

NHR OVERVIEW/USER GUIDE

Sandra Schneider 20/08/2025

WHAT IS NHR?

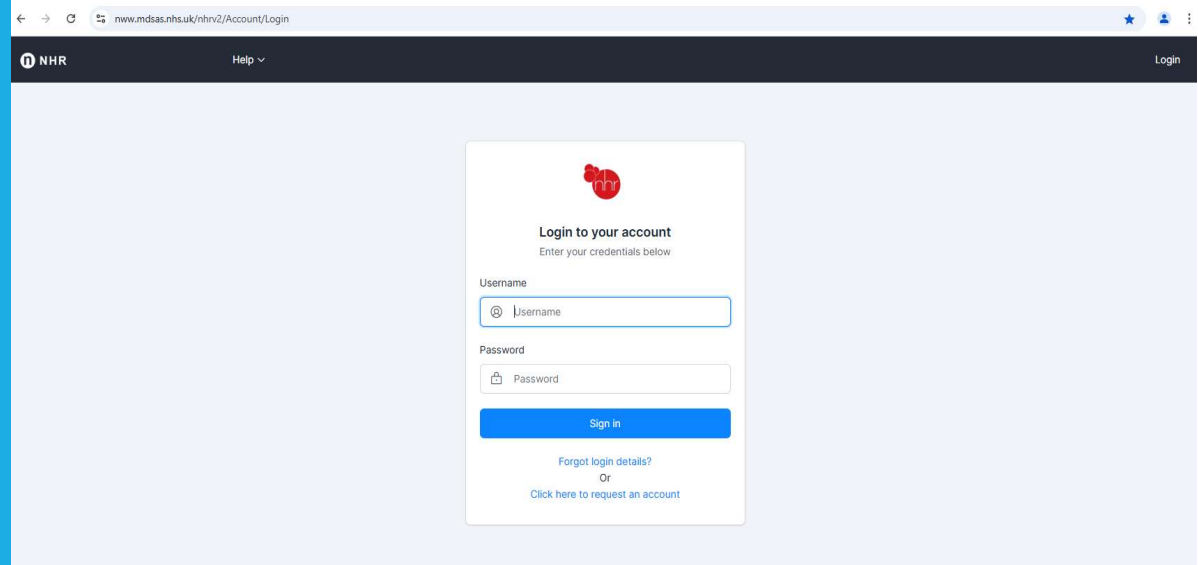
The National Haemoglobinopathy Registry (NHR) is a vital database in the UK that collects and manages information on patients with red cell disorders, primarily sickle cell disease and thalassaemia but also rare inherited anaemias, to improve patient care and support research.

Purpose of the NHR

The NHR serves as a confidential database for patients with various haemoglobin disorders, including sickle cell disease, thalassaemia, and rare inherited anaemias. Its primary aim is to ensure that clinically important information regarding patients' health, treatment, and complications is readily available to specialised haemoglobinopathy services and teams involved in their care.

LOG IN

<https://nww.mdsas.nhs.uk/nhrv2/Account/Login>



The screenshot shows a web browser window with the URL nww.mdsas.nhs.uk/nhrv2/Account/Login. The page features the NHS logo at the top left and a navigation bar with 'NHR' and 'Help' options. The main content area is a white box with a red NHS logo at the top, followed by the heading 'Login to your account' and the instruction 'Enter your credentials below'. Below this are two input fields: 'Username' with an '@' icon and 'Password' with a lock icon. A blue 'Sign in' button is positioned below the password field. At the bottom of the form, there are links for 'Forgot login details?' and 'Click here to request an account'.

If you don't have a log in but would require one, please contact Sandra Schneider (Service Manager) via HaemoglobinopathyBristol@uhbw.nhs.uk

