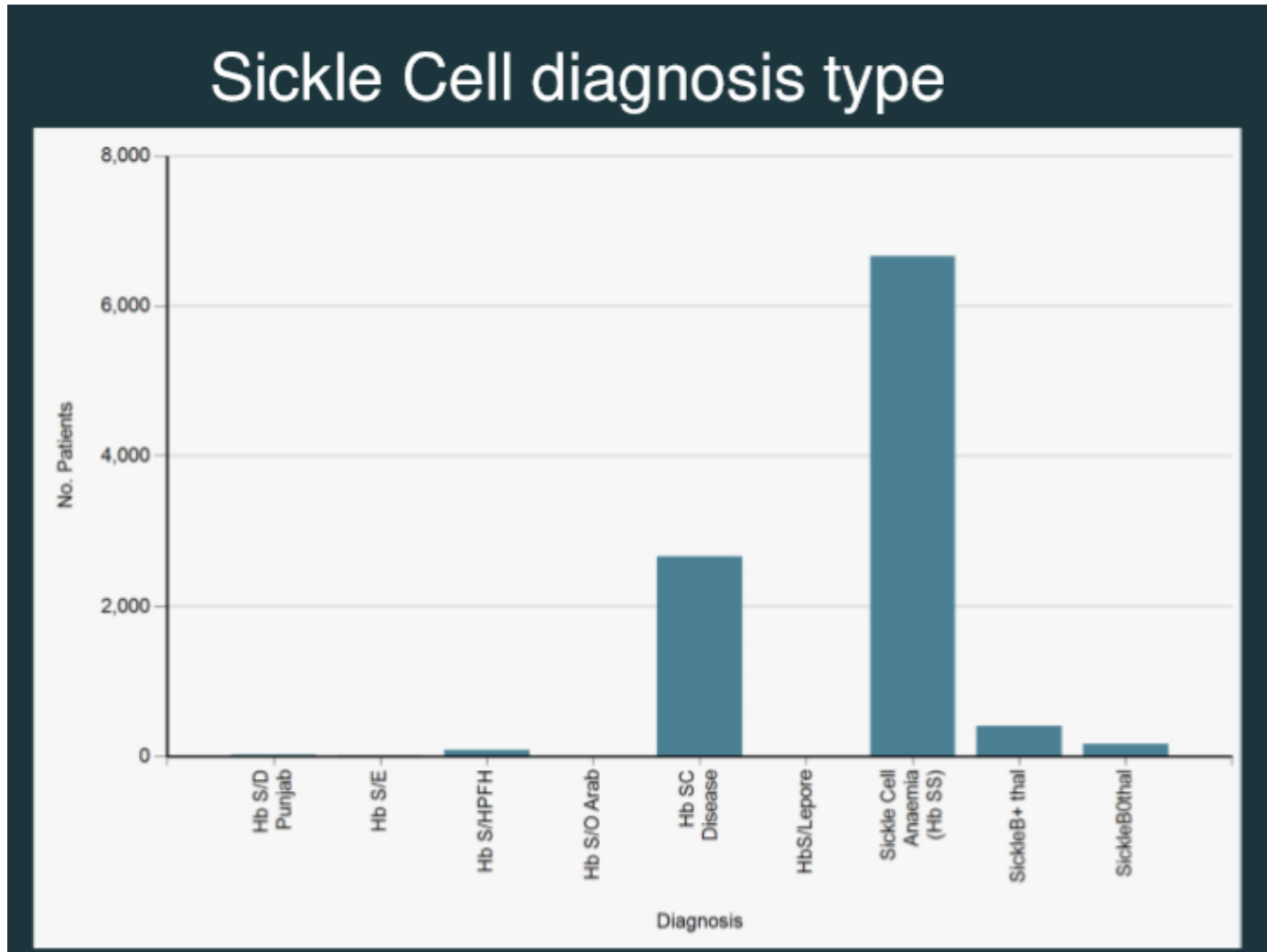


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# The UK National Haemoglobinopathy Registry and Dashboard



