GIG CYMRU NHS WALES

Pwyllgor Gwasanaethau Iechyd Arbenigol Cymru (PGIAC)

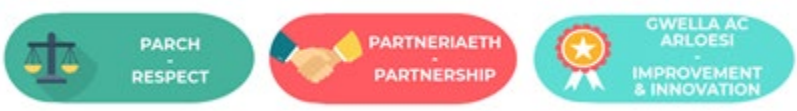
Welsh Health Specialised Services Committee (WHSSC)

Specialised Services
Service Specification: CP77

Bleeding Disorders Services
All Ages

June 2022

Version 2.0



Document information	
Document purpose	Service Specification
Document name	Bleeding Disorders
Author	Welsh Health Specialised Services Committee
Publication date	June 2022
Commissioning Team	Cancer and Blood
Target audience	Chief Executives, Medical Directors, Directors of Finance,
Description	NHS Wales commission this specialised service in accordance with the criteria described in this document
Document No	CP77
Review Date	2025

Contents

Statement

Welsh Health Specialised Services Committee (WHSSC) commission the service of Bleeding Disorders for people of all ages in accordance with the criteria outlined in this specification.

In creating this document WHSSC has reviewed the requirements and standards of care that are expected to deliver this service.

Disclaimer

WHSSC assumes that healthcare professionals will use their clinical judgment, knowledge and expertise when deciding whether it is appropriate to apply this document.

This document may not be clinically appropriate for use in all situations and does not override the responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or their carer or guardian.

WHSSC disclaims any responsibility for damages arising out of the use or non-use of this document.

1. Introduction

This document has been developed as the Service Specification for the planning and delivery of Bleeding Disorders services for people of all ages resident in Wales. This service will only be commissioned by the Welsh Specialised Services Committee (WHSSC) and applies to residents of all seven Health Boards in Wales.

1.1 Background

Bleeding disorders are relatively rare group of inherited or acquired disorders characterised by increased or prolonged bleeding due to abnormal coagulation (the ability of the blood to clot). The cause is a decrease in the amount or function of either a protein in the blood, called a clotting factor, or platelets. However, often no deficiency or defect is demonstrable, and this is termed an unclassified bleeding disorders.

Haemophilia is the most widely recognised inherited bleeding disorder. There are two main forms of haemophilia, the most common being Haemophilia A (deficiency of coagulation factor VIII) with a prevalence of between 1:5,000 and 1:10,000 males. Haemophilia B (deficiency of factor IX) is less common with a prevalence of between 1:35,000 and 1:50,000 males[1] and Acquired Haemophilia is even more rare, affecting about 4/1,000,000/year[2]. Women who carry the haemophilia gene may have low factor levels and therefore be diagnosed with haemophilia A or B.

A deficiency or a defect of the coagulation protein von Willebrand factor is known as von Willebrand Disease (VWD). It is a more common but generally milder bleeding disorder affecting both males and females with a prevalence of at least 1:1,000[1]. A small number of people have VWD type 3 which is a severe disorder requiring regular clinical review.

Other inherited bleeding disorders of clinical importance include deficiencies of other clotting factors (e.g. factor V, factor X, factor XI and fibrinogen) and abnormalities of platelet function.

Acquired deficiencies of clotting factors or von Willebrand factor are caused by an antibody to the relevant protein. They are often termed inhibitors, due to the effect on function.

There is a spectrum of severity for each of these conditions and the service should cover all severities.

[1] NHS England service specification for haemophilia
[2] "*Acquired Haemophilia in the UK: a 2 year national surveillance study*", Blood 2007, Vol 109, pp1870-1877

1.2 Aims and Objectives

The aim of this service specification is to define the requirements and standard of care essential for delivering services for people with Bleeding Disorders.

The objectives of this service specification are to:

- detail the specifications required to deliver a Bleeding Disorders service for people who are resident in Wales
- ensure minimum standards of care are met for the delivery of a Bleeding Disorders service
- ensure equitable access to a Bleeding Disorders service
- identify centres that are able to provide a Bleeding Disorders service for Welsh patients
- improve outcomes for people accessing Bleeding Disorders service.