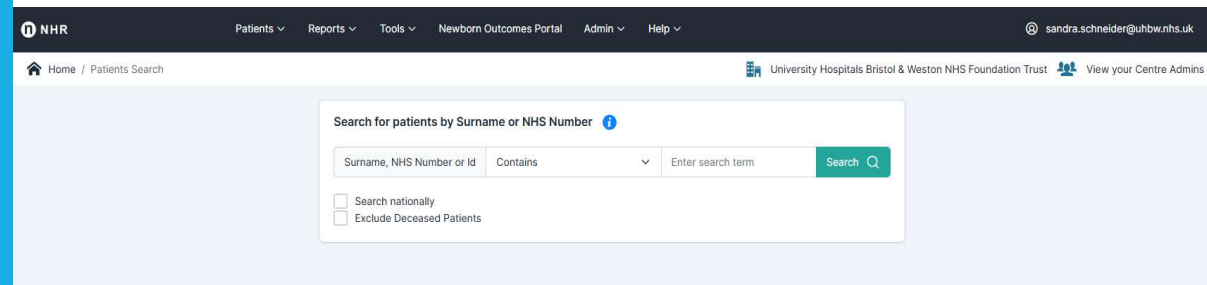
HOME PAGE

From here you can:

Search for patients (when searching by NHS number do not enter any space in between the numbers)

Register a new patient

View/print reports



The screenshot shows the 'Patients Search' page of the NHR system. The page has a dark header with navigation links: Patients, Reports, Tools, Newborn Outcomes Portal, Admin, and Help. The user's email address, sandra.schneider@uhbw.nhs.uk, is displayed in the top right. Below the header, the breadcrumb 'Home / Patients Search' is visible. The main content area features a search box titled 'Search for patients by Surname or NHS Number'. The search criteria are set to 'Surname, NHS Number or Id' with a 'Contains' operator. The search term field is empty, and a green 'Search' button is present. Below the search box, there are two checkboxes: 'Search nationally' and 'Exclude Deceased Patients', both of which are currently unchecked.

SUMMARY PAGE

Home / Search / Summary

Patient Card Sickle Cell (HbSC)

Patient Details	Centres	Annual Reviews
Database ID: [REDACTED]	HCC: South West	2023 - 2024 University Hospitals Bristol & Weston NHS Foundation Trust
Surname: [REDACTED]	SHT: University Hospitals Bristol & Weston NHS Foundation Trust	2022 - 2023 University Hospitals Bristol & Weston NHS Foundation Trust
Forename: [REDACTED]	LHT: University Hospitals Bristol & Weston NHS Foundation Trust	
Date of Birth: [REDACTED]	Annual Review: University Hospitals Bristol & Weston NHS Foundation Trust	
NHS Number: [REDACTED]	Treating Centres: University Hospitals Bristol & Weston NHS Foundation Trust	
Diagnosis	Serious Adverse Events & Comorbidities	Dashboard / Annual Review Exclusions
Primary: Sickle Cell	09/12/2022 Simple painful crisis at University Hospitals Bristol & Weston NHS Foundation Trust	<input type="checkbox"/> No exclusions for patient
Secondary: HbSC	01/02/2021 Pulmonary embolism at University Hospitals Bristol & Weston NHS Foundation Trust	
	Unknown Date Chronic renal failure Stage 4 CKD: eGFR between 15 and 29 at Unknown Centre	

SUMMARY PAGE CONTINUED

Transfusions

- No Transfusions for patient.

Immunisations

- 24/03/2021
Covid-19 AstraZeneca
- 06/02/2021
Covid-19 AstraZeneca
- 28/11/2020
Annual influenza vaccine
- more...

Treatments

- 01/01/1900
Codeine
- 01/01/1900
Paracetamol
- 01/01/1900
Aspirin
- more...

TCD Scans

- No TCD Scans for patient

Specialist Images

- No Specialist Images for patient

Images

- No Images for patient

Investigations

- 24/06/2021
Creatinine
- 22/06/2021
Creatinine
- 22/06/2021
Total bilirubin
- more...

Body Measurements

- 02/12/2020
Weight: 82 Kg

Surgical and Other Procedures

- No procedures for patient

Novel Therapies

- No Novel Therapies for patient

Documents

- No Documents for patient

Delete

↑

SUMMARY PAGE CONTINUED

Information available on summary page:

Patient Details ie. name, DOB, NHS No

Centres patient is assigned to

Annual review

Diagnosis

Serious Adverse Events & Comorbidities

Dashbord/Annual Review Exclusions

Transfusions/Red Cell Exchanges

Immunisation

Treatment/Medications

TCD

Specialist Images

Images

Investigations/Blood test results

Body Measurements

Surgical and Other Procedures

Novel Therapies

Documents ie pain plans or transfusion protocols

REGISTERING A NEW PATIENT

Register Patient

[Home](#) / Register Patient

Enter the patient details



Personal Information

2

Demographics

3

Diagnosis

4

Centres

NHS Number: *

NHS Number

NHS number not known

First Name: *

Enter First Name

Date of Birth: *

dd/MM/yyyy

Surname: *

Enter Surname

Gender: *

Select gender ...