# The UK National Haemoglobinopathy Registry and Dashboard

NHR Information Service



## Number of Patients at Each Centre

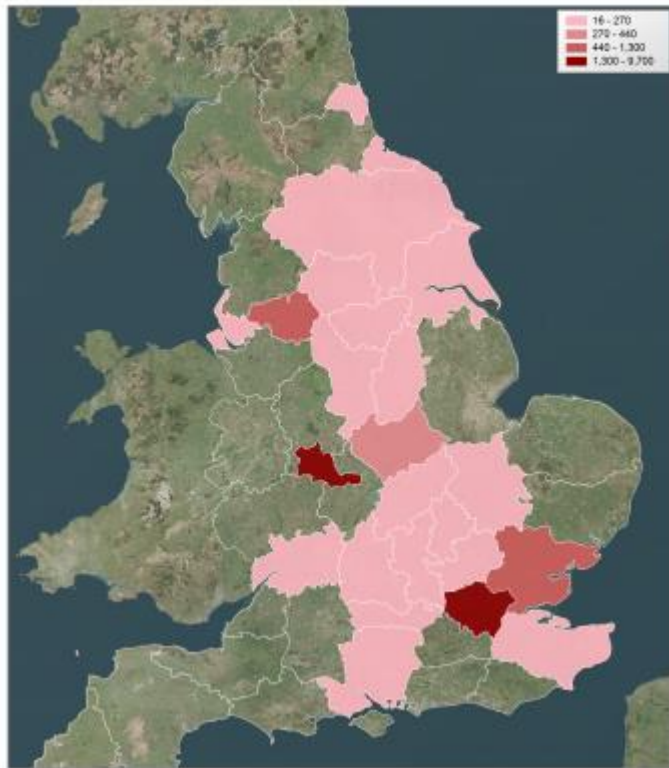
Centre	Sickle	Thal	Other	Total
Guy's and St Thomas	1,081	25	26	1,132
Kings College Hospital	911	26	5	942
Royal London	730	109	29	868
Manchester University NHS Foundation Trust	617	149	41	807
North Middlesex	541	48	1	590
Birmingham - City Hospital	451	88	15	554
The Whittington Hospital NHS Trust	318	220	6	544
Newham University Hospital	498	10	6	514
Queens Hospital (BHR)	438	36	15	489
University College London Hospitals	282	159	44	485
Imperial College Healthcare NHS Trust	410	59	14	483



# The UK National Haemoglobinopathy Registry and Dashboard



NHR Patient Numbers Map

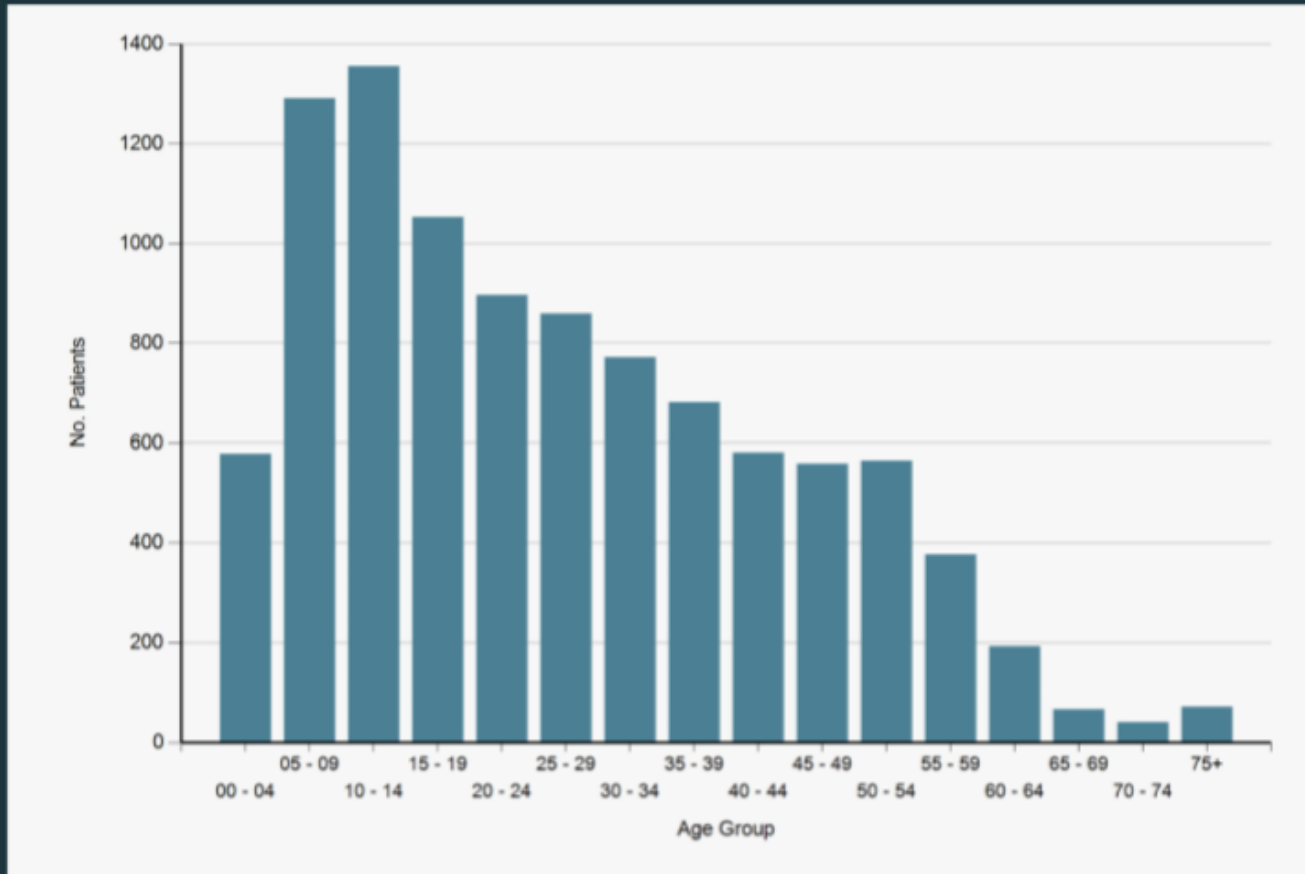


Area	Patients
Greater London	9610
West Midlands	1615
Greater Manchester	1158
Essex	597
Leicestershire	296
South Yorkshire	257
Nottinghamshire	232
North Yorkshire	185
Buckinghamshire	171
Northamptonshire	164
Merseyside	156

