Information governance and data collection to support screening

- Robyn O’Loughlin - NHS Sickle Cell and Thalassaemia Screening Programme

Overview

- Linked antenatal and newborn screening programme for Sickle Cell & Thalassaemia (SCT) in England
- SCT newborn screening is part of the NHS Newborn Blood Spot Screening Programme, which screens for 9 conditions
- Programme standards define what is required to deliver a high quality, effective screening programme and encourage continuous improvement
- Key performance indicators (KPIs) focus on standards that require closer monitoring and/or improvement

Data & information governance

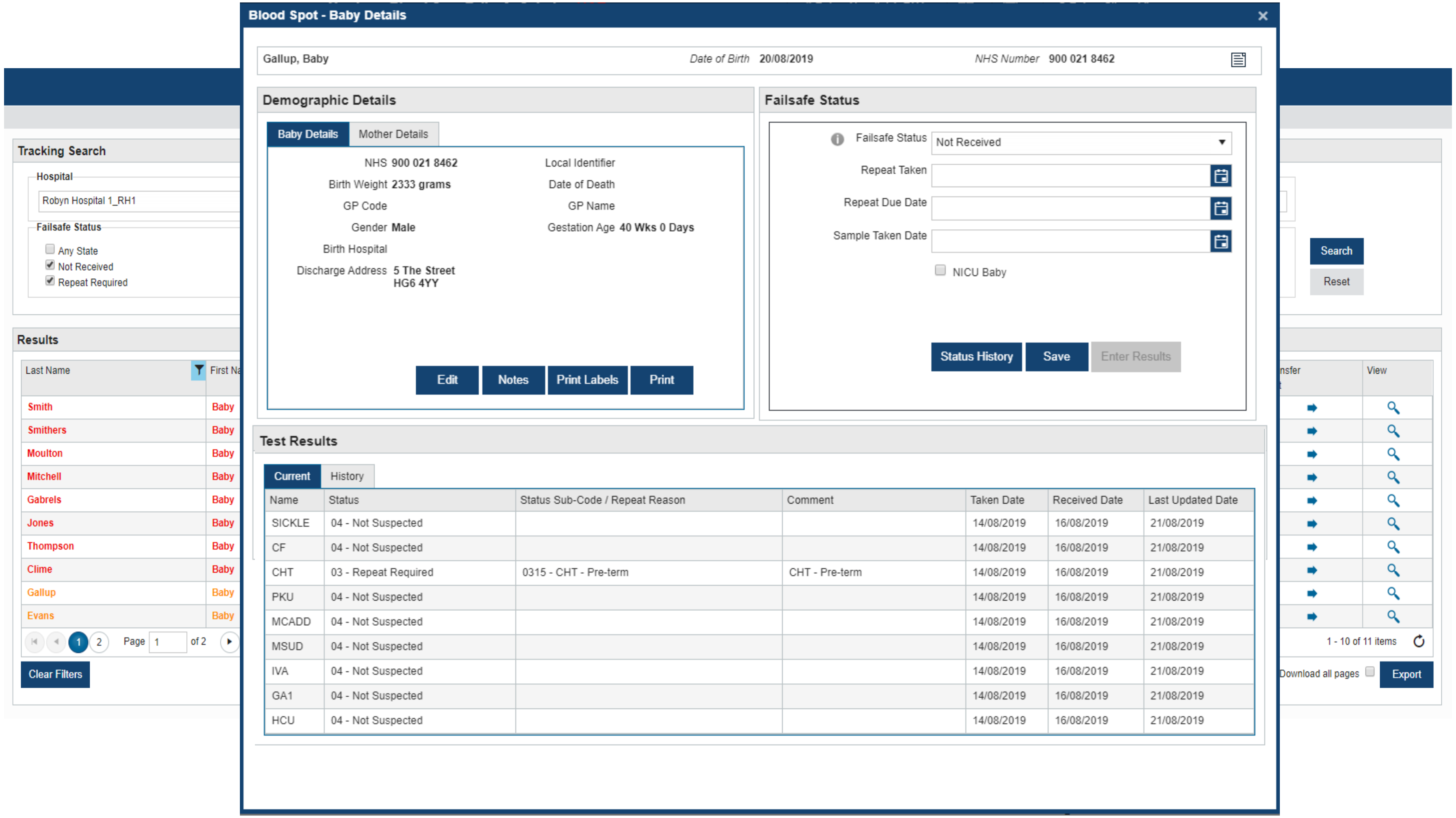
- Data collection is important for:
  - understanding prevalence and demand for services
  - monitoring performance
  - evaluating the programme
  - identifying areas for development
  - updating best practice to improve outcomes

- Information governance systems support:
  - robust referral processes
  - the effectiveness of the screening programme
  - equality of delivery

Newborn Blood Spot Failsafe Solution

- The failsafe system is used to ensure all children born in England are screened and results are recorded for each of the 9 conditions
- Live birth information feeds into the system and records are matched with maternity units
- Newborn blood spot results are uploaded to baby records. Repeat test requirements are included
- Where no initial sample cards are recorded, baby records are flagged on amber on day 12 and red day 17
- Where repeats are required and not recorded on the system, baby records are flagged on day 35
- The failsafe system is used in addition to existing pathways; it acts to provide assurance that screening is being delivered correctly

System screenshot



Tracking Search

Hospital

Robyn Hospital 1_RH1

Failsafe Status

☐ Any State
☑ Not Received
☑ Repeat Required

Results

Last Name	First Na	nsfer	View
Smith	Baby	➡	🔍
Smithers	Baby	➡	🔍
Moulton	Baby	➡	🔍
Mitchell	Baby	➡	🔍
Gabrels	Baby	➡	🔍
Jones	Baby	➡	🔍
Thompson	Baby	➡	🔍
Clime	Baby	➡	🔍
Gallup	Baby	➡	🔍
Evans	Baby	➡	🔍

Blood Spot - Baby Details

Gallup, Baby
Date of Birth 20/08/2019
NHS Number 900 021 8462

Demographic Details

NHS **900 021 8462**
Birth Weight **2333 grams**
GP Code
Gender **Male**
Birth Hospital
Discharge Address **5 The Street HG6 4YY**
Local Identifier
Date of Death
GP Name
Gestation Age **40 Wks 0 Days**

Failsafe Status

Failsafe Status: Not Received
Repeat Taken:
Repeat Due Date:
Sample Taken Date:
☐ NICU Baby

Test Results

Name	Status	Status Sub-Code / Repeat Reason	Comment	Taken Date	Received Date	Last Updated Date
SICKLE	04 - Not Suspected			14/08/2019	16/08/2019	21/08/2019
CF	04 - Not Suspected			14/08/2019	16/08/2019	21/08/2019
CHT	03 - Repeat Required	0315 - CHT - Pre-term	CHT - Pre-term	14/08/2019	16/08/2019	21/08/2019
PKU	04 - Not Suspected			14/08/2019	16/08/2019	21/08/2019
MCADD	04 - Not Suspected			14/08/2019	16/08/2019	21/08/2019
MSUD	04 - Not Suspected			14/08/2019	16/08/2019	21/08/2019
IVA	04 - Not Suspected			14/08/2019	16/08/2019	21/08/2019
GA1	04 - Not Suspected			14/08/2019	16/08/2019	21/08/2019
HCU	04 - Not Suspected			14/08/2019	16/08/2019	21/08/2019

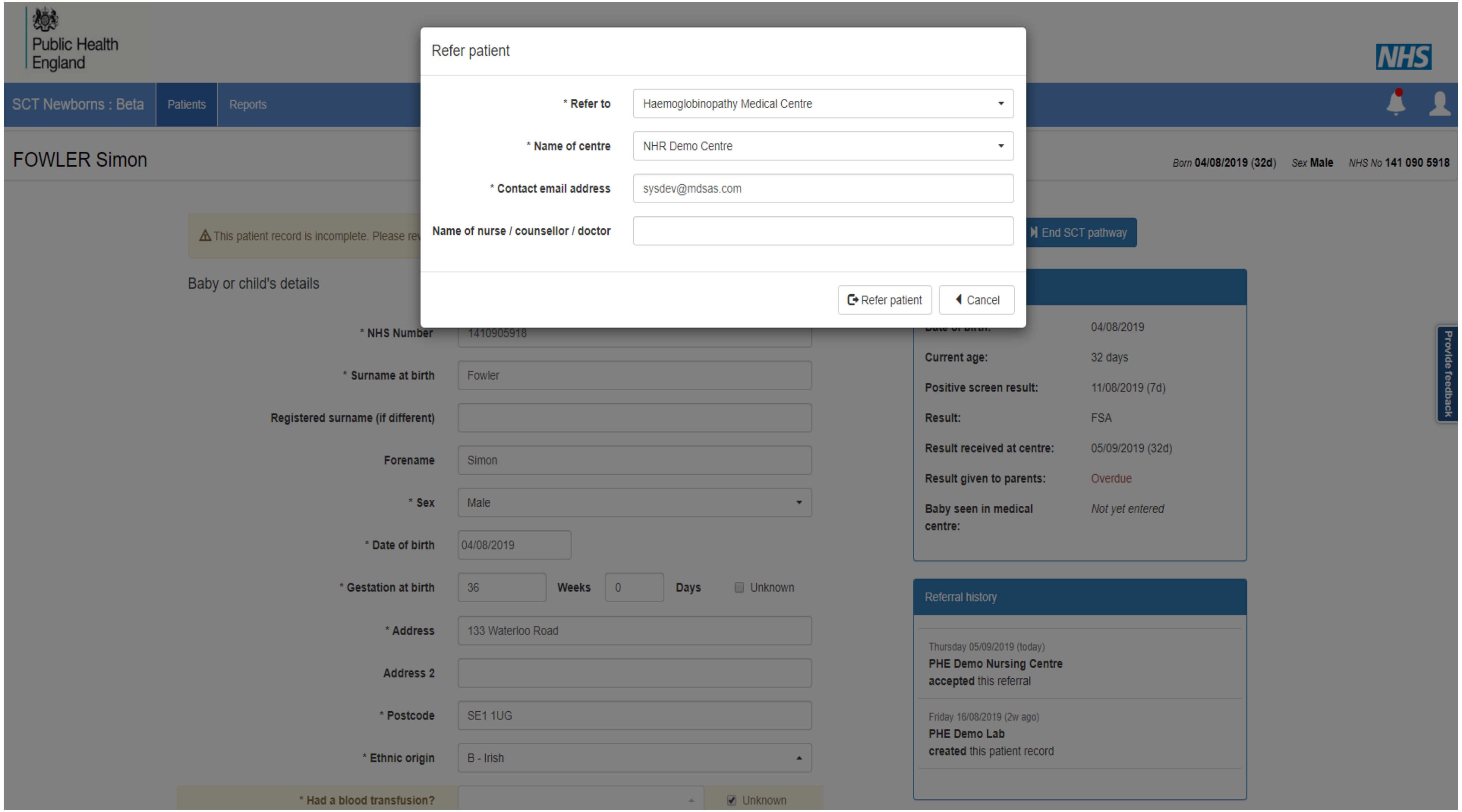
SCT newborn outcomes system

- The Sickle Cell and Thalassaemia newborn outcomes system is currently being implemented in England

- The system aims to:
- support referral of screen positive infants from screening laboratories into treatment services
- improve patient safety by allowing users to view the status of patients along the care pathway
- improve quality and completeness of data to evaluate the programme
- reduce duplication of data entry
- reduce manual chasing through automated alerts

Demonstration

Screen shots of system



Refer patient

* Refer to: Haemoglobinopathy Medical Centre
* Name of centre: NHR Demo Centre
* Contact email address: sysdev@mdsas.com
Name of nurse / counsellor / doctor:

FOWLER Simon

Born **04/08/2019 (32d)** Sex **Male** NHS No **141 090 5918**

⚠ This patient record is incomplete. Please re

Baby or child's details

* NHS Number: 1410905918
* Surname at birth: Fowler
Registered surname (if different):
Forename: Simon
* Sex: Male
* Date of birth: 04/08/2019
* Gestation at birth: 36 Weeks 0 Days ☐ Unknown
* Address: 133 Waterloo Road
Address 2:
* Postcode: SE1 1UG
* Ethnic origin: B - Irish
* Had a blood transfusion? ☑ Unknown

	04/08/2019
Current age:	32 days
Positive screen result:	11/08/2019 (7d)
Result:	FSA
Result received at centre:	05/09/2019 (32d)
Result given to parents:	Overdue
Baby seen in medical centre:	*Not yet entered*

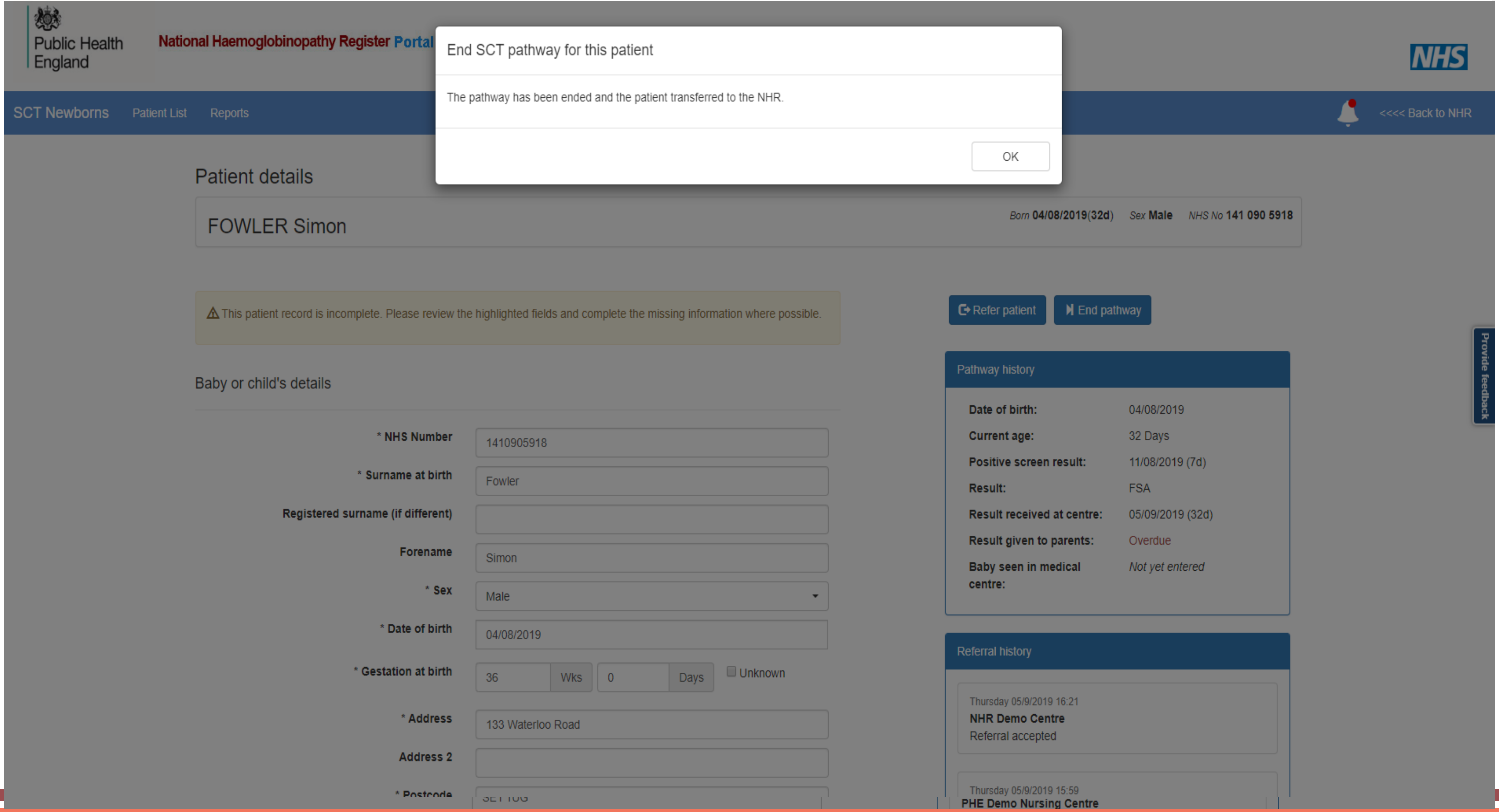
Referral history

Thursday 05/09/2019 (today)
PHE Demo Nursing Centre
accepted this referral

Friday 16/08/2019 (2w ago)
PHE Demo Lab
created this patient record

ARISE

Screenshots (NHR access)



End SCT pathway for this patient

The pathway has been ended and the patient transferred to the NHR.