[Previous](#)

[Next](#)

REGISTERING A NEW PATIENT CONTINUED

[Home](#) / [Register Patient](#)

Enter the patient details



Country of Birth: *

Select Country ...

Postcode: *

POSTCODE

Ethnic Group: *

Select ethnicity

Employment/Education: *

Select status

[Previous](#) [Next](#)

[Home](#) / [Register Patient](#)

Enter the patient details



Diagnosis: *

Select diagnosis

Other Diagnosis:

[Previous](#) [Next](#)

REGISTERING A NEW PATIENT CONTINUED

Home / Register Patient

Enter the patient details

Progress: Personal Information (✓) Demographics (✓) Diagnosis (✓) Centres (✎)

GP Practice Code: [Lookup here](#)

GP PRACTICE CODE

Annual Review Centre: Select...

LHT: * University Hospitals Bristol & Weston NHS Foundation Trust

Specialist Centre: * Select SHT centre

Transfusion Location: Select location

Haemoglobinopathy Coordinating Centre: * Select HCC

Previous Submit form

Everything with a red asterisk * has to be filled in. Once all details have been entered, submit the form. You can now go into the patient record and update any other details, ie regular transfusions, medication, vaccinations, blood results etc.

Centres allocation:

Sickle Cell – LHT = local centre, SHT = University Hospital Bristol & Weston NHS FT, HCC = South West

Thal & RIA – LHT = local centre, SHT = University Hospital Bristol & Weston NHS FT, HCC = London, South Central and South West

DIAGNOSIS ON NHR

Sickle Cell

HbSS

HbSC

HbS O Arab

HbS D Punjab

HbS Lepore

HbSE

HbS Beta 0 Thalassaemia

HbS Beta + Thalassaemia

HbS HPFH

HbS: Variant

Thalassaemia

Beta Thalassaemia major (excluding HbE Beta Thal)

E beta thal (transfusion dependant)

E beta thal (not transfusion dependant)

Beta Thalassaemia intermedia (excluding HbE thal)

HbH Disease

HbH: constant spring

HbH: Variant

Alpha Thalassaemia Major

Other Thalassaemia

Another rare inherited anaemia

Diamond Blackfan Anaemia

ADA 2

CDA Type I

CDA Type II

CDA Type III

CDA Type IV

CDA Type VI

CDA Type other

Pyruvate Kinase Deficiency

Glucose Phosphate Isomerase Deficiency

Hexokinase Deficiency

Sideroblastic anaemia

Unstable Haemoglobin (incl Hb Koln)

Methaemoglobin

High Affinity haemoglobin haemoglobin

Transfusion dependent membrane disorders

Other rare anaemia cause unknown

SERIOUS ADVERSE EVENTS (SAE) & COMORBIDITIES

Cardiac failure

Ischaemic stroke

Haemorrhagic stroke

Intrauterine death

Pneumococcal Infection

Death

Delayed HTR - Associated with a new antibody (conventional DHTR)

Delayed HTR - Associated with previous antibody

Delayed HTR - Not thought to be associated with antibody:hyperhaemolysis

Acute Haemolytic Transfusion Reaction (HTR Acute)

Acute HTR - Associated with a new antibody (conventional DHTR)