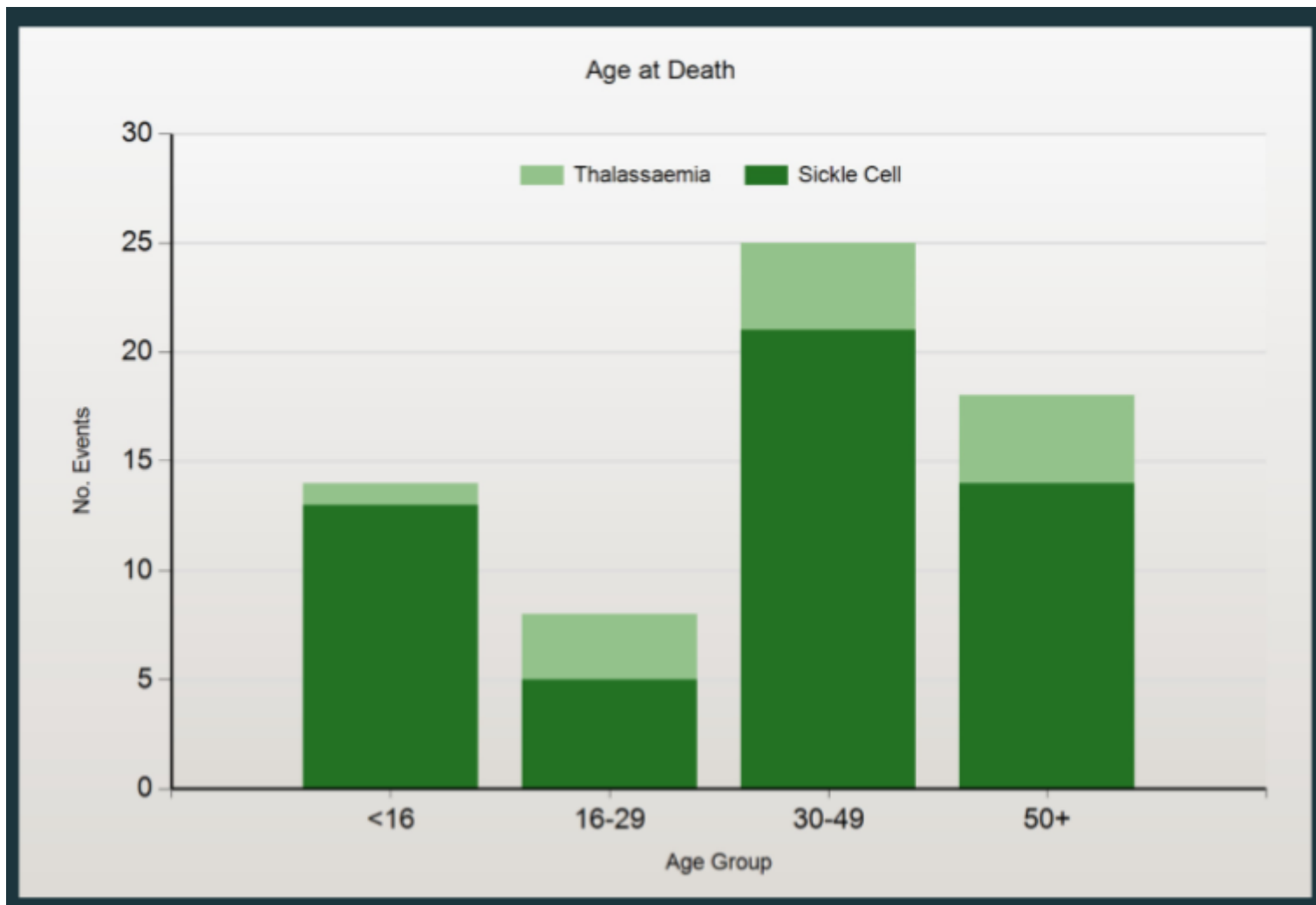


# The UK National Haemoglobinopathy Registry and Dashboard

## Sickle Cell patients by age group

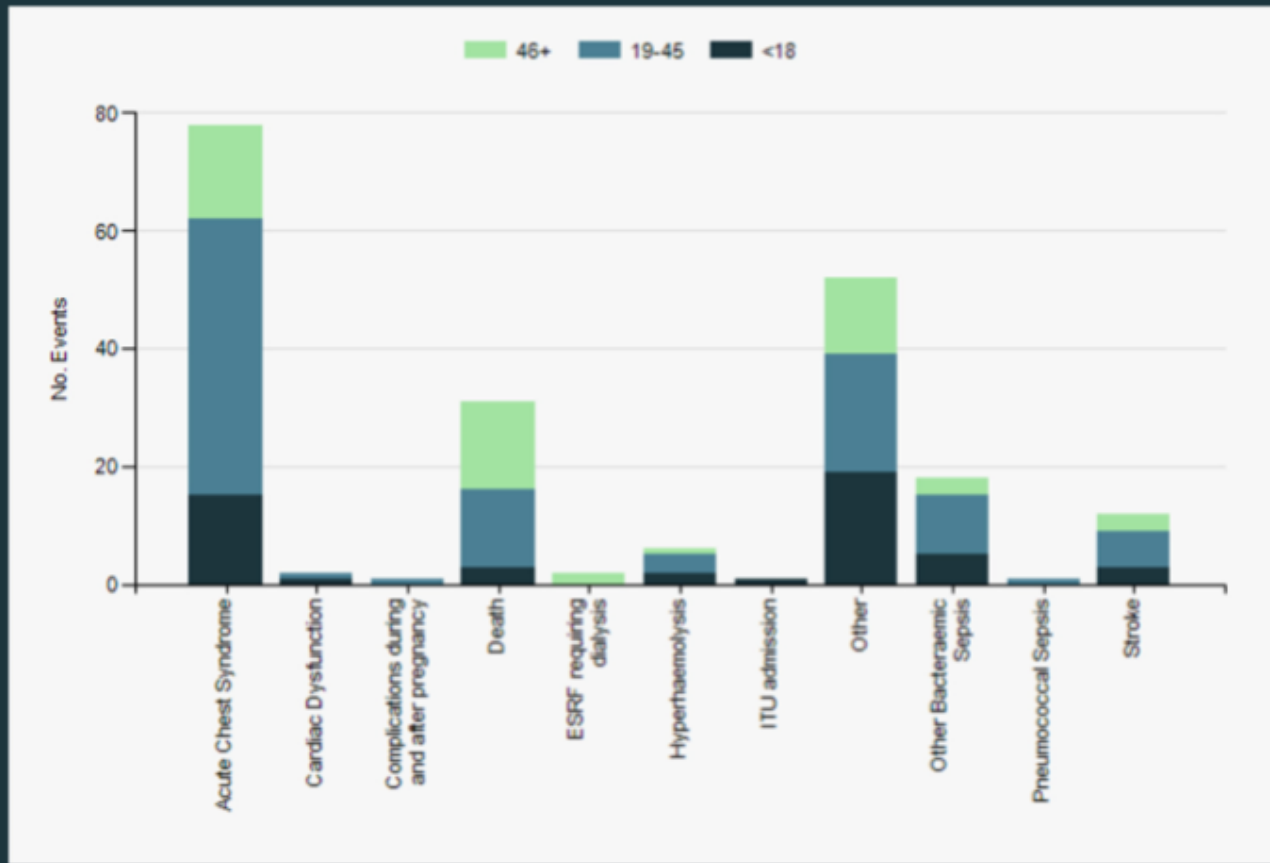


# The UK National Haemoglobinopathy Registry and Dashboard



# The UK National Haemoglobinopathy Registry and Dashboard

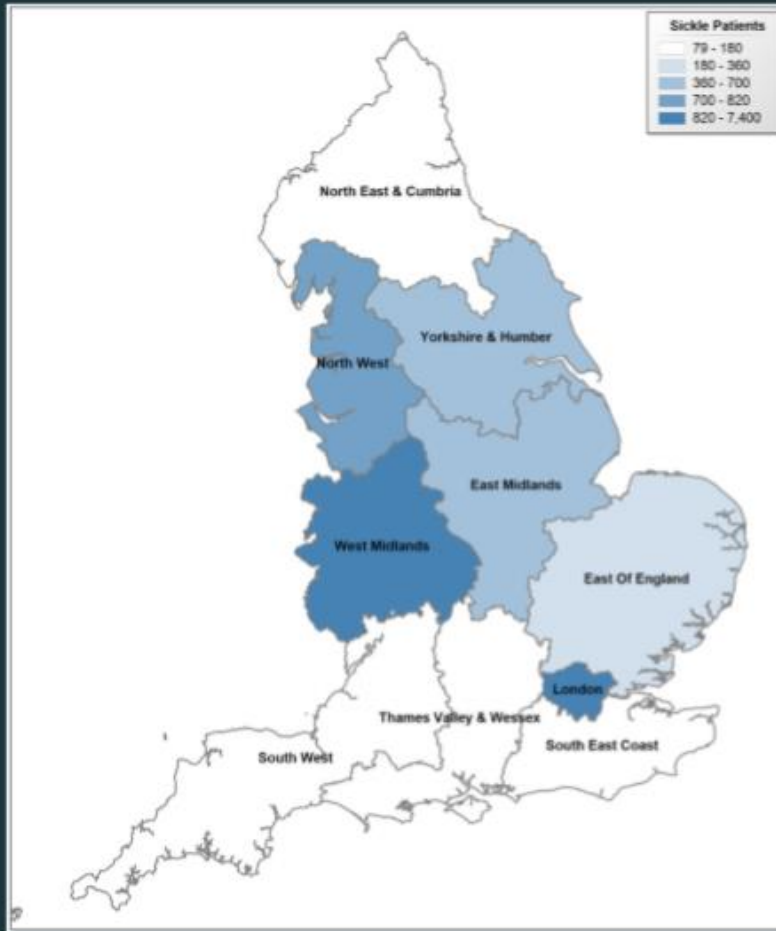
## Sickle Cell serious events 17/18





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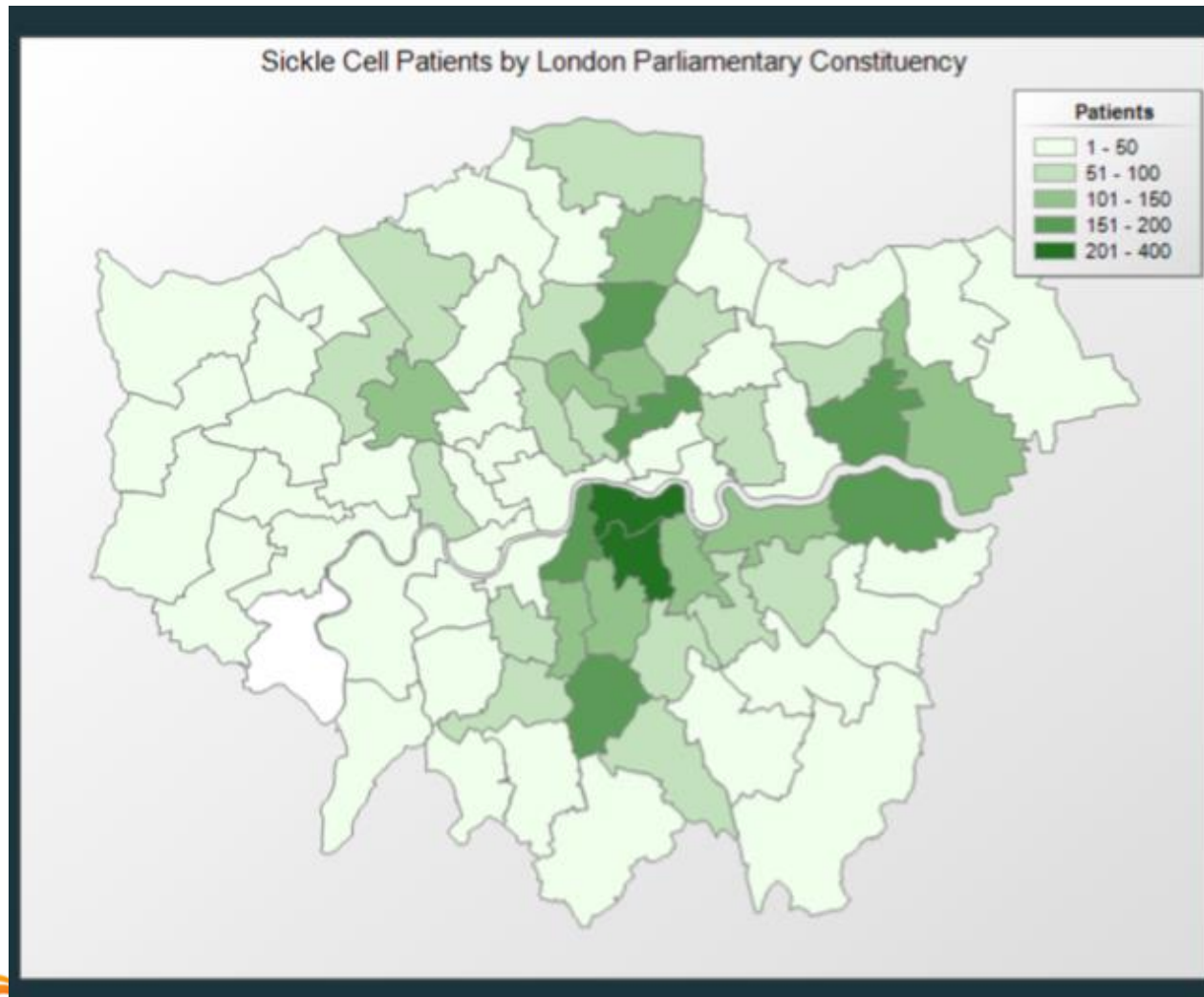
## Sickle Cell patients by Commissioning Hub



Commissioning Hub  
= Nigerian States



# The UK National Haemoglobinopathy Registry and Dashboard



We can engage our lawmakers as advocates



# The UK National Haemoglobinopathy Registry and Dashboard



# The UK National Haemoglobinopathy Registry and Dashboard

- Support commissioning and management of specialist centres