Patient details

FOWLER Simon

Born **04/08/2019**(32d) *Sex* **Male** *NHS No* **141 090 5918**

⚠ This patient record is incomplete. Please review the highlighted fields and complete the missing information where possible.

Baby or child's details

*** NHS Number**	1410905918
*** Surname at birth**	Fowler
Registered surname (if different)	
Forename	Simon
*** Sex**	Male
*** Date of birth**	04/08/2019
*** Gestation at birth**	36 Wks 0 Days ☐ Unknown
*** Address**	133 Waterloo Road
Address 2	
*** Postcode**	SE1 1UG

Pathway history

Date of birth:	04/08/2019
Current age:	32 Days
Positive screen result:	11/08/2019 (7d)
Result:	FSA
Result received at centre:	05/09/2019 (32d)
Result given to parents:	Overdue
Baby seen in medical centre:	*Not yet entered*

Referral history

Thursday 05/9/2019 16:21
NHR Demo Centre
Referral accepted

Thursday 05/9/2019 15:59
PHE Demo Nursing Centre

ARISE

Link to national registry

- 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.
- It collects data required by the Department of Health and its aim is to improve patient care.
- The newborn outcomes system enables clinicians to ‘pull through’ patient information and create records on the National Haemoglobinopathy Registry (NHR)
- There is a national drive to use it more comprehensively and this process reminds clinicians to gain consent and use the NHR
- The link also reduces the need to create a new entry manually

Safety and evaluation

- Having systems like these in place:
  - improves patient safety
  - standardises processes nationally
  - makes the programme more robust
  - enables more effective evaluation and monitoring of screening processes – locally and nationally
  - facilitates service design based on prevalence/ demand for services
  - provides an audit trail for tracing back issues or investigating incidents

Thank you

Haemoglobinopathy Registries / Dashboards

Dr Wale Atoyebi

Consultant Haematologist

Oxford University Hospitals, Oxford, UK

This project has received funding from the European Union’s Horizon 2020 research and innovation programme under the Marie Skłodowska-Curie grant agreement No. 824021

The UK National Haemoglobinopathy Registry and Dashboard

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

NHR
WWW.NHR.NHS.UK

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.

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

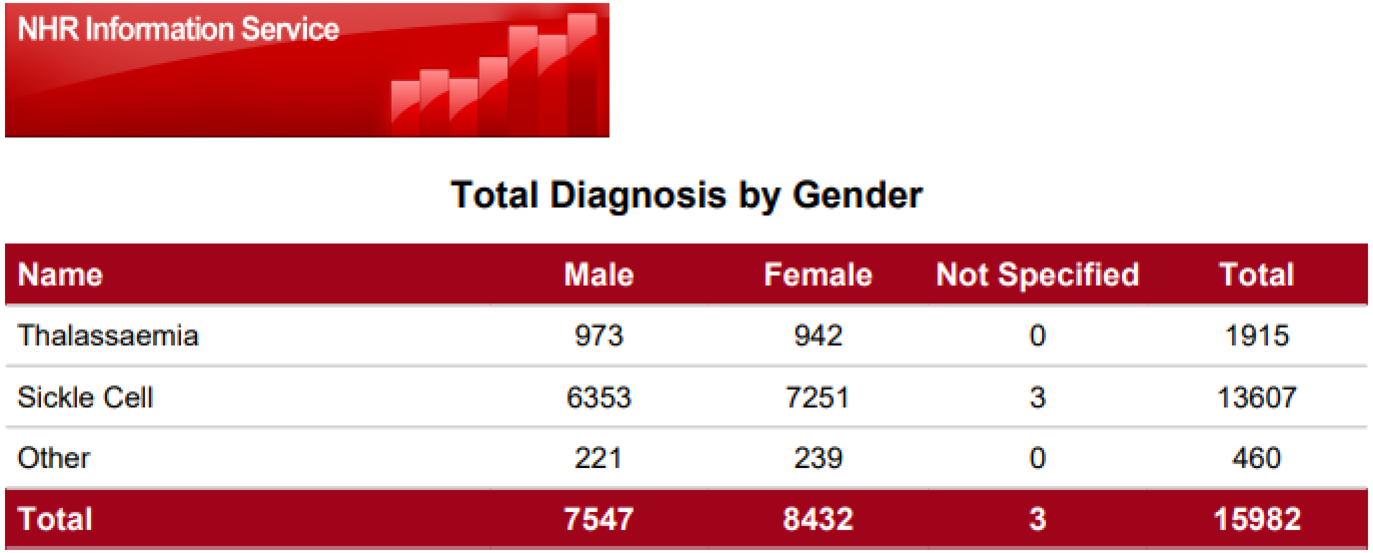
Active Registrations
13,357

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

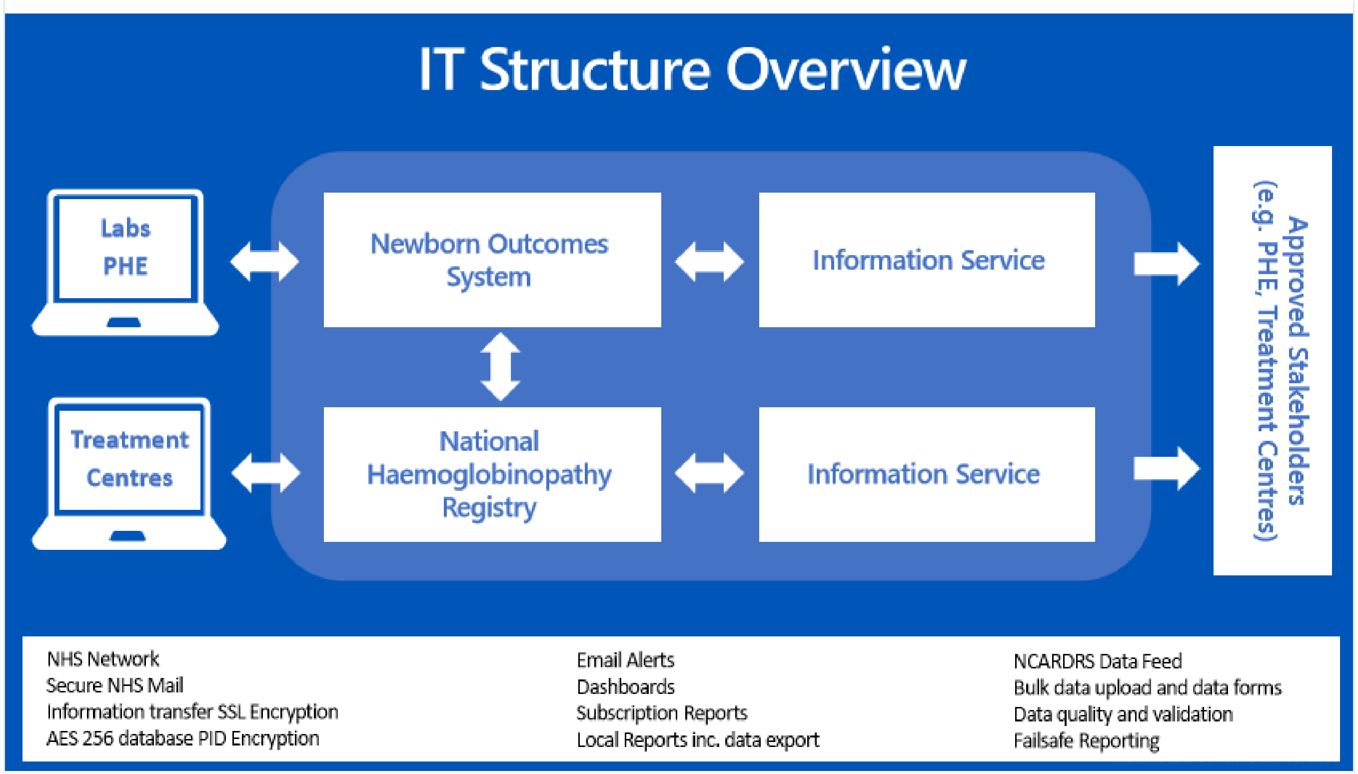


NHR Information Service

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
Total	**7547**	**8432**	**3**	**15982**

The UK National Haemoglobinopathy Registry and Dashboard



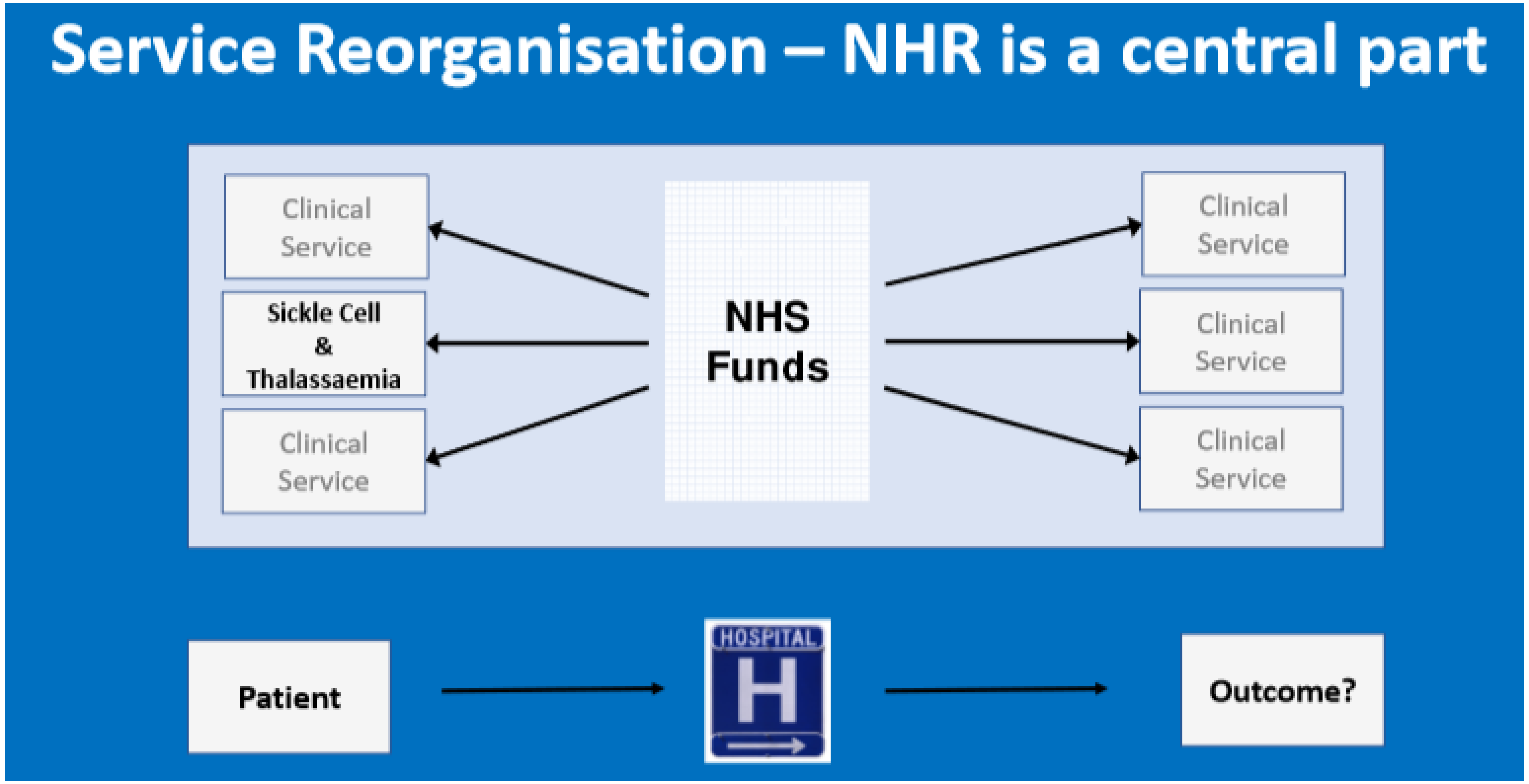
NHS Network
Secure NHS Mail
Information transfer SSL Encryption
AES 256 database PID Encryption

Email Alerts
Dashboards
Subscription Reports
Local Reports inc. data export

NCARDRS Data Feed
Bulk data upload and data forms
Data quality and validation
Failsafe Reporting