1.3 Relationship with other documents

This document should be read in conjunction with the following documents:

- **NHS Wales**
  - All Wales Policy: Making Decisions in Individual Patient Funding requests (IPFR).

- **WHSSC policies and service specifications**
  - PP167 Emicizumab as prophylaxis in people with congenital haemophilia A with Factor VIII inhibitors (all ages) Policy Position, November 2018
  - PP189 Emicizumab as prophylaxis in people with congenital haemophilia A without Factor VIII inhibitors (all ages) Policy Position, August 2019
  - PP215 Vonicog alfa for adults with von Willebrand Disease Policy Position

- **Relevant NHS England documents**
  - B05/S/a Haemophilia (all ages) Service Specification 2013/14
  - Haemophilia (All ages) Quality Dashboard 2019/20

- **Other published documents**
  All United Kingdom Haemophilia Centre Doctors Organisation (UKHCDO) Guidelines
  - Haemophilia Chartered Physiotherapists Association Standards of Care: Service Provision of Physiotherapy For Children with Haemophilia & other Inherited Bleeding Disorders March 2020

- Haemophilia Chartered Physiotherapists Association Standards of Care: Service Provision of Physiotherapy for Adults with Haemophilia & other Inherited Bleeding Disorders March 2020
- Quality Standards: Care of People with Inherited and Acquired Haemophilia and Other Bleeding Disorders, West Midlands Quality Review Service and UK Haemophilia Centre Doctors' Organisation

2. Service Delivery

The Welsh Health Specialised Services Committee commission a Bleeding Disorders service for people of all ages resident in Wales, in line with the criteria identified in this specification.

2.1 Access Criteria

This specialised service is for patients of all ages in the following groups:

- Haemophilia A
- Haemophilia B
- Females with haemophilia
- Von Willebrand Disease
- Other coagulation factor deficiencies
- Inherited platelet disorders.
- Unclassified bleeding disorders – those patients who have a significant bleeding history in whom it has not been possible to identify a specific abnormality.

Services for patients with other acquired haemostatic problems are commissioned separately through health boards.

2.2 Service description

In addition to the standards required within the Contract, specific quality standards and measures will be expected. The provider should also meet the standards as set out below.

- All patients with bleeding disorders should have access to a comprehensive care programme. This may be provided by a Comprehensive Care Centre (CCC) or a Haemophilia Centre (HC) working with a CCC.

Comprehensive Care Centre

The CCC provides specialist diagnosis and care, and have the following on-site services:

- A laboratory capable of carrying out all tests necessary for the definitive diagnosis of haemophilia and other bleeding disorders during routine working hours with 24 hour access to tests required for diagnosis of haemophilia and monitoring of its treatment e.g. factor VIII and IX , GP1b
- 24 hour access to a blood transfusion laboratory. Particularly for patients with inherited platelet disorders who may require platelet transfusion support and for the rare factor deficiencies where a

specific factor concentrate does not exist and plasma may be required.

- 24 hour access to haemostatic agents (eg tranexamic acid, factor concentrates)
- Access to laboratories able to provide compatibility testing and matched components, including human leucocyte (HLA class I), human platelet (HPA) and red cell compatibility.

Haemophilia Centres

A Haemophilia Centre (HC) provides a local, shared care service, and should be part of the comprehensive care programme network with a CCC. Clear plans for care should be developed between the HC and the CCC. All interventions should be discussed between the HC and CCC. Local secondary care paediatric support/liaison should be established.

The HC will need to ensure they have formal agreed and documented outreach arrangements and transfer protocols in place with the CCC. Transfer protocols should be clear and easy to organise given the potential for deterioration in patients with bleeding disorders.

Model of Care

The principle of the Comprehensive Care Network is to provide care closer to home in line with Welsh Government policy across health and social care.