- Development of hand held records
- Evolve into a patient management system
- Year of care funding
- Overall improving outcomes



# The UK National Haemoglobinopathy Registry and Dashboard

Involving Patients in their own care

## Patient Home Diary System



**1.5 Million Patient Entries**



**20,000+ Patient Entries per Month**



**Multiple language support**



**Image capture support**



# The UK National Haemoglobinopathy Registry and Dashboard

## Conclusion

The National Haemoglobinopathy Registry (NHR) is vital to support the management and improvement of the Haemoglobinopathy service



# The UK National Haemoglobinopathy Registry and Dashboard

## UK Haemoglobinopathy Dashboard

- Commissioned by NHS England
  - Quality surveillance reporting system
  - Identical standards across the UK
  - Continuously monitored
  - Data flow from NHR
- 
- Poor performance – Investigations/sanctions





# The UK National Haemoglobinopathy Registry and Dashboard

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NHS commissioning

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National Programmes of Care and Clinical Reference Groups

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Blood and Infection

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## Specialised services quality dashboards

Specialised Services Quality Dashboards (SSQD) are designed to provide assurance on the quality of care by collecting information about outcomes from healthcare providers. SSQDs are a key tool in monitoring the quality of services, enabling comparison between service providers and supporting improvements over time in the outcomes of services commissioned by NHS England.