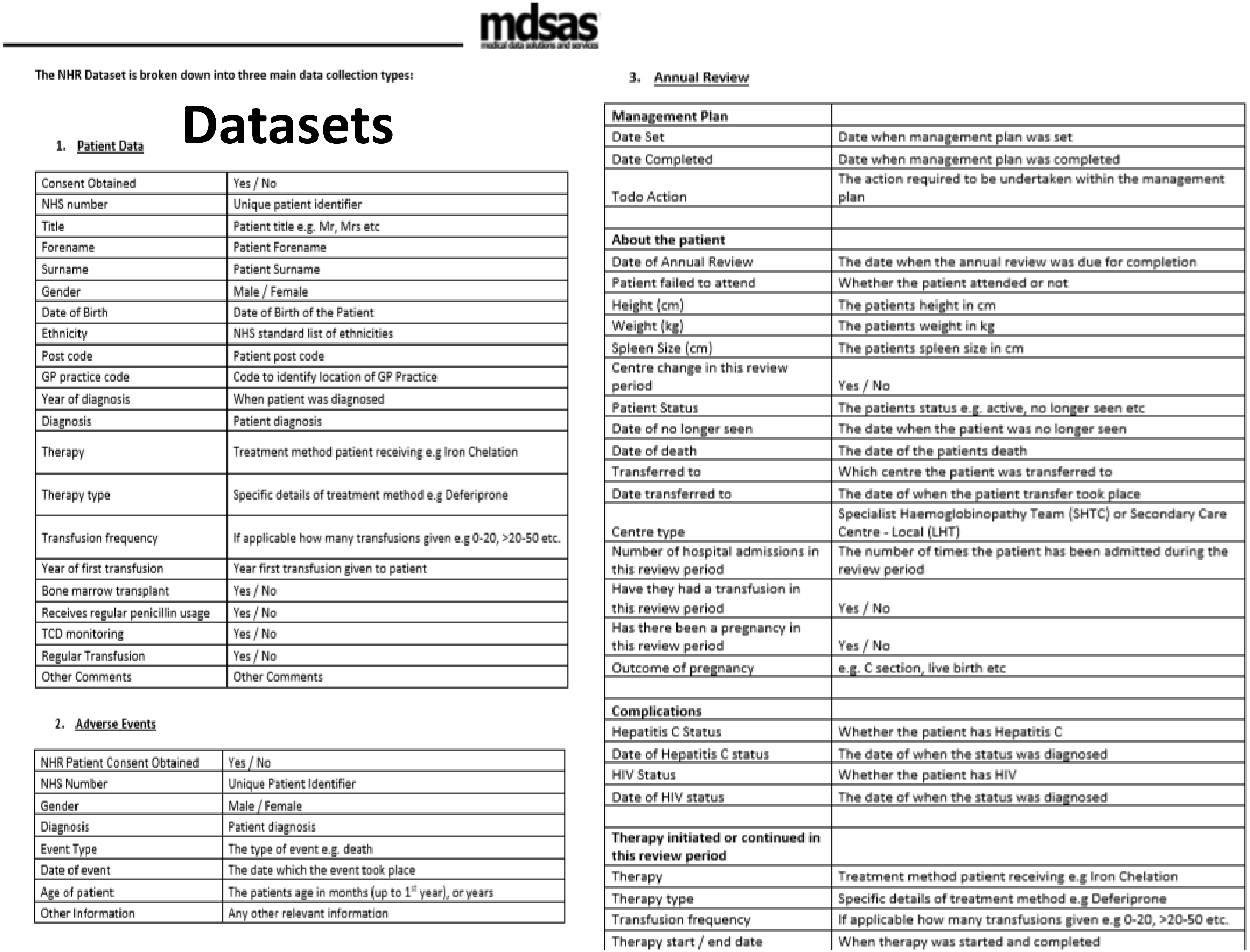
E.g. In Kaduna State
Laboratory = Patrick Yakowa Hospital, Kafanchan
PHE = Primary Health Care Development Agency
Treatment Centre = Barau Dikko Teaching Hospital (BDTH)

The UK National Haemoglobinopathy Registry and Dashboard



Service Reorganisation – NHR is a central part

Datasets



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

1. **Patient Data**

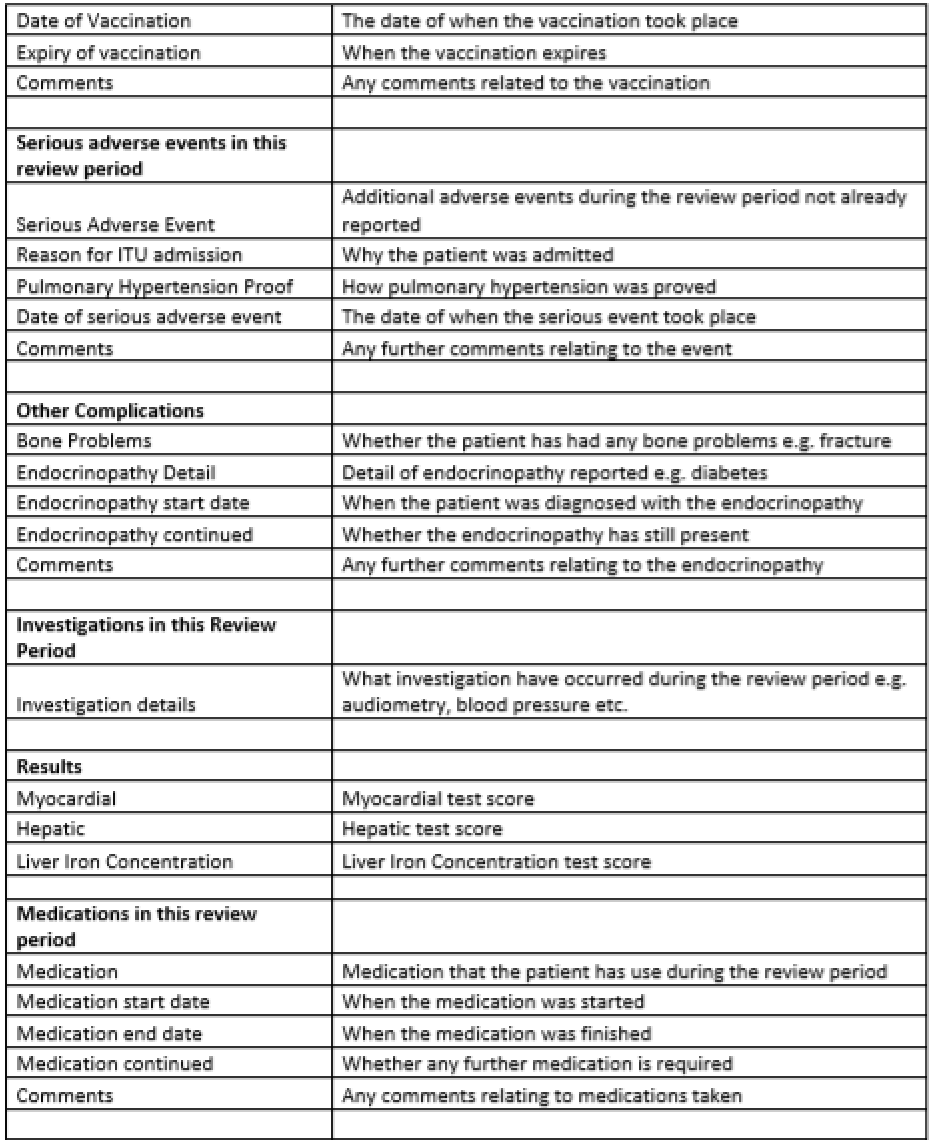
Consent Obtained	Yes / No
NHS number	Unique patient identifier
Title	Patient title e.g. Mr, Mrs etc
Forename	Patient Forename
Surname	Patient Surname
Gender	Male / Female
Date of Birth	Date of Birth of the Patient
Ethnicity	NHS standard list of ethnicities
Post code	Patient post code
GP practice code	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 1st year), or years
Other Information	Any other relevant information

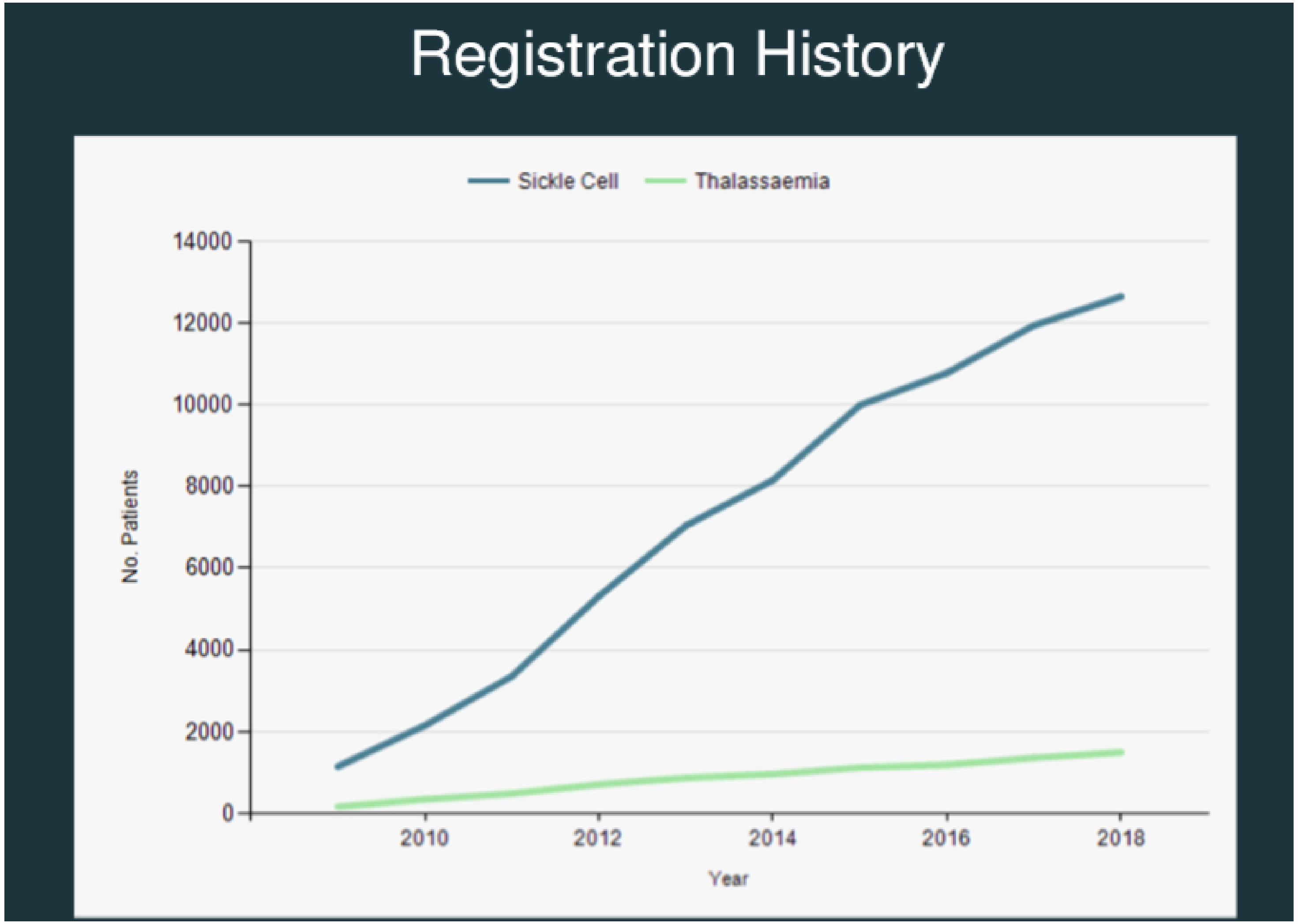
3. **Annual Review**

Management Plan	
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
About the patient	
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
Complications	
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
Therapy initiated or continued in this review period	
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



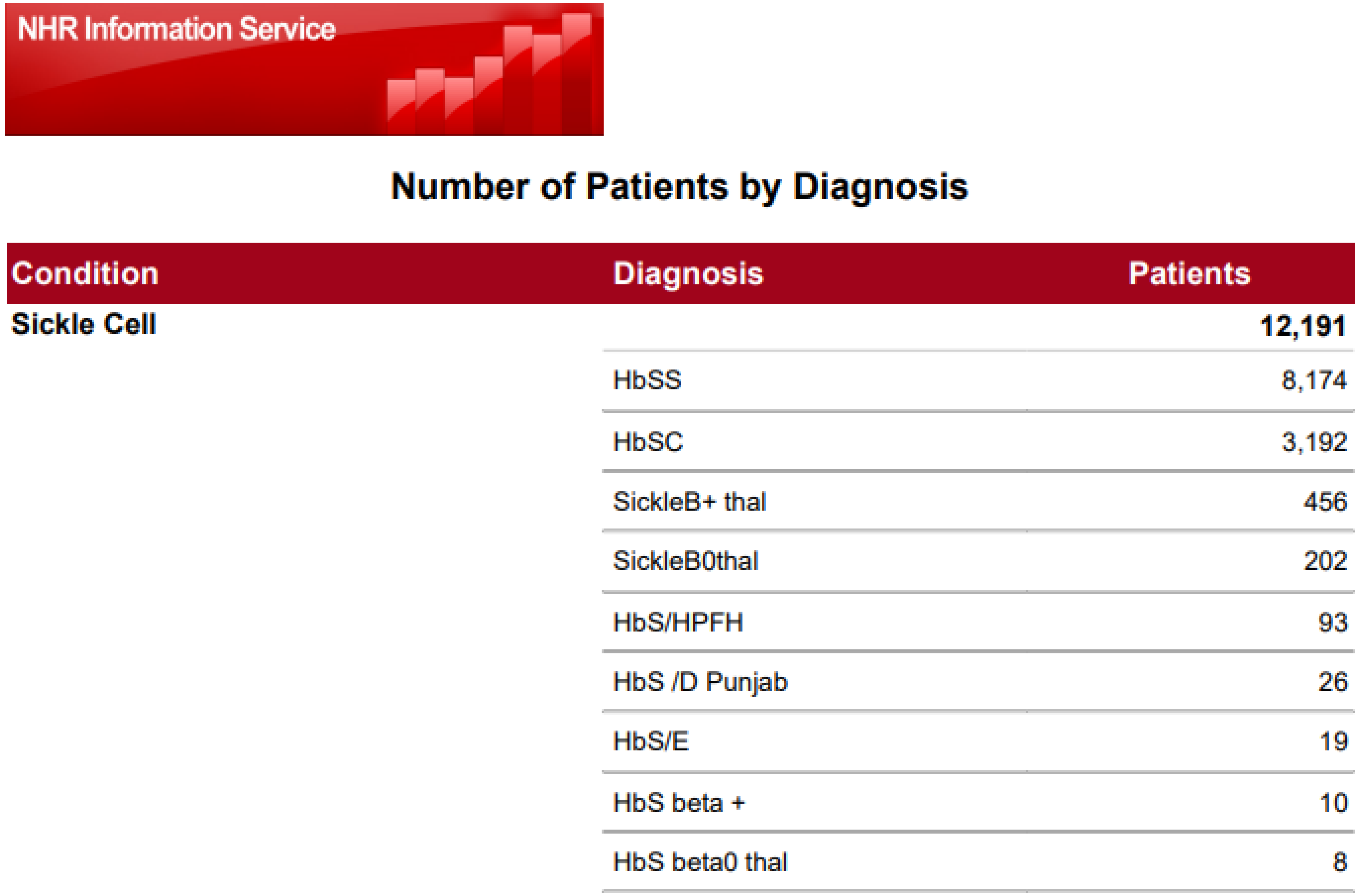
Date of Vaccination	The date of when the vaccination took place
Expiry of vaccination	When the vaccination expires
Comments	Any comments related to the vaccination
Serious adverse events in this review period	
Serious Adverse Event	Additional adverse events during the review period not already reported
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
Other Complications	
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
Investigations in this Review Period	
Investigation details	What investigation have occurred during the review period e.g. audiometry, blood pressure etc.
Results	
Myocardial	Myocardial test score
Hepatic	Hepatic test score
Liver Iron Concentration	Liver Iron Concentration test score
Medications in this review period	
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