Acute HTR - Associated with previous antibody

Acute HTR - Not thought to be associated with antibody:hyperhaemolysis

Cardiorespiratory

Pneumonia

Acute Chest Syndrome

Angina

Cardiac arrhythmia

Pulmonary hypertension

Myocardial infarction

Asthma

Deep vein thrombosis

Restrictive Lung disease

Valvular heart disease

Fat embolism syndrome

Obstructive lung disease

Cardiorespiratory continued

Other thrombotic complication related to central catheter

Pulmonary embolism

Superior venocaval obstruction secondary to previous central lines

Genitourinary

Acute renal failure

Renal Stones

Haematuria

Glomerulonephritis

SERIOUS ADVERSE EVENTS (SAE) & COMORBIDITIES CONTINUED

Genitourinary continued

Chronic renal failure Stage 1 CKD: eGFR 90 or greater

Chronic renal failure Stage 2 CKD: eGFR Between 60 and 89

Chronic renal failure Stage 3 CKD: eGFR Between 30 and 59

Chronic renal failure Stage 4 CKD: eGFR Between 15 and 29

Chronic renal failure Stage 5 CKD: eGFR Less than 15

Hydronephrosis

Renal replacement therapy

Nephrotic syndrome

Papillary necrosis

Priapism

Renal mass/tumour

Orthopaedic

Fracture

Acute Osteomyelitis

Chronic Osteomyelitis

Septic Arthritis

Avascular necrosis

Osteopenia

Osteoporosis

Degenerative disc disease

Leg ulcers

Extramedullary haemopoiesis

Neurological disorders

Silent cerebral infarcts

Seizure without diagnosis of epilepsy

Central venous thrombosis

Epilepsy

Spinal cord compression

Visual loss

Retinopathy Stage I Peripheral arterial occlusion

Retinopathy Stage II Peripheral arteriovenous anastomoses (hairpin loop)

Retinopathy Stage III Neovascular and fibrous proliferations (sea fan)

Retinopathy Stage IV Vitreous hemorrhage

Retinopathy Stage V Retinal detachment

SERIOUS ADVERSE EVENTS (SAE) & COMORBIDITIES CONTINUED

Neurological disorders continued

Moya moya

Chronic pain

Haematological

Acute haemolytic event not related to blood transfusion

Agranulocytosis

Disseminated intravascular coagulation

Neutropenia

Pure red cell aplasia

Simple painful crisis

Hepatobiliary

Liver failure

Intrahepatic cholestasis

Cholestasis

Biliary colic

Ascending cholangitis

Acute Pancreatitis

Pancreatic exocrine insufficiency

Cirrhosis of liver

Fibrosis of liver

Fatty liver disease

Hepatocellular carcinoma

Acute infective hepatitis

Hepatobiliary continued

Hepatic mass

Hepatic sequestration

Endocrine

Insulin dependent diabetes

Non-insulin dependent diabetes

Diet controlled diabetes

Hypothyroidism

Hypoparathyroidism

Adrenal insufficiency

Hypogonadotropic hypogonadism

Other endocrine complication

SERIOUS ADVERSE EVENTS (SAE) & COMORBIDITIES CONTINUED

Obstetric/gynaecological

Recurrent miscarriage

Bacterial infection

Salmonella sp.

Klebsiella sp.

Coagulase negative staphylococcus

Mycoplasma

Bacterial infectious disease (Other)

Viral infection

Influenza

Covid 19

Parvovirus

Hepatitis A

Hepatitis B

Hepatitis C

Hepatitis E

Other viral illness

Other

Cancer

Other complication not listed above

Splenic sequestration

SERIOUS ADVERSE EVENTS (SAE) & COMORBIDITIES CONTINUE

Serious adverse events should be entered as and when they happen but definitely in the annual review period. This counts from 1st April until 31st March each year.

IMMUNISATIONS

Annual influenza vaccine

Covid vaccination

Covid-19 AstraZeneca

Covid-19 Moderna

Covid-19 Pfizer-BioNTech

Hepatitis B

Hib/Meningitis C

Meningitis ACWY

Meningitis B

Meningococcal B

PCV13

PPV23

SPECIALIST IMAGES

Bone densitometry - osteopenia

Bone densitometry - osteoporosis

Bone densitometry - normal

Cardiac T2*

Ejection Fraction % - MRI

Ejection Fraction % - Echo

Ferriscan Liver iron

Liver T2*

INVESTIGATIONS

Blood Tests:

- Alpha fetoprotein
- AST
- Blood group
- Creatinine
- Ferritin
- Fructosamine
- FSH
- FT4
- Glucose Tolerance Test
- Hb pre transfusion
- HbA

Blood Tests cont:

- HbF
- HCV antibody
- HCV RNA
- LH
- Oestrogen
- PTH
- Steady state Hb
- Testosterone
- Total bilirubin
- Vitamin D3 total