For each SSQD, there is a list of agreed measures for which data is to be collected. These measures are included in a 'Metric Definition Set'.

**Information downloaded from the National Haemoglobinopathy Register**



# The UK National Haemoglobinopathy Registry and Dashboard

Haemoglobinopathy Quality Dashboard 2018/19



Indicator Reference Number	Domain	Theme	Measures	Criteria	Name of Indicator / Description	Numerator	Denominator	Period Type	Frequency	Data Source / Manufacturer	Data Source / Denominator	Target	Improvement Guidance	Notes	Reporting Periods			
															Q1	Q2	Q3	Q4
HAEM001	Domain 3: Helping people to recover from episodes of ill health or following injury	Clinical process	Serious events entered on to NHR system and reviewed within network morbidity/mortality meetings	Evidence that each adverse event has been reviewed within network by either registry review or serious case review input to national review of all adverse events.	Proportion of serious events entered on to NHR system and reviewed within network morbidity/mortality meetings	Number of adverse events reported that have been reviewed within the network by either mortality or serious case review	Total number of adverse events reported on NHR within the reporting period	6 month rolling	Quarterly	Provider submitted data	Provider submitted data		Higher is better	Serious incident information: Serious incidents requiring investigation defined by the NPSA's 2010 National Framework for Reporting and Learning from Serious Incidents Requiring Investigation. In summary, this definition describes a serious incident as an incident that occurred during NHS funded healthcare (including in the community), which resulted in one or more of the following: <ul style="list-style-type: none"> <li>• unexpected or avoidable death or severe harm of one or more patients, staff or members of the public;</li> <li>• a near event – all near events are defined as serious incidents although not all near events necessarily result in severe harm or death;</li> <li>• a scenario that prevents, or threatens to prevent, an organisation's ability to continue to deliver healthcare services, including data loss, property damage or incidents in population programmes like screening and immunisation where harm potentially may extend to a large population;</li> <li>• allegations, or incidents, of physical abuse and sexual assault or abuse; and/or</li> <li>• loss of confidence in the service, adverse media coverage or public concern about healthcare or an organ below.</li> </ul>	Jun 18 - Jun 18			
HAEM002	Domain 3: Helping people to recover from episodes of ill health or following injury	Clinical process	Trans Cranial Doppler (TCD) monitoring	TCD being reviewed to at risk group after awareness that national guidelines on frequency, methodology and training are being followed	Proportion of children (aged between 2 and 16 years old) within at risk group (S5 and S5ets @ T1)0) receiving trans cranial doppler monitoring within Trust	Number of children having TCD monitoring within national guidelines	Total number who are eligible for TCD monitoring	6 month rolling	Quarterly	Provider submitted data	Provider submitted data		Higher is better		Jan 18 - Jun 18	Apr 18 - Sep 18	Jul 18 - Dec 18	Oct 18 - Mar 19
HAEM003	Domain 3: Helping people to recover from episodes of ill health or following injury	Clinical process	Timeliness of pain relief in sickle cell disease	Indicator to measure that patients are given pain relief within half an hour of presentation with sickle crisis, as per NICE guidelines.	Percentage of patients given pain relief within half an hour of presentation with sickle crisis, as per NICE guidelines	Number of patients achieving this standard	Total number of events (patients presenting with sickle crisis), within the reporting period	Annual	Annual	Provider submitted data	Provider submitted data		Higher is better	Annual reporting. If a specialist centre is supervising other Trusts then a minimum of an audit from those centres of this annually. This should only relate to pain relief given as an urgency with either within Emergency department or acute admissions unit.				Apr 18 - Mar 19
HAEM004	Domain 3: Helping people to recover from episodes of ill health or following injury	Clinical process	Screening to access to specialist care	Indicator to measure that all patients with possible sickle disorders identified by neonatal screening who have entered care pathway.	Proportion of patients with possible sickle disorders identified by neonatal screening who have entered onto care pathway	Number of patients entered onto care pathway	Total number of identified patients, within reporting period	Annual	Annual	Provider submitted data	Provider submitted data		Higher is better					Apr 18 - Mar 19
HAEM005	Domain 3: Helping people to recover from episodes of ill health or following injury	Clinical process	Screening to access to specialist care	Indicator to measure the number of children beginning penicillin at or before 3 months of age, as per screening programme guidelines	Percentage of eligible children beginning penicillin at or before 3 months of age as per screening programme guidelines	Number of children beginning penicillin within screening guidelines	Total number of children eligible to begin penicillin within reporting period	Annual	Annual	Provider submitted data	Provider submitted data		Higher is better					Apr 18 - Mar 19
HAEM006	Domain 3: Helping people to recover from episodes of ill health or following injury	Clinical process	Annual review via NHR	To measure data entry each year into annual review system of NHR.	Data entry each year into annual review system of NHR	Number of annual reviews undertaken by the centre as recorded by NHR entry within that year	Total number of registered patients eligible for annual reviews on NHR by that centre	Annual	Annual	Provider submitted data	Provider submitted data		Higher is better					Apr 18 - Mar 19
HAEM007	Domain 2: Enhancing quality of life for people with long-term conditions	Clinical process	Assessment of adequacy of chelation; Access to transfusion; Armed prescribers in primary care; If any high risk sickle included please identify in return	Assessment of adequacy of chelation; Access to transfusion; Armed prescribers in primary care; If any high risk sickle included please identify in return	Proportion of eligible patients on long term transfusion who receive cardiac MRI	Number of eligible patients (adults and children) on long term transfusion patients who receive cardiac MRI	Number of patients (adults and children) eligible for cardiac MRI, within the reporting period	Annual	Annual	Provider submitted data	Provider submitted data		Higher is better	If any high risk Sickle included, please note in the indicator comments/notes.				Apr 18 - Mar 19
HAEM008	Domain 2: Enhancing quality of life for people with long-term conditions	Clinical process	Assessment of adequacy of chelation; Armed prescribers in primary care; If any high risk sickle included please identify in return	Measures adequacy of chelation; Cardiac MRI of more than 20mins.	Proportion of patients receiving cardiac MRI who achieved more than 20 mins	Number of those who had MRI who achieved figure more than 20mins	Number of patients who received cardiac MRI within reporting period	Annual	Annual	Provider submitted data	Provider submitted data		Higher is better	If any high risk Sickle included, please note in the indicator comments/notes.				Apr 18 - Mar 19