ARISE

The UK National Haemoglobinopathy Registry and Dashboard

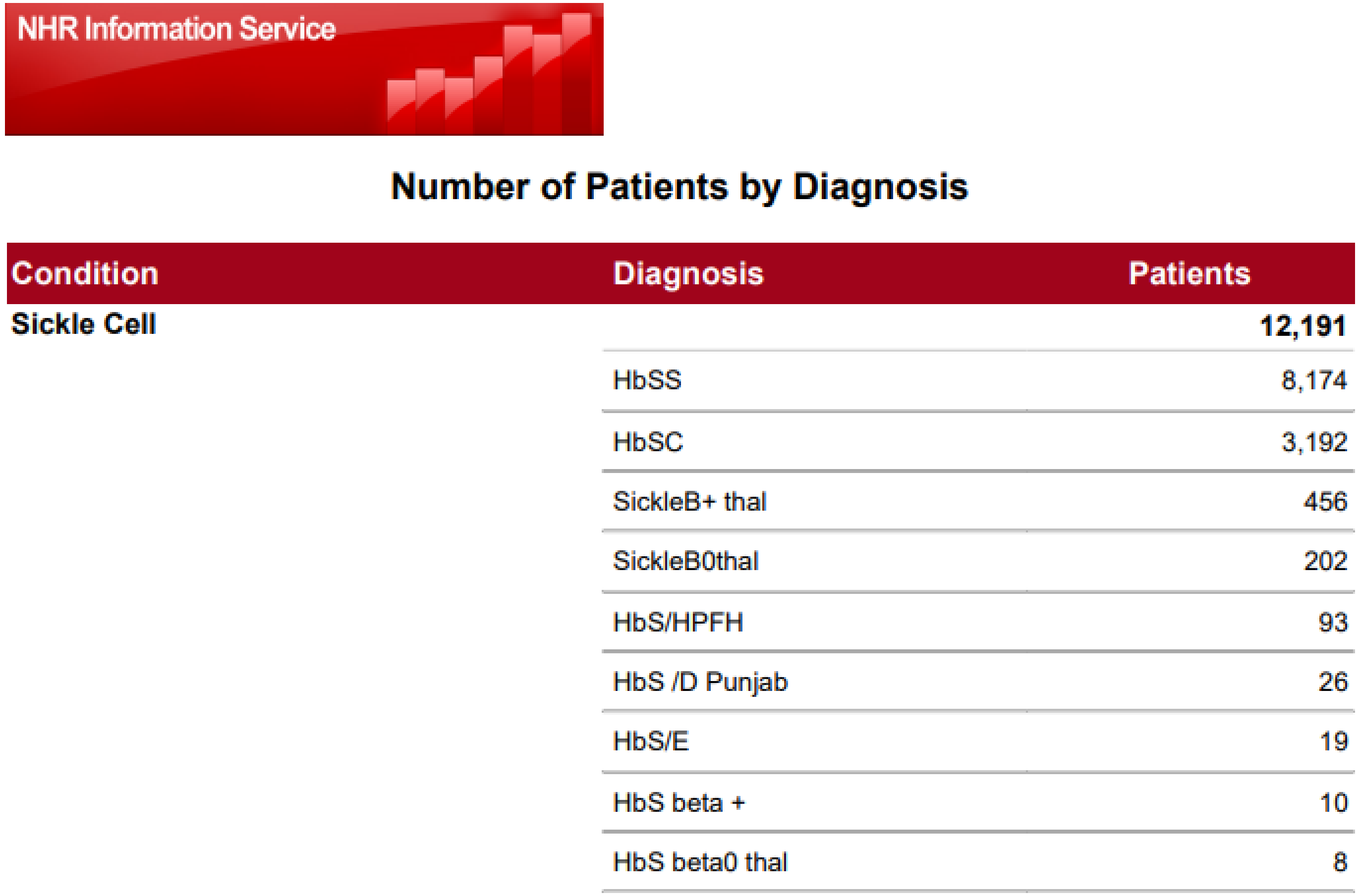


NHR Information Service

Number of Patients by Diagnosis

Condition	Diagnosis	Patients
Sickle Cell		**12,191**
	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

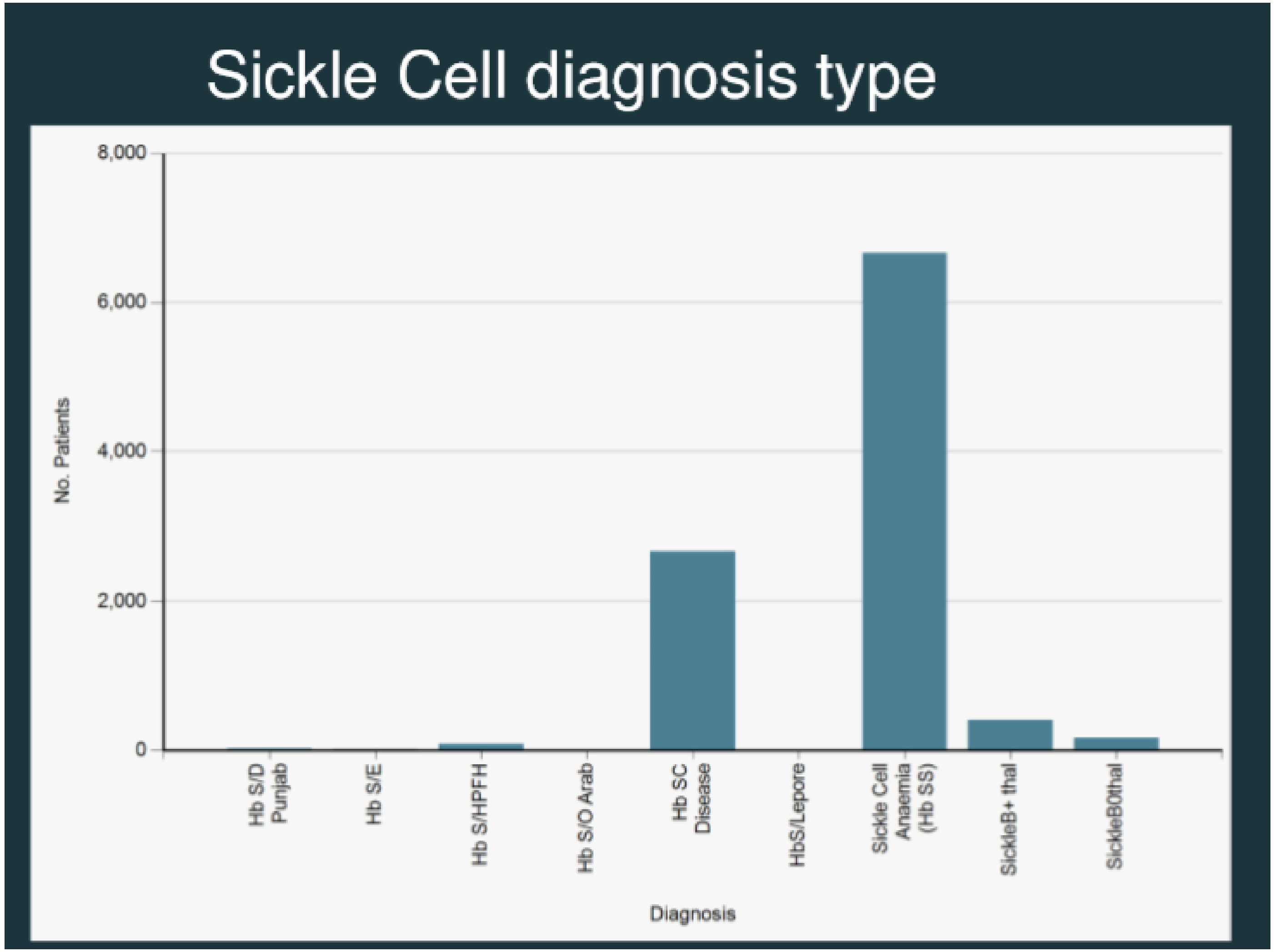


NHR Information Service

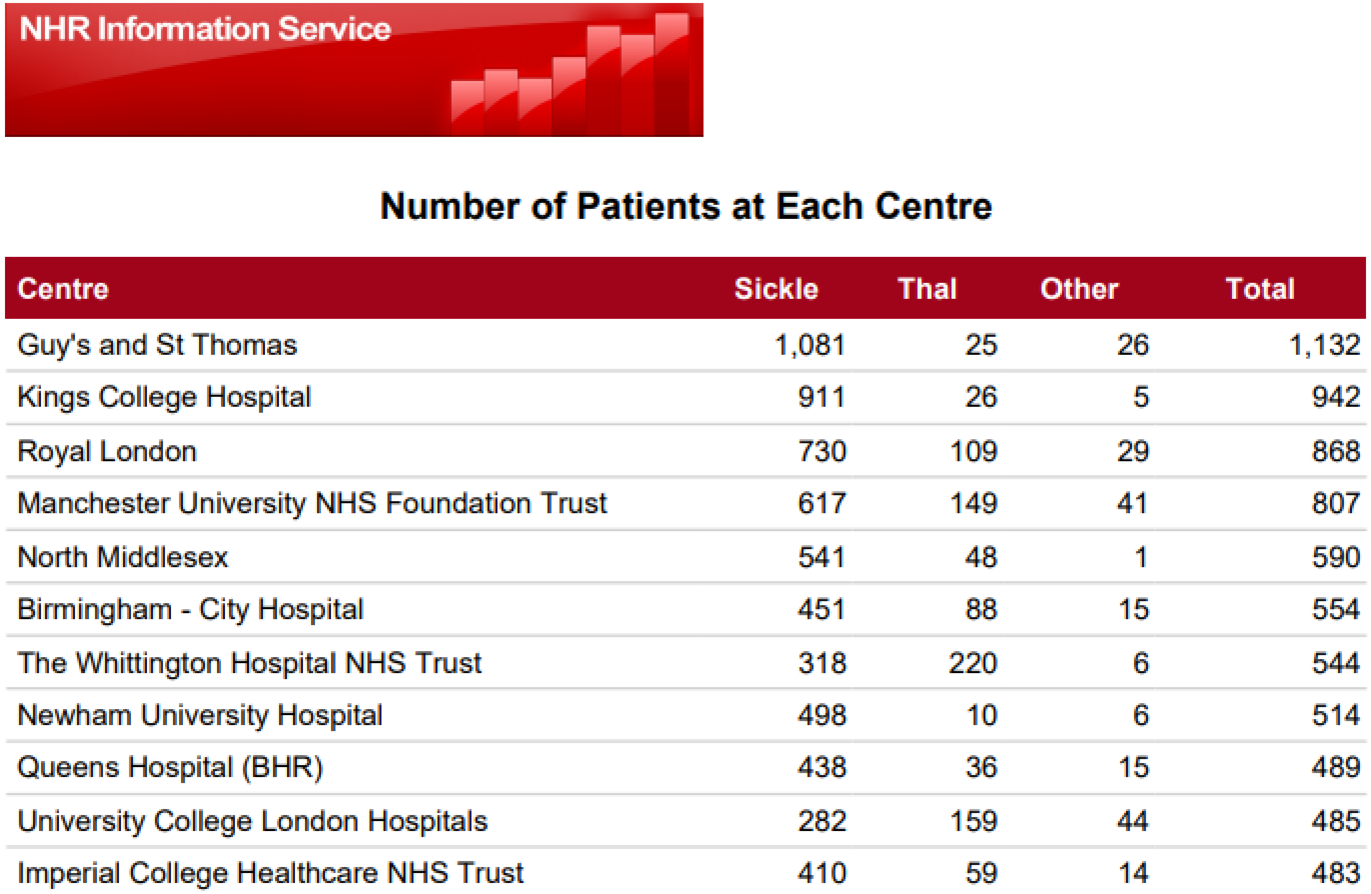
Number of Patients by Diagnosis

Condition	Diagnosis	Patients
Sickle Cell		**12,191**
	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