Other Assessments:

- Audiology assessment
- Echocardiography Ejection Fraction
- Echocardiography TR jet velocity
- Endoscopy
- ERG for patients on Desferioxamine
- Ophthalmology assessment
- Ultrasound scan

Other Tests:

- Blood pressure
- Oxygen saturation
- Urine albumin:creatinine ratio
- Urine calcium
- Urine pr:creatinine ratio

SURGICAL PROCEDURES

Adenoidectomy

Adenotonsillectomy

Allogenic bone marrow transplant – haploidentical

Allogenic bone marrow transplant – matched unrelated donor

Allogenic bone marrow transplant – other family donor

Allogenic bone marrow transplant – sibling

AV Fistula

Cholecystectomy

Cochlear implant

Coronary artery stent

Coronary artery bypass

Gene therapy transplant

Hip replacement

Knee replacement

Liver resection

Liver transplant

Nephrostomy

Pacemaker insertion

Penile aspiration

Penile implant

Penile stent

Permanent Indwelling cvc > 4 weeks

Pulmonary endarterectomy

Renal transplant

Resection of mass

Retinal surgery

Shoulder replacement

Splenectomy

Tonsillectomy

ANNUAL REVIEW

Annual Reviews

Filter:

Show: 10 

Period

Centre

Complete

No data available in table

Showing 0 to 0 of 0 entries



Back 

Add 

ANNUAL REVIEW CONTINUED

Annual Review

You can save progress and complete later

Period and Centre

Period: * Annual reviews are reported by financial year (April to March)

2025 - 2026

Did not attend: i

Offered appointment but did not attend

Date Annual Review Carried Out: *

DD/MM/YYYY

Centre completing review: *

Select Centre

Centre Designation: *

Select centre designation

Resource Utilisation Enter figures in this section for the previous financial year, ie 2024 - 2025

Number of emergency department attendances: *

Enter a number

Number of unscheduled inpatient admissions: *

Enter a number

Number of bed days in hospital: *

Enter a number

Number of planned daycase attendances: *

Enter a number

ANNUAL REVIEW CONTINUED

Support Services

Patient required access to psychology services to support their care:

Yes No Unknown

Patient required other mental health support services:

Yes No Unknown

Patient discussed at National MDT panel:

Yes No Unknown

Patient received psychology support:

Yes No Unknown

Patient accessed haemoglobinopathy community services:

Yes No Unknown

Disease Modifying Therapy

Patient eligible for hydroxycarbamide:

Yes No Unknown

Patient declined hydroxycarbamide:

Yes No Unknown

Patient offered for hydroxycarbamide:

Yes No Unknown

Patient currently receiving hydroxycarbamide:

Yes No Unknown

Patients on Long Term Transfusions

Is patient on long term transfusion?

Yes No Unknown

ANNUAL REVIEW CONTINUED


Other


Patient declined antibiotic prophylaxis:
 Yes No Unknown

Was referred for HSCT?:
 Yes No Unknown

Reproduction

Pregnancy this year?
 Yes No Unknown

Cancel 

Save Progress Submit 

You can save the progress along the way and once you are happy all the information has been entered, press submit.

REPORTS

[Home](#) / [All Reports](#)

Centre

Patients Without Immunisations [View](#)

A report listing patients without the selected immunisations.

TCD Scans by Patient [View](#)

A report listing TCD scans recorded for your patients.

Centre Patient Listing [View](#)

A report listing patients registered at your home centre.

Specialist Imaging by Patient [View](#)

Summary of specialist imaging recorded for your patients.

Immunisations by Patient [View](#)

Summary of immunisations recorded for your patients.

Transfusions by Patient [View](#)

Summary of transfusions recorded for your patients.

Comorbidities by Patient [View](#)

Summary and listing of comorbidities recorded for your patients.

Patient Medications [View](#)

A report showing patient medications.

Transfusion Patient List [View](#)

A report showing patient transfusions.

Centre Annual Reviews [View](#)

A report to manage centre annual reviews.

Centre Patient Annual Review Data [View](#)

A report listing annual review data for your patients.

Centre Data Validation [View](#)

A report listing patients with data validation results to check.