# The UK National Haemoglobinopathy Registry and Dashboard

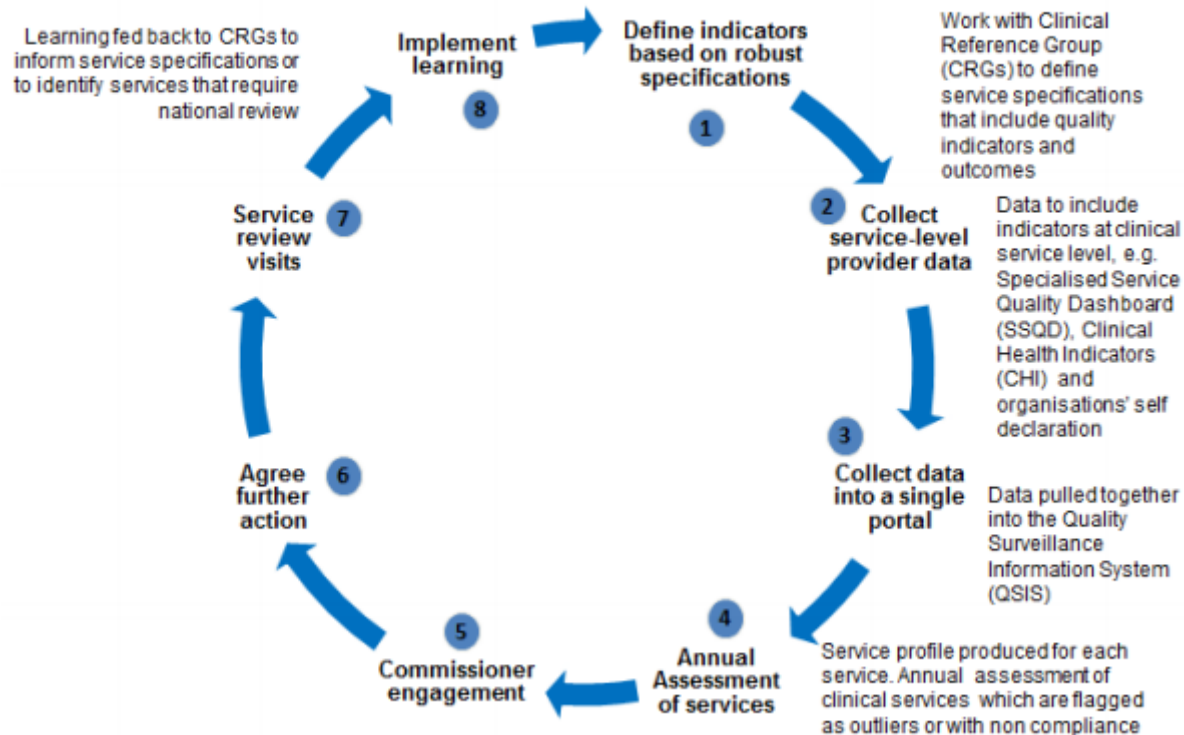
## Shared commitment to quality

**Our single shared definition of quality**  
which as national bodies we have  
committed to embed at every level of our  
work and in all our interactions.