The UK National Haemoglobinopathy Registry and Dashboard

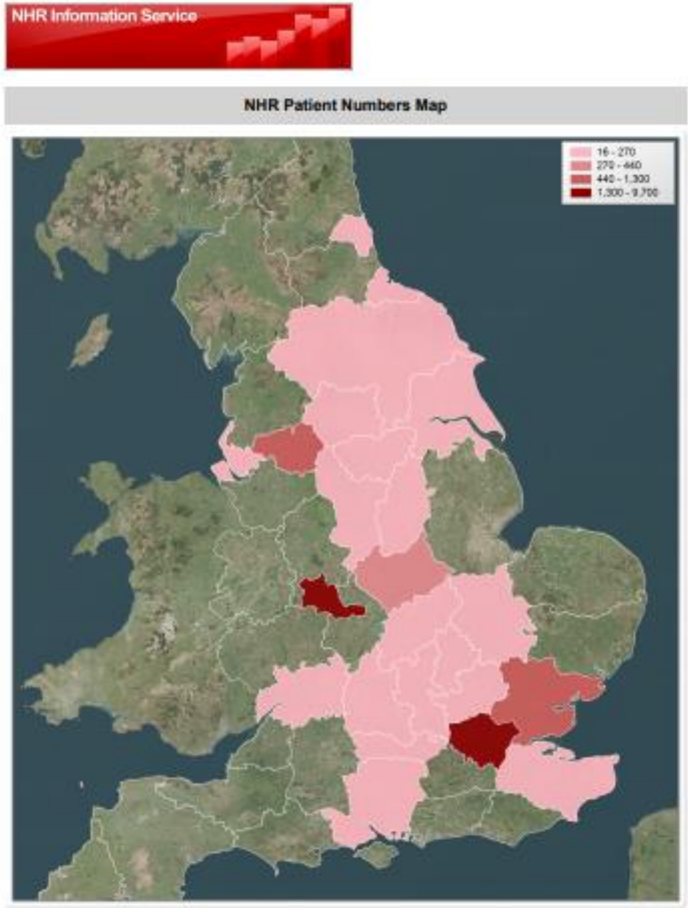


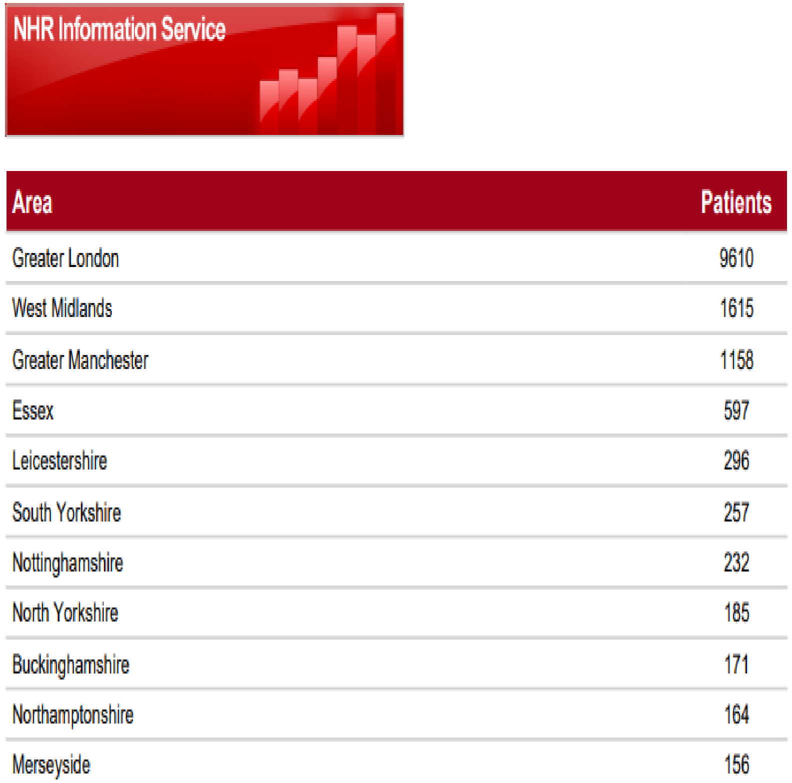
NHR Information Service

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

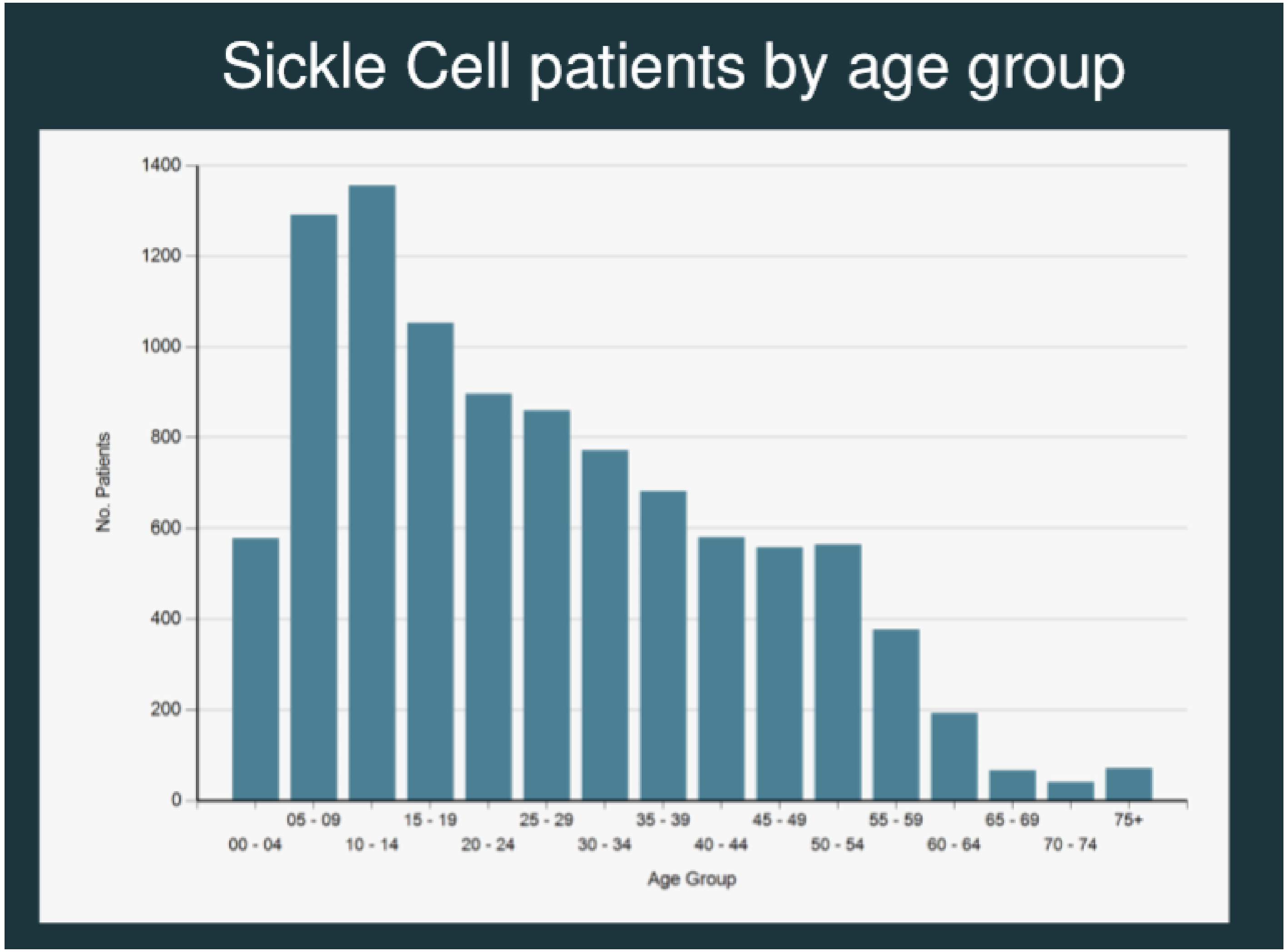




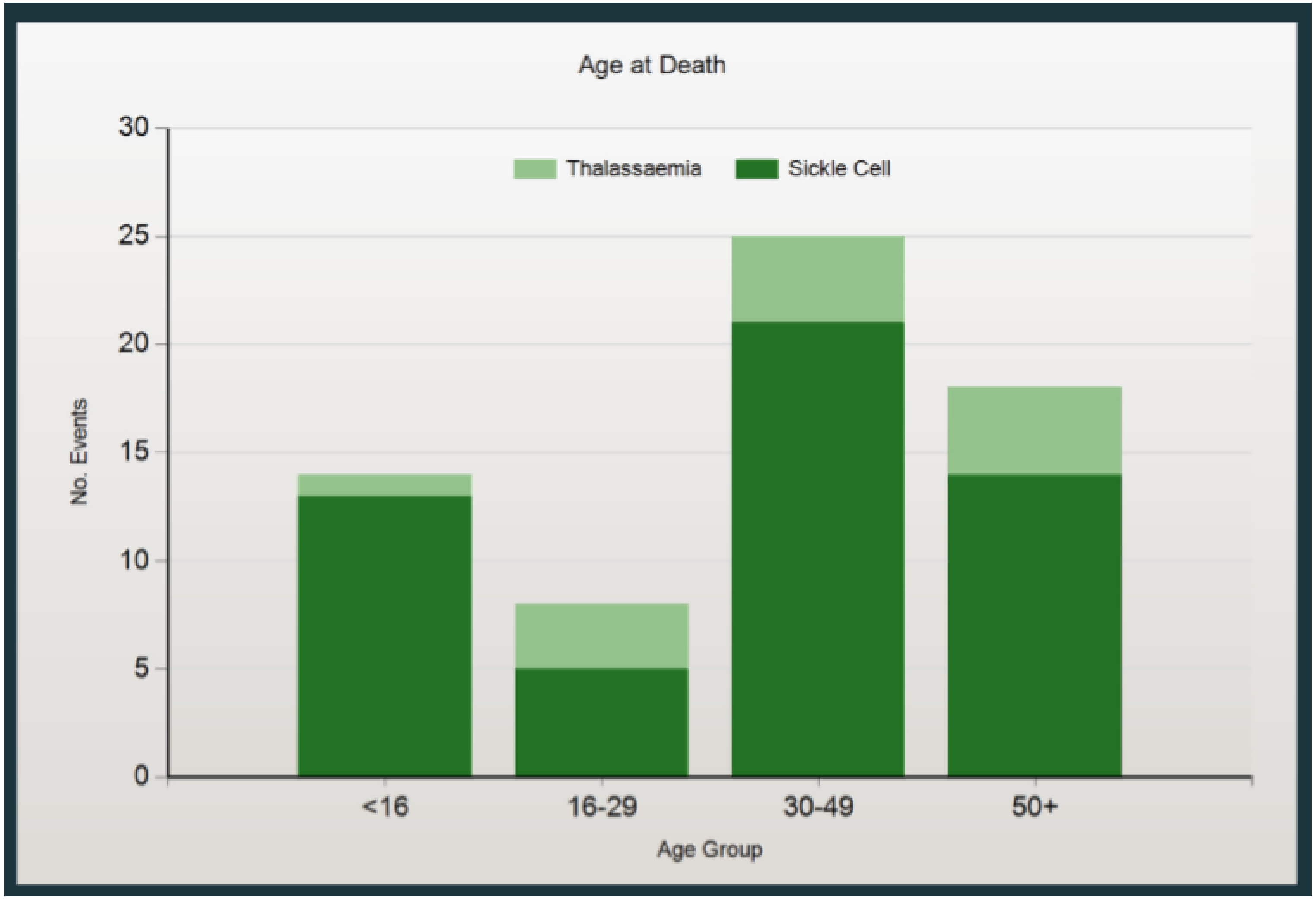
NHR Information Service

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

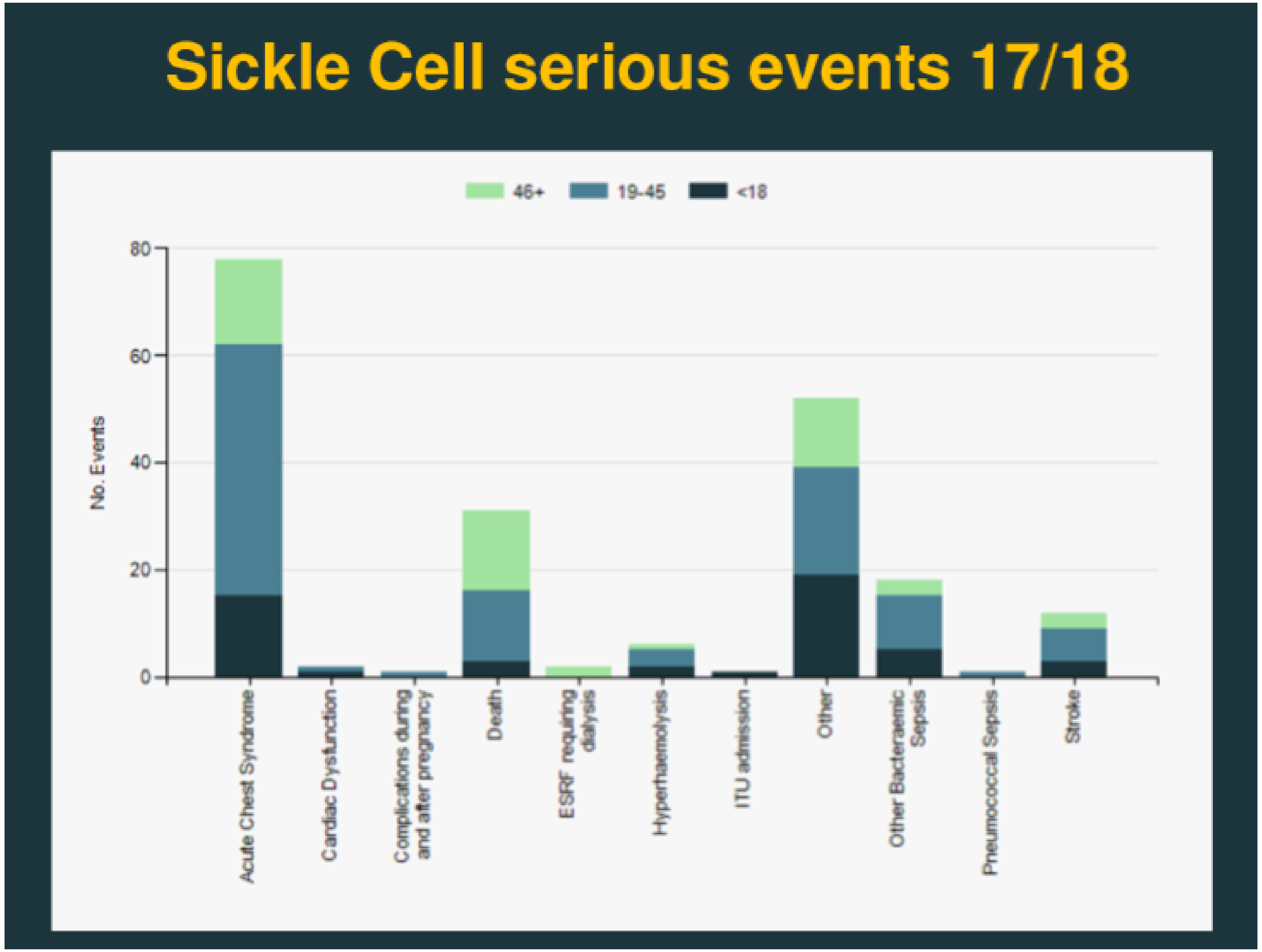
The UK National Haemoglobinopathy Registry and Dashboard



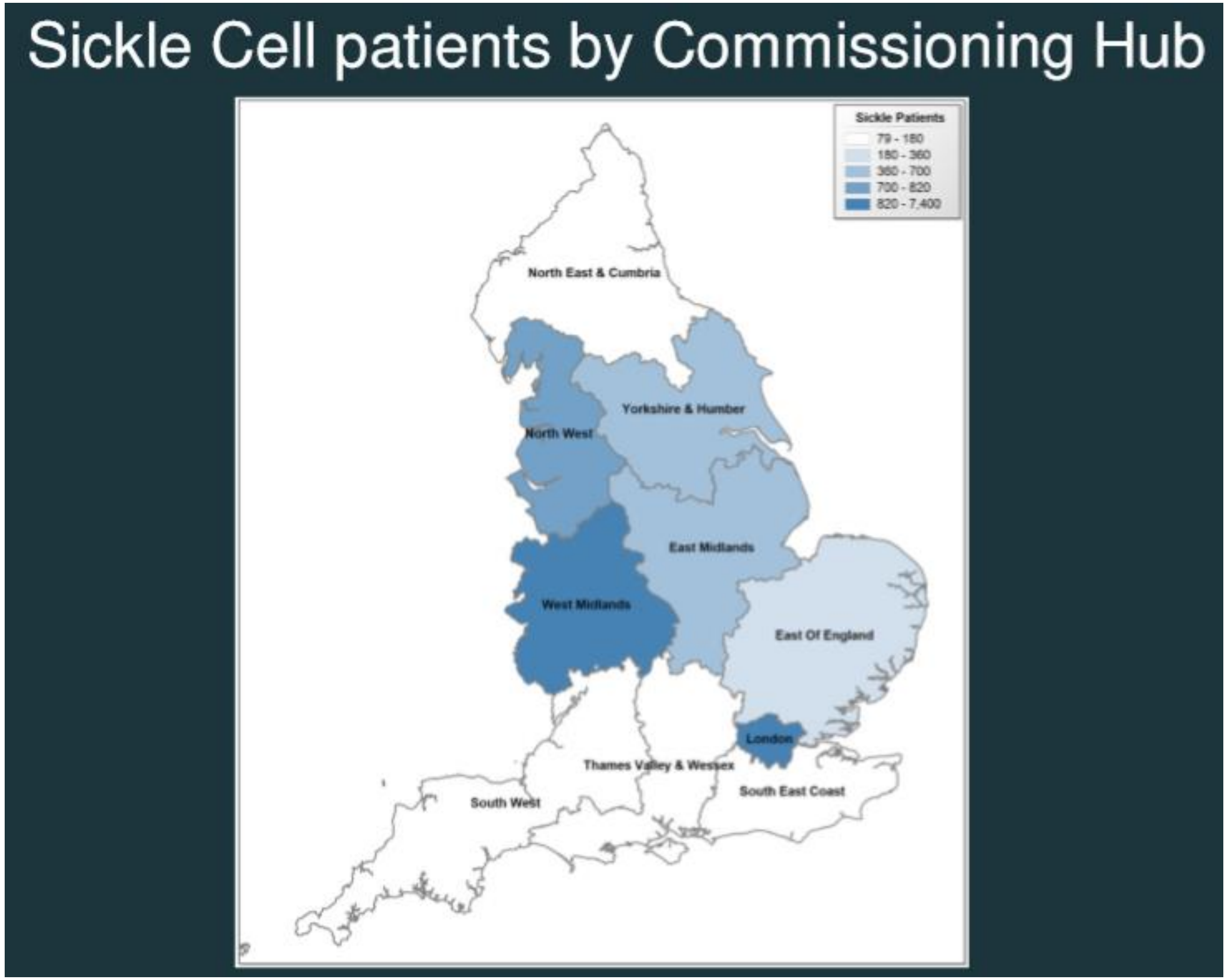
The UK National Haemoglobinopathy Registry and Dashboard