Services should be developed so that the care a person needs is delivered closer to home, such as by providing home visits to give treatment, undertake surveillance (e.g. blood tests/physiotherapy review) and facilitating surgical procedures in local hospitals, by haemophilia centre clinical oversight at the relevant hospital.

Patients should only be expected to travel out of their locality for care that can only be delivered in the CCC.

The following model of care should ensure people with bleeding disorders have access to a comprehensive care programme:

- A clinical service provided by healthcare professionals experienced in the treatment of haemophilia and other bleeding disorders, including consultant haematologists with a specialist interest in haemostasis.
- Specialist nurses trained in line with the Haemophilia Nurses Association and specialist physiotherapists who adhere to the UK Standards of Care Service Provision of Physiotherapy For Children with Haemophilia & other Inherited Bleeding Disorders and the UK Standards of Care Service Provision of Physiotherapy For Adults with Haemophilia & other Inherited Bleeding Disorders as set out by the Haemophilia Chartered Physiotherapy Association.

- A laboratory service accredited by United Kingdom Accreditation Service (UKAS) capable of carrying out all tests necessary for the definitive diagnosis of haemophilia and other bleeding disorders, including the identification and assay of the relevant specific haemostatic factors. These laboratories will be capable of monitoring therapy and screening for inhibitors with quantification of any inhibitor detected in accordance with published UKHCDO guidelines.
- Maintenance of satisfactory quality control and assurance for all laboratory tests offered in relation to clinical services, both by establishing the appropriate level in the UK National External Quality Assessment Scheme in blood coagulation (NEQAS), and other relevant approved external quality assessment schemes.
- Further investigation of relatives of patients with haemophilia and other bleeding disorders. The CCC service will also include the diagnosis of atypical cases, genotypic analysis, the assay of inhibitors, haemostatic factors, diagnosis of hereditary platelet disorders and molecular diagnostic testing. HCs should refer to the CCC for the specialist elements of care where they are not available locally.
- An advisory service to patients and close relatives on matters specific to haemophilia and other bleeding disorders. Advice will also be provided to other healthcare professionals. A CCC will provide a 24-hour advisory service to HCs and clinicians working at other hospitals in Wales where patients might present within their managed clinical network and support to such centres as appropriate.
- Easy and open access to experienced specialist physiotherapists who are members of the Haemophilia Chartered Physiotherapists Association for:
    - regular musculoskeletal reviews
    - treatment of acute bleeds
    - pre-operative and post-operative rehabilitation
    - education and bleed prevention.
- A formal annual assessment of joint health (HJHS) should be performed by a specialist haemophilia physiotherapist for all patients with severe and moderate disease, or any patient requiring long-term prophylaxis. This should be recorded in the patient record, to monitor long term MSK and the results should be submitted to the National Haemophilia Database. The specialist physiotherapists should work closely together providing physiotherapy care across the Network and act as a point of contact with appropriate local physiotherapy services.
- Paediatric services that are provided by clinicians specialising in paediatric bleeding disorders. When treating children, the service will follow current standards and guidance for the safe treatment of

children. The environment in which the service is delivered should be child-friendly and appropriate to the standards elsewhere in the UK and commensurate to those available for similar life-long services. There should be robust arrangements for access to care close the child's home for urgent treatment, especially out of routine working hours.

- Access and referral to clinical services for all aspects of bleeding disorder care including:
    - Orthopaedic surgical services.
    - Dental services.
    - HIV and hepatology services including access to consultants in hepatology and infectious diseases.
    - Psychology services specialising in bleeding disorders.
    - Obstetric services, including reproductive counselling and direct access to pre-implantation sexing and diagnosis.
    - Genetics services, including access to genetic counselling and genetic testing.
- Access to social care support.
- Good quality medical records maintained for all patients, which include details of all treatment administered and any adverse reactions reported. All relevant patients should be formally registered with the treating centre and with the UKHCDO National Haemophilia Database.
- Special medical cards that are issued to patients, which include details of their bleeding disorder, usual treatment, treatment centre and out of hours contact details for the centre.
- Education facilities and training opportunities for medical staff, nurses, counsellors and other personnel as required, promoting optimal comprehensive care of patients.
- Participation in research programmes, including the conduct of clinical trials.
- Access to evolving and novel therapies, either through clinical trials or soon after licensing in agreement with WHSCC. The clinical team should develop the expertise to deliver new therapies e.g. gene therapy, non-factor replacement therapies.
- Establishment and participation in suitable regional and national programmes of clinical audit.
- A patient self-reporting tool for administration of factors and treatment of bleeds.