# The UK National Haemoglobinopathy Registry and Dashboard

## Quality Surveillance Process



# The UK National Haemoglobinopathy Registry and Dashboard

## TCD monitoring

Hb SS & Hb SC Patients aged between 2 and 17

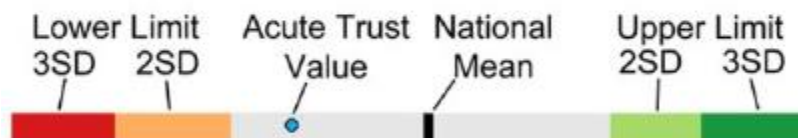
Patients	TCD monitoring
3605	2171 (60%)



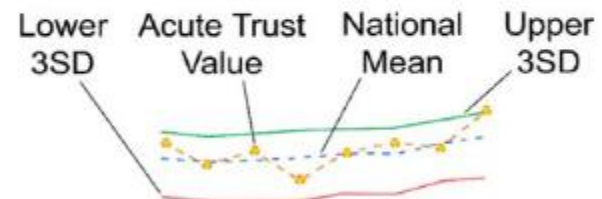
# The UK National Haemoglobinopathy Registry and Dashboard

## SSQD Dashboard

Spine Charts



SPC Sparklines



# The UK National Haemoglobinopathy Registry and Dashboard

17/07/2019

[https://www.qst.england.nhs.uk/teams/1795/specialised\\_services\\_quality\\_dashboards/surveys/90053](https://www.qst.england.nhs.uk/teams/1795/specialised_services_quality_dashboards/surveys/90053)

## Q4 2018/2019 - SSQD Q4 2018/2019 Dashboard

Ref	Description	Period	Nurm	Denom	Value	Nat Avg	Chart	Trend
HAEM02	Proportion of children (aged between 2 and 16 years old) within at risk group (S/S and S/bets 0 Thal) receiving Trans cranial doppler monitoring within Trust	Oct 18 to Mar 19	20.0	20.0	100.0	90.1		
HAEM03i	Proportion of patients given pain relief within half an hour of presentation with sickle crisis, as per NICE guidelines	Apr 18 to Mar 19	15.0	39.0	38.5	54.9		
HAEM04A	Proportion of patients with possible sickle disorders identified by neonatal screening who have been entered onto care pathway	Apr 18 to Mar 19	0.0	0.0		98.4	Insufficient data to produce chart.	
HAEM04B	Percentage of eligible children beginning penicillin at or before 3 months of age as per screening programme guidelines	Apr 18 to Mar 19	0.0	0.0		92.5	Insufficient data to produce chart.	
HAEM05	Data entry each year into annual review system of NHR	Apr 18 to Mar 19	87.0	88.0	98.9	79.4		
HAEM06Ai	Proportion of eligible patients on long term transfusion who receive cardiac MRI	Apr 18 to Mar 19	*	*	100.0	82.2		
HAEM06Aii	Proportion of patients receiving cardiac MRI who achieved more than 20 ms	Apr 18 to Mar 19	*	*	33.3	84.5		
HAEM06Bi	Proportion of eligible patients who receive MRI for liver iron - sickle only	Apr 18 to Mar 19	7.0	7.0	100.0	83.8		





# The UK National Haemoglobinopathy Registry and Dashboard

17/07/2019

[https://www.qst.england.nhs.uk/teams/1795/specialised\\_services\\_quality\\_dashboards/surveys/90053](https://www.qst.england.nhs.uk/teams/1795/specialised_services_quality_dashboards/surveys/90053)



## Specialised Services for Haemoglobinopathy Care (All Ages) at Churchill Hospital

SSQD description: SSQD Q4 2018/2019

Last AA Outcome (2018/2019): Routine surveillance

Last SD Score (2018/2019): 100.0

Latest SSQD Alerts (Q4 2018/2019):  
Positive Alerts: 2, Negative Alerts: 1,  
Neutral Alerts: 5

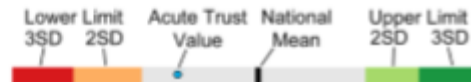
Alerts:

Negative  
1

Positive  
2

Neutral  
5

Spine Charts



SPC Sparklines



# The UK National Haemoglobinopathy Registry and Dashboard

## Action plan to improve performance



Thames Valley Haematology Network

### Adult Haemoglobinopathy Service

The audit tool requires review, as not everyone presenting always requires analgesia within 30mins, but because assessment and prior analgesia is currently inadequately documented, this is difficult to quantify.

**What can we do to reduce delay in prescription and raise the profile of SCD management?**

Action plan:

	Adult Plan	By whom by when	Done
1.	Contact triage, email data and outline a plan: <ul style="list-style-type: none"> <li>Assessing nurses to take more detailed assessment of pain, analgesia use: drug, time, dose; length of crisis</li> <li>Triage to contact Haem SPR to request pre-prescription of appropriate first dose analgesia before patient arrives.</li> </ul>	SH, 14/7/2019	Yes
	Plan meeting with triage in Sept <ul style="list-style-type: none"> <li>To review data and co-develop plan.</li> <li>Review criteria of 'chest pain' referral to ED</li> <li>Review possibility of haem SpR prescribing first dose when patients need to present to the ED and that this is handed over the ED staff</li> </ul>	SH, 14/7/19	Yes
	Promote further teaching for triage re SCD management	SH, , July 19	Awaiting triage response
	Advise SpR's of pre-prescription plan	NR, new and existing SpR's 9/19	
	Continue: ward case based teaching, at new starter orientation, new SHO induction(haem), new SpR induction(haem)	SH/NR ongoing	Ongoing
2	Develop SCD specific assessment tool for joint use across adults and paedes?	SH/LM Oct 19	





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