The UK National Haemoglobinopathy Registry and Dashboard



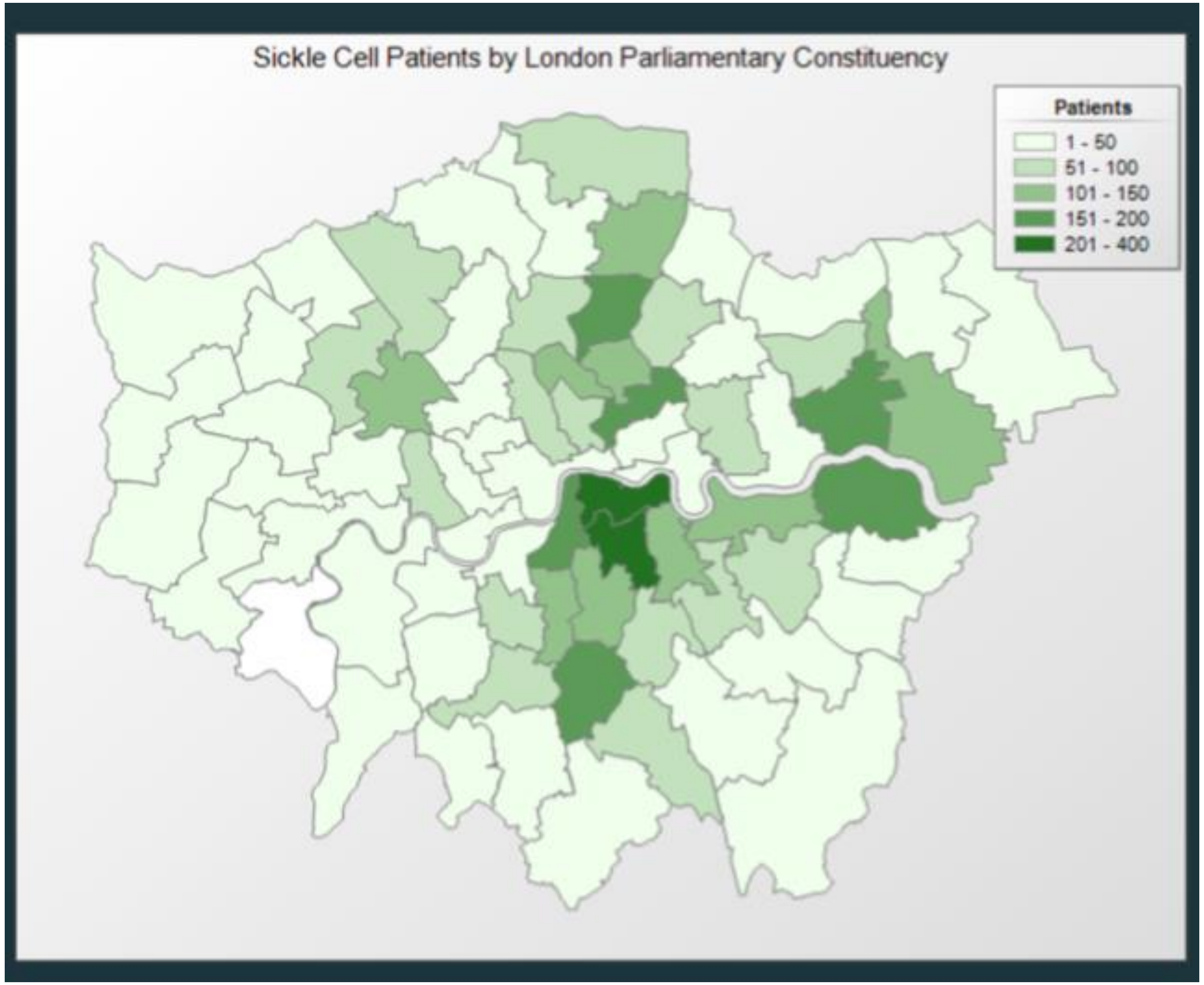
The UK National Haemoglobinopathy Registry and Dashboard



Sickle Cell patients by Commissioning Hub

Commissioning Hub
= Nigerian States

The UK National Haemoglobinopathy Registry and Dashboard



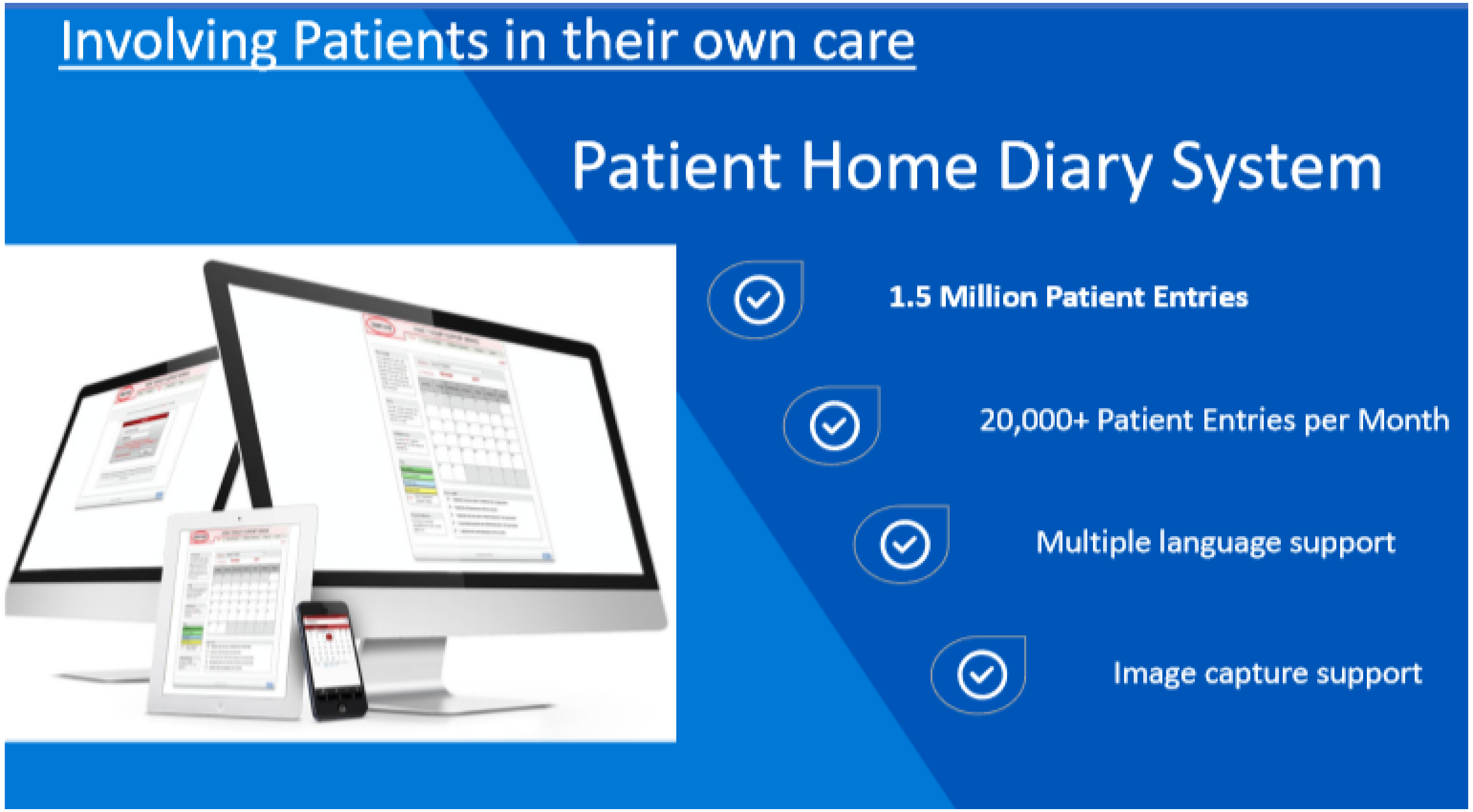
We can engage our lawmakers as advocates