Patient Deaths and Comorbidities [View](#)

A report listing patients with the patient status set to "Deceased" or patients with "Death" recorded as a serious adverse event.

Centre Bulk Imports Results [View](#)

A report listing bulk import file results.

SPECIALISED SERVICES QUALITY DASHBOARD (SSQD)

Going forward information for the SSQD is being taken from NHR. This is a new development and it not yet entirely clear how this will work in practice. We will update you as and when we receive further information especially in regards to what sections on NHR will have to be completed.

HCC HELP FOR REGISTERING/UPDATING DETAILS OF PATIENTS ON NHR

The HCC Service Manager and Data Manager can help with registering patients on NHR or updating existing patients details on NHR. The following information needs to be provided:

New patients:

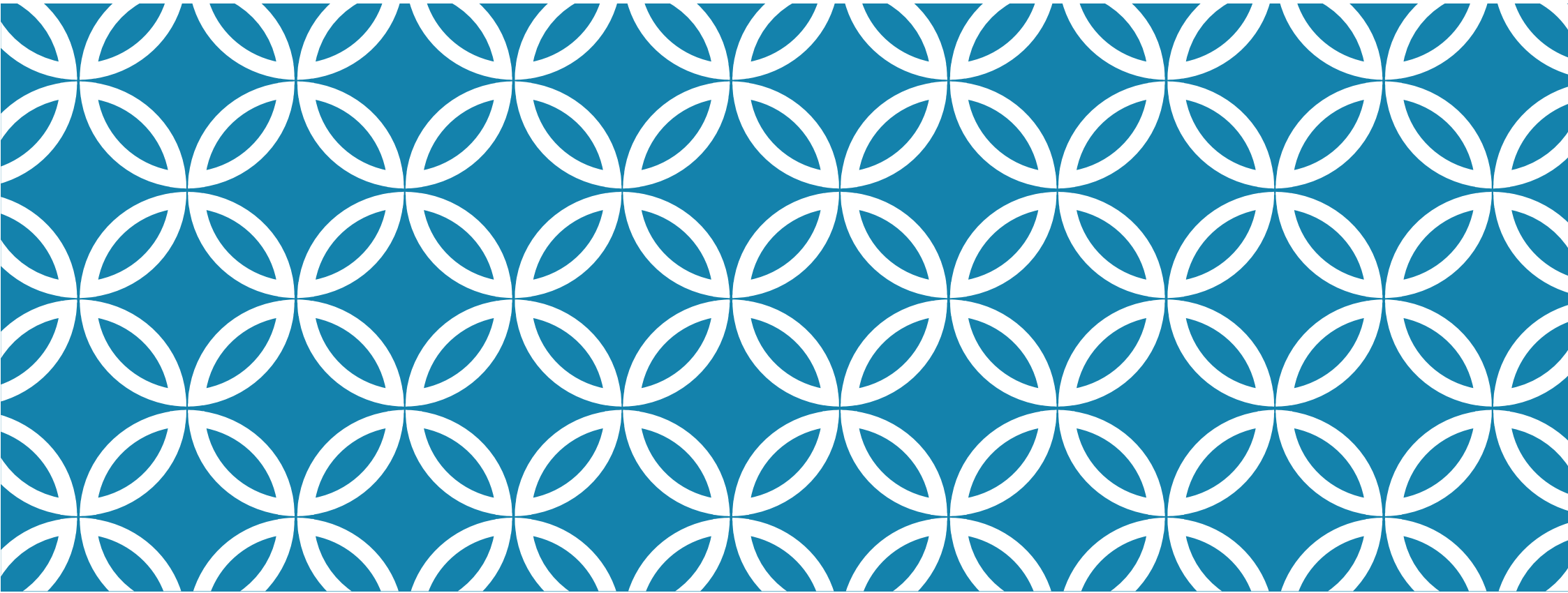
- Copy of clinic letter that has patient details incl DOB, NHS no, confirmed diagnosis etc (as per slides 7-9)

Existing patients:

- Copy of annual review (if done at LHT)
- Copy of discharge summary to enter any SAE, comorbidities and/or surgical procedures

MORBIDITY AND MORTALITY (M&M)

These events should be recorded on NHR and also be discussed at our South West HCC MDT meeting.



QUESTIONS???