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

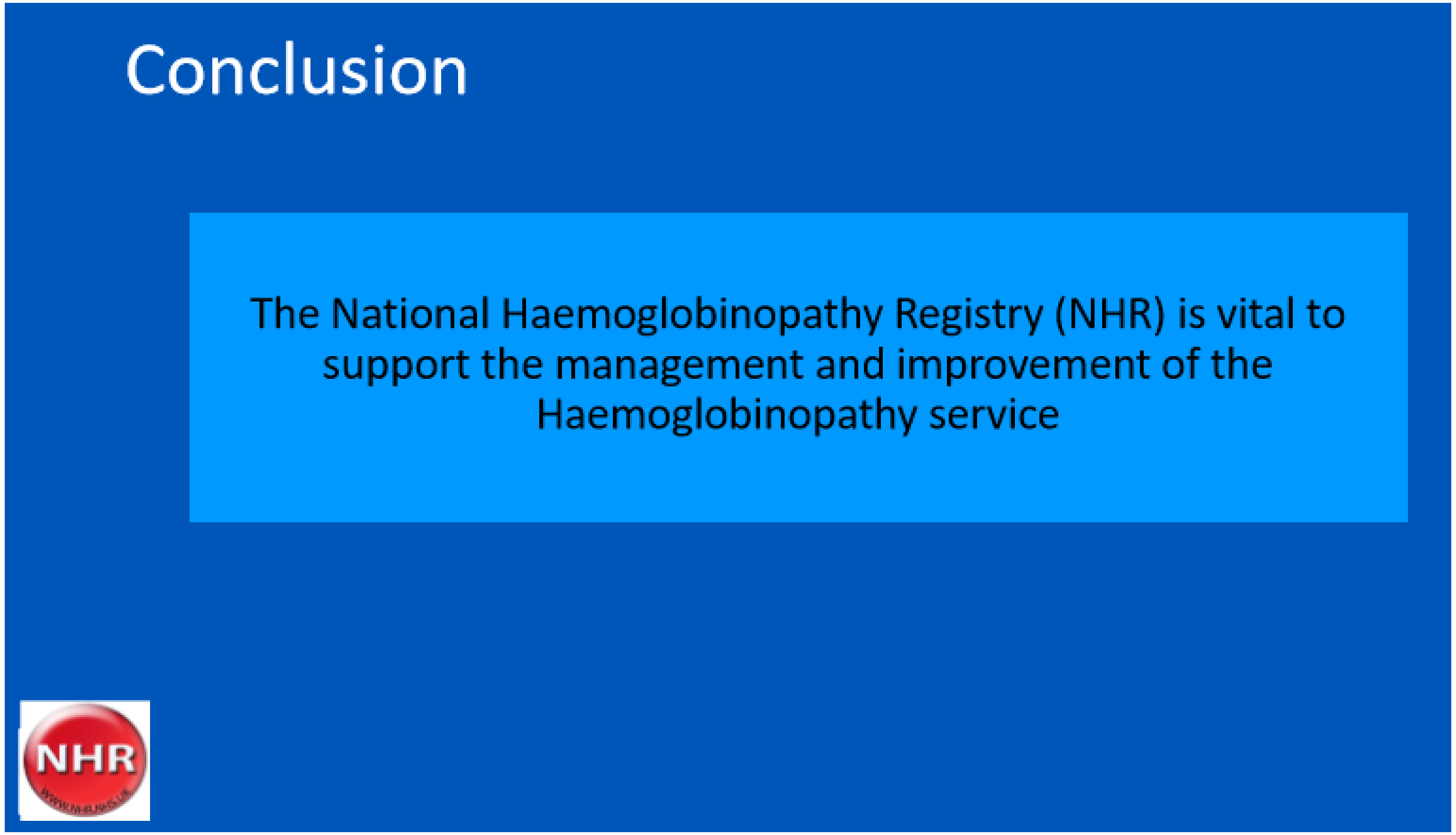


Involving Patients in their own care

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

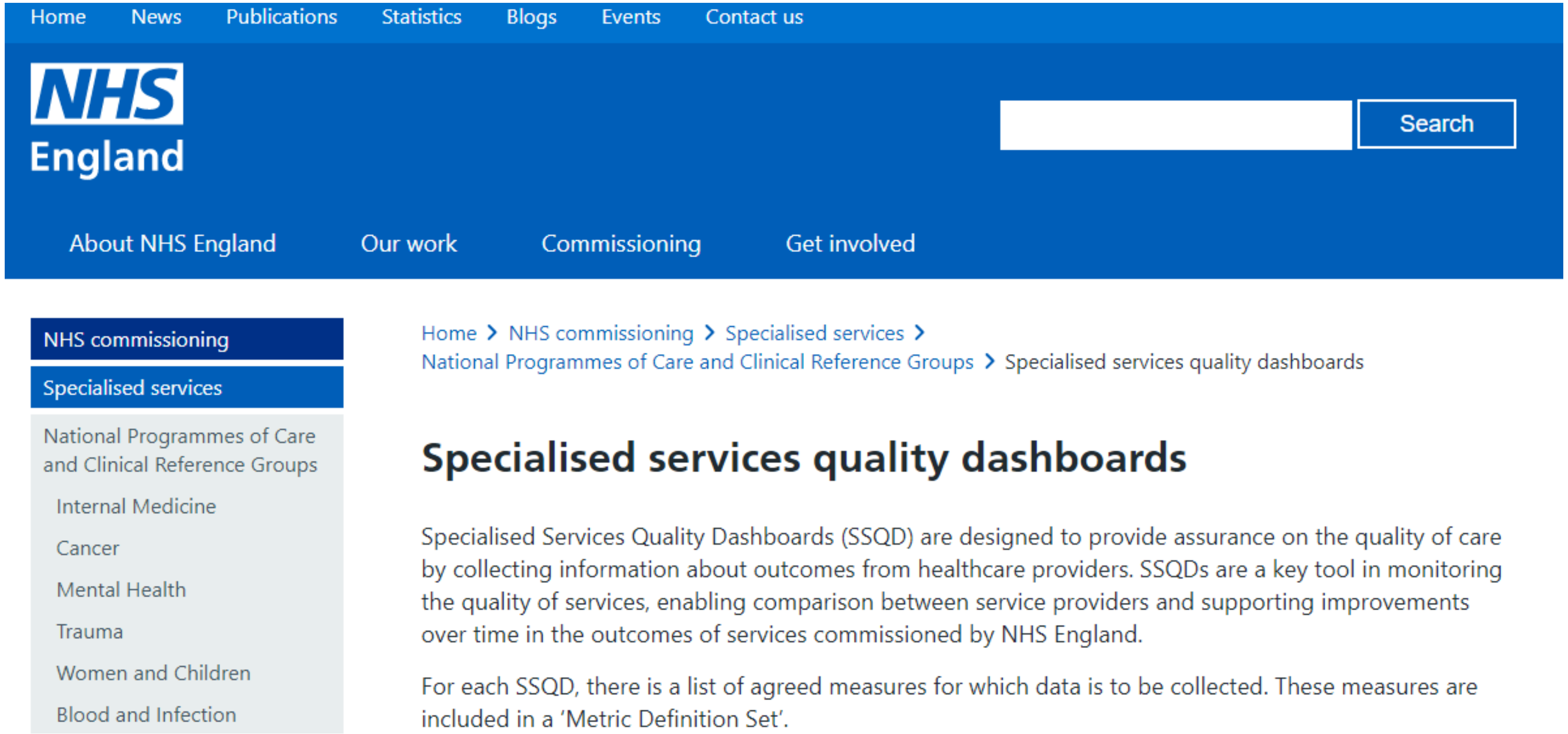
UK Haemoglobinopathy Dashboard

- 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



Home > NHS commissioning > Specialised services > National Programmes of Care and Clinical Reference Groups > Specialised services quality dashboards

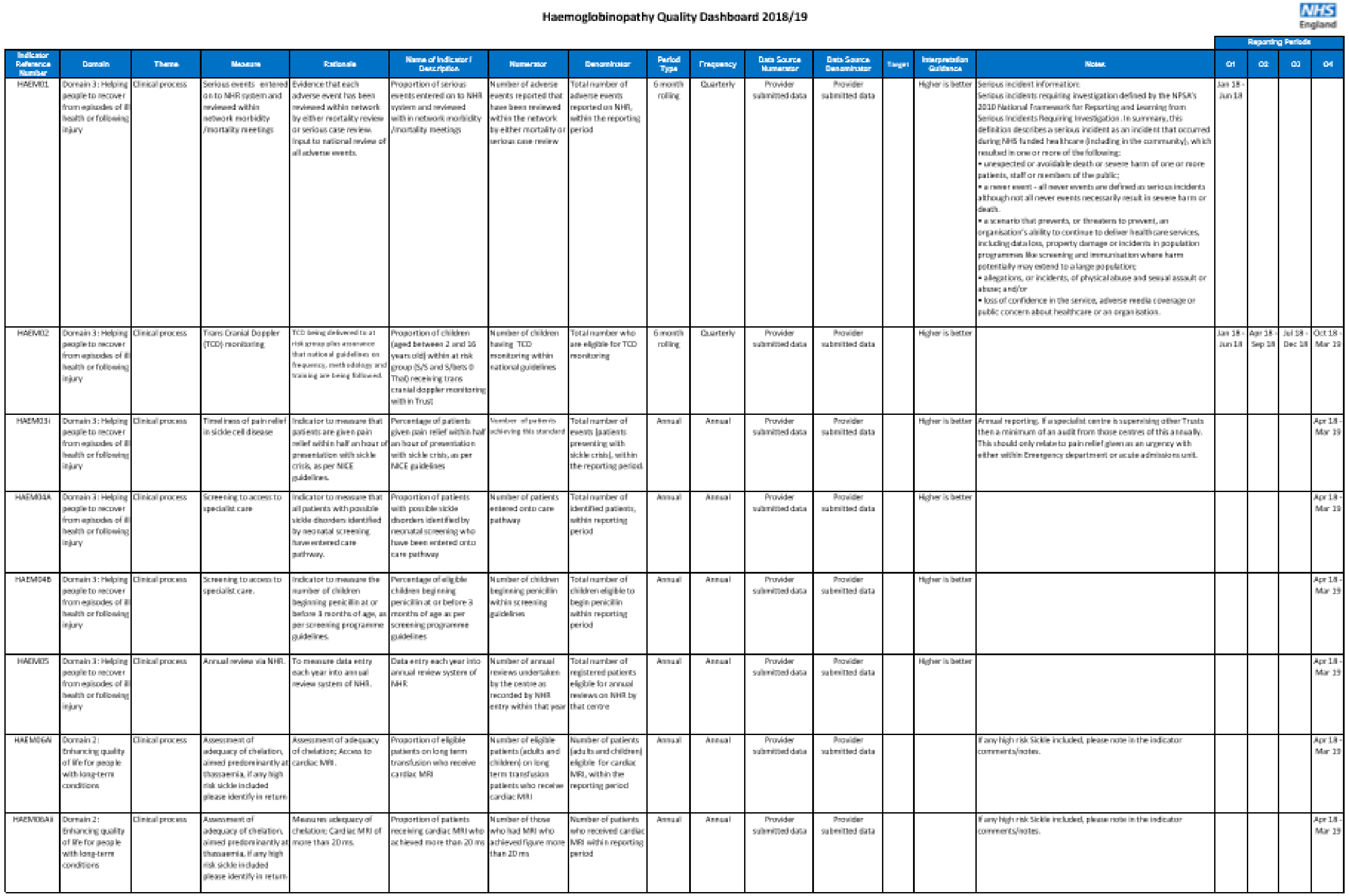
Specialised services quality dashboards

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

															Reporting Periods			
Indicator Reference Number	Domain	Theme	Measure	Rationale	Name of Indicator / Description	Numerator	Denominator	Period Type	Frequency	Data Source Numerator	Data Source Denominator	Target	Interpretation Guidance	Notes	Q1	Q2	Q3	Q4
HAEM01	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 mortality 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: ▪ unexpected or avoidable death or severe harm of one or more patients, staff or members of the public; ▪ a never event - all never events are defined as serious incidents although not all never events necessarily result in severe harm or death. ▪ 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; ▪ allegations, or incidents, of physical abuse and sexual assault or abuse; and/or ▪ loss of confidence in the service, adverse media coverage or public concern about healthcare or an organisation.	Jan 18 - Jun 18			
HAEM02	Domain 3: Helping people to recover from episodes of ill health or following injury	Clinical process	Trans Cranial Doppler (TCD) monitoring	TCD being delivered to at risk group plus assurance 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 (S/S and S/beta 0 Thal) 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
HAEM03i	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
HAEM04A	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 have entered care pathway.	Proportion of patients with possible sickle disorders identified by neonatal screening who have been 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
HAEM04B	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
HAEM05	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
HAEM06Ai	Domain 2: Enhancing quality of life for people with long-term conditions	Clinical process	Assessment of adequacy of chelation, aimed predominantly at thassaemia, if any high risk sickle included please identify in return	Assessment of adequacy of chelation; Access to cardiac MRI.	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			If any high risk Sickle included, please note in the indicator comments/notes.				Apr 18 - Mar 19
HAEM06Aii	Domain 2: Enhancing quality of life for people with long-term conditions	Clinical process	Assessment of adequacy of chelation, aimed predominantly at thassaemia, if any high risk sickle included please identify in return	Measures adequacy of chelation; Cardiac MRI of more than 20 ms.	Proportion of patients receiving cardiac MRI who achieved more than 20 ms	Number of those who had MRI who achieved figure more than 20 ms	Number of patients who received cardiac MRI within reporting period	Annual	Annual	Provider submitted data	Provider submitted data			If any high risk Sickle included, please note in the indicator comments/notes.				Apr 18 - Mar 19

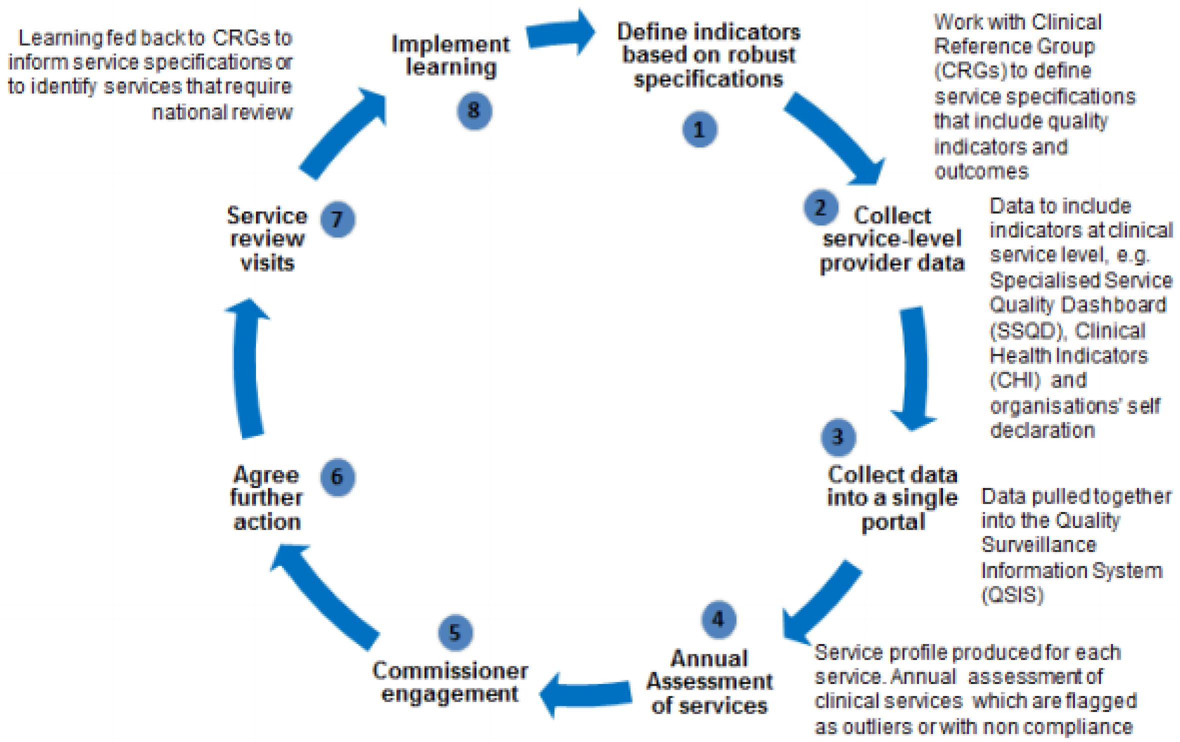
The UK National Haemoglobinopathy Registry and Dashboard

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



1 **Define indicators based on robust specifications**

Work with Clinical Reference Group (CRGs) to define service specifications that include quality indicators and outcomes

2 **Collect service-level provider data**

Data to include indicators at clinical service level, e.g. Specialised Service Quality Dashboard (SSQD), Clinical Health Indicators (CHI) and organisations' self declaration

3 **Collect data into a single portal**

Data pulled together into the Quality Surveillance Information System (QSIS)

4 **Annual Assessment of services**

Service profile produced for each service. Annual assessment of clinical services which are flagged as outliers or with non compliance

5 **Commissioner engagement**

6 **Agree further action**

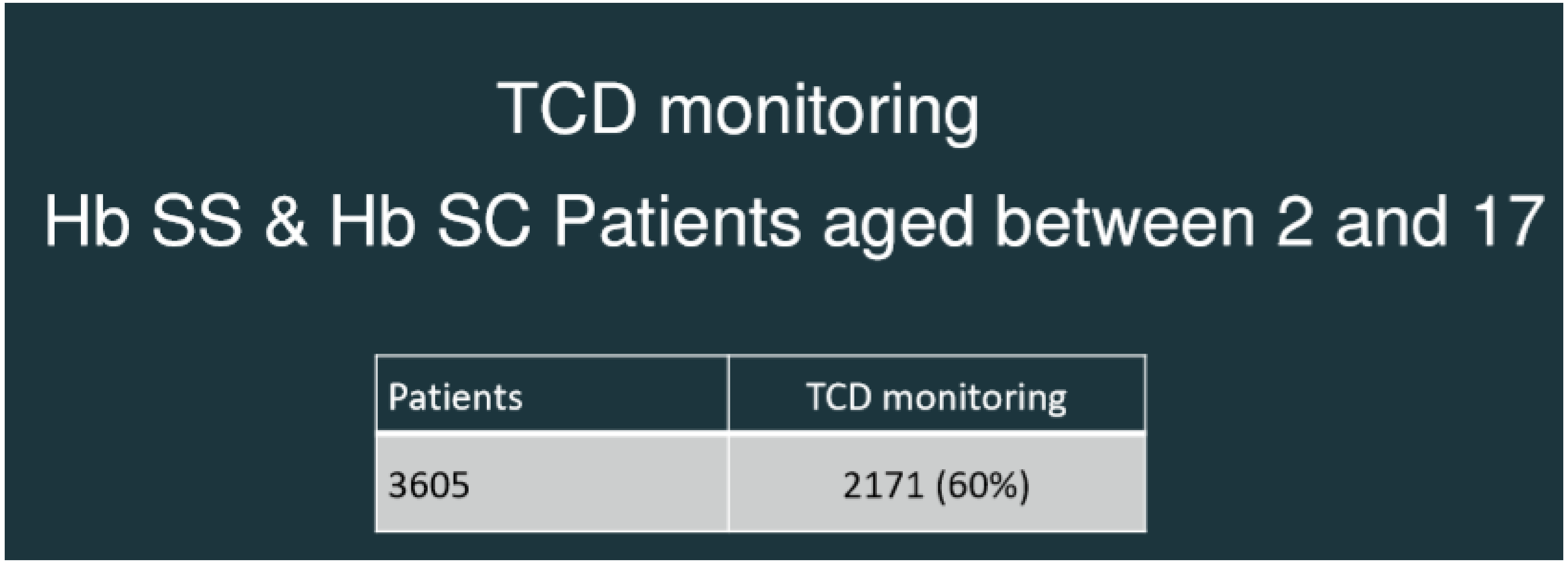
7 **Service review visits**

8 **Implement learning**

Learning fed back to CRGs to inform service specifications or to identify services that require national review

ARISE

The UK National Haemoglobinopathy Registry and Dashboard

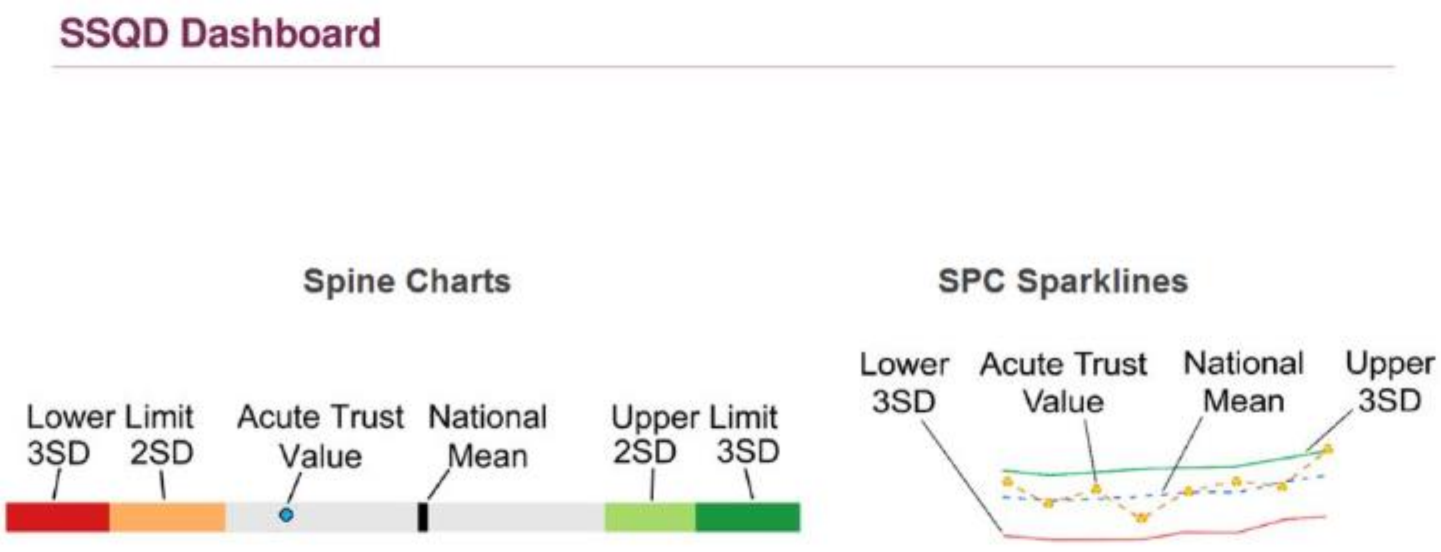


TCD monitoring

Hb SS & Hb SC Patients aged between 2 and 17

Patients	TCD monitoring
3605	2171 (60%)

The UK National Haemoglobinopathy Registry and Dashboard

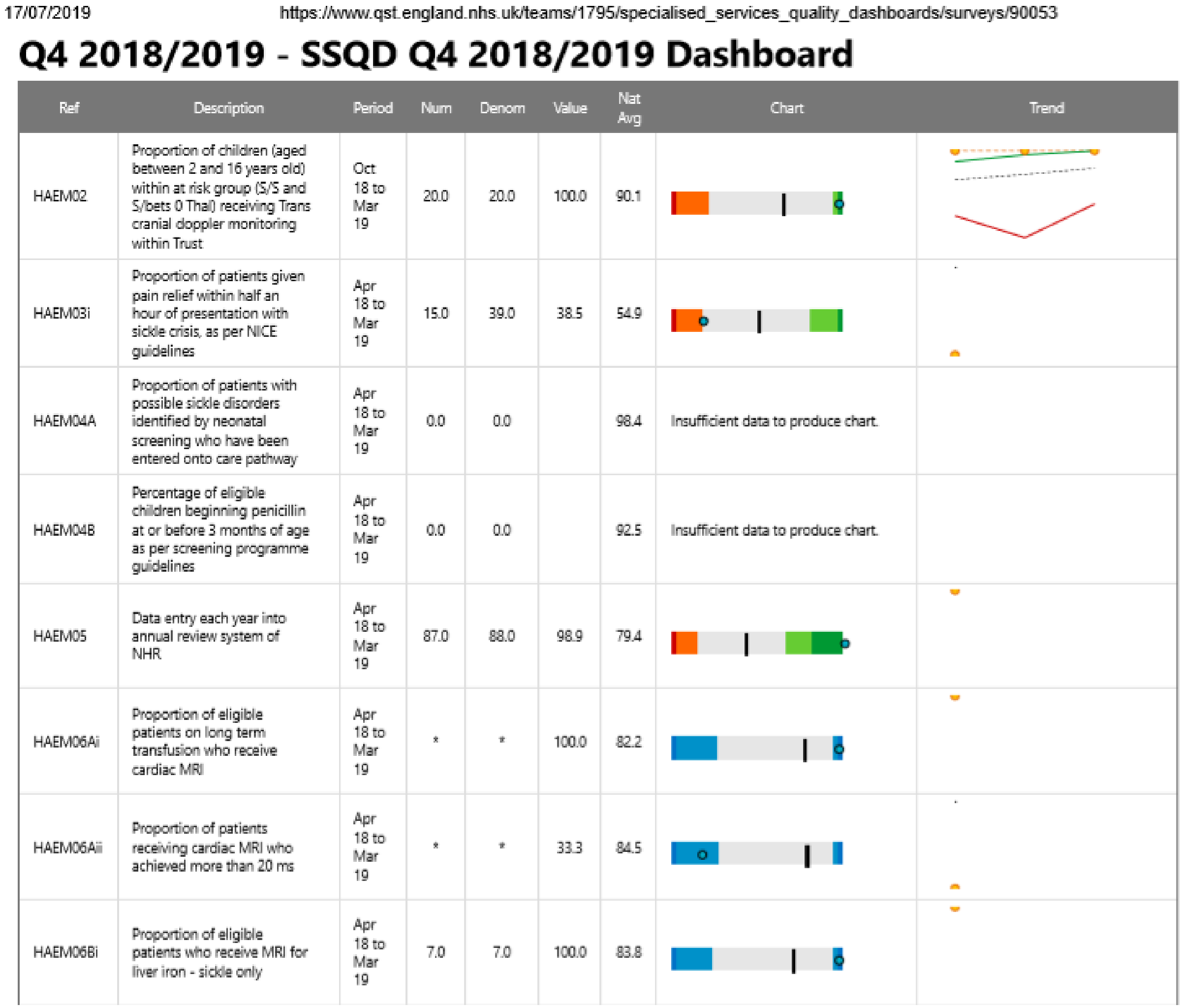


SSQD Dashboard

Spine Charts

SPC Sparklines

The UK National Haemoglobinopathy Registry and Dashboard

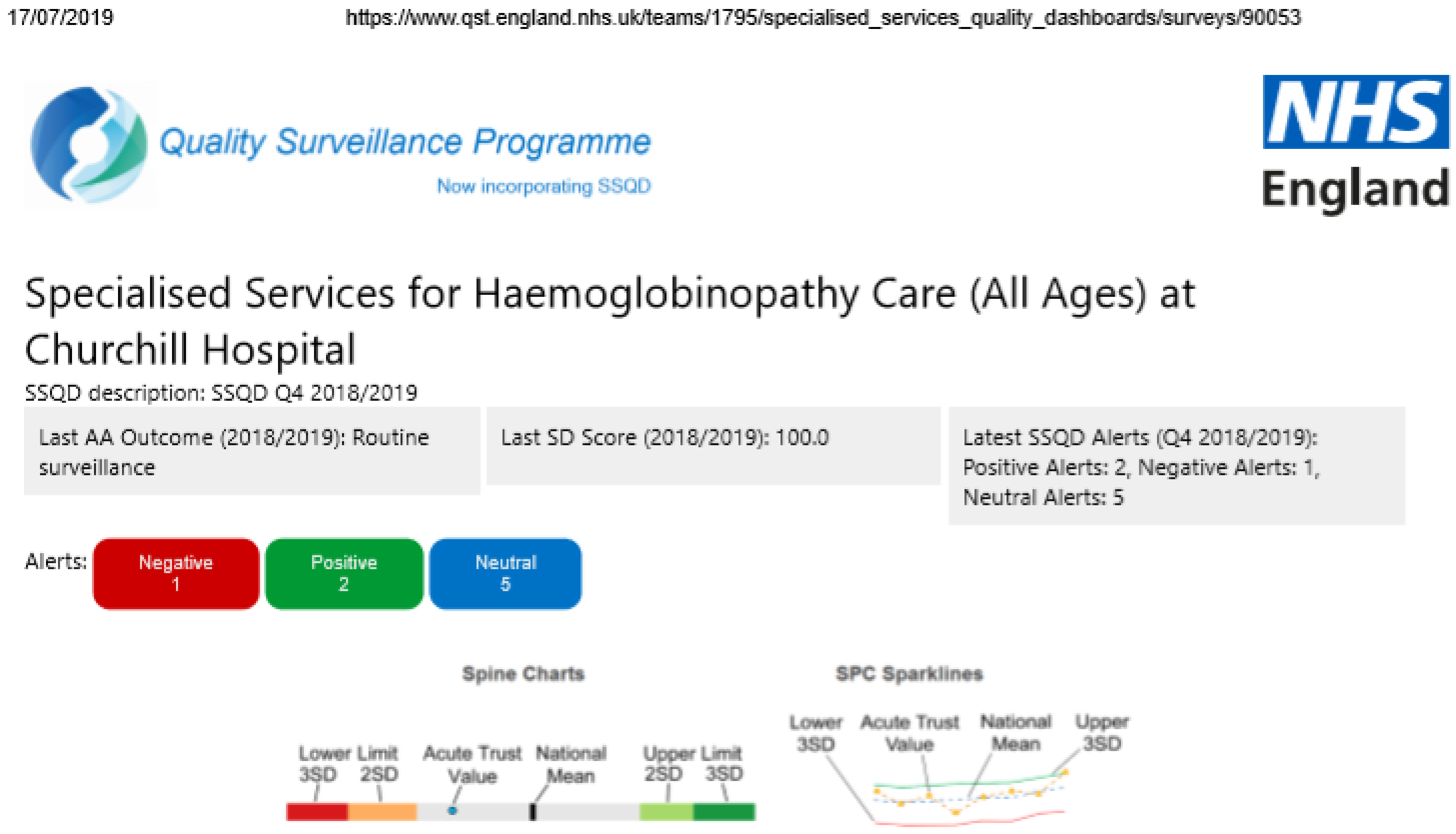


17/07/2019 https://www.qst.england.nhs.uk/teams/1795/specialised_services_quality_dashboards/surveys/90053

Q4 2018/2019 - SSQD Q4 2018/2019 Dashboard

Ref	Description	Period	Num	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

Quality Surveillance Programme
Now incorporating SSQD

NHS England

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

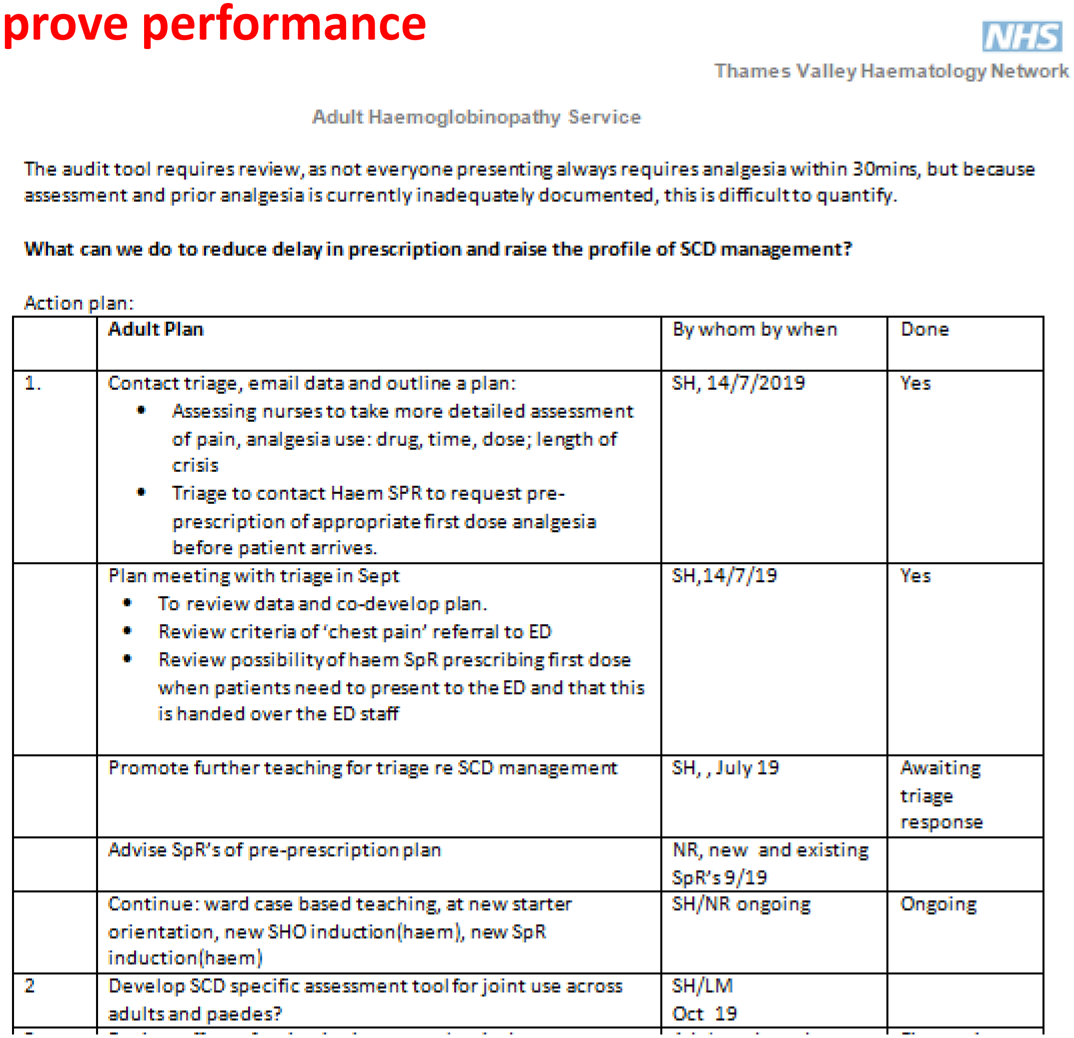
SSQD description: SSQD Q4 2018/2019

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

The UK National Haemoglobinopathy Registry and Dashboard

Action plan to improve performance



NHS
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: • Assessing nurses to take more detailed assessment of pain, analgesia use: drug, time, dose; length of crisis • Triage to contact Haem SPR to request pre-prescription of appropriate first dose analgesia before patient arrives.	SH, 14/7/2019	Yes
	Plan meeting with triage in Sept • To review data and co-develop plan. • Review criteria of 'chest pain' referral to ED • 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	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	