Home Therapy

- A home therapy programme should support home treatment for patients across the network including the administration of prophylactic therapy and home and school visits where appropriate.

Haemostatic treatment

- Providers should purchase haemostatic treatment products via the national framework agreement.
- People with bleeding disorders should have access to clotting factor concentrates and non-factor replacement therapies depending on individual need and preference.

Transfer Planning

- Transfer planning should take place between the paediatric and adult provider to ensure a smooth transition to adult care for adolescents.

Pregnancy

Pregnant women with a known bleeding disorder, should be referred for assessment and/or management to antenatal services with experience in the management of bleeding disorders. More serious bleeding disorders will be managed in the tertiary centre, e.g. a woman with a severe bleeding disorder such as type 3 VWD, Glanzmann's thrombasthenia or a fetus known to have severe haemophilia.

All women with bleeding disorders, or carriers of haemophilia should be given the opportunity to consult with members of the MDT as required, including haemophilia services, genetic counselling and where appropriate to discuss reproductive choices, such as PGD, free fetal DNA testing and antenatal diagnosis of severe haemophilia.

During pregnancy, a woman should have an individualised care plan for ante natal, intrapartum and postnatal periods. The plan should include clear instructions for shared care with secondary services, when appropriate including escalation and transfer protocols and clear guidelines for planned and emergency delivery. This should allow optimal management during pregnancy, and reduce avoidable morbidity, mortality and inappropriate management or intervention for mother and baby.

When termination of pregnancy is required, a clear plan should be made and communicated to the gynaecology or obstetric teams.

The service should have access to appropriate tertiary medical, surgical, fetal medicine, clinical genetics and level 3 Neonatal Intensive Care services.

Whilst it is important that the MDT supporting pregnant women with bleeding disorders has the appropriate training and experience to deliver this service, there are different models by which this will occur. All models should demonstrate the appropriate quality, standards of care and governance to ensure this.

It is important to be able to deliver care as close to home as far as is safe and practicable, and at times this may require a virtual approach/team working to minimise travel for pregnant women who often have young families for whom they are also caring, provided that the governance is robust.

Access to dental care

- Every haemophilia centre should have ready access to a hospital dental service[3]. Access to hospital and community dental services should be audited as part of the UK-wide external peer review process.
- For patients with mild congenital bleeding disorders the majority of routine non-surgical dental treatment can be provided in general dental practice; close liaison with the hospital dental service and the haemophilia centre is necessary.

Clinical Standards

The clinical service will be provided by healthcare professionals experienced in the treatment of haemophilia and other bleeding disorders. This includes:

- haematology consultants with a specialist interest in haemostasis
- specialist nurses trained in line with the Haemophilia Nurses Association
- specialist physiotherapists who adhere to the UK Standards of Care Service Provision of Physiotherapy For Children with Haemophilia & other Inherited Bleeding Disorders and the UK Standards of Care Service Provision of Physiotherapy For Adults with Haemophilia & other Inherited Bleeding Disorders as set out by the Haemophilia Chartered Physiotherapy Association.

All CCCs should participate in the UK-wide external peer review process and achieve the accreditation standards.

CCCs will normally provide treatment for 40 or more severely affected patients per year.

There should be clear and agreed pathways within the managed clinical network to ensure that all patients have access to comprehensive care 24

[3] Guidance on the dental management of patients with haemophilia and congenital bleeding disorders British Dental Journal 2013

hours a day, 7 days a week. Protocols should be in place for out-of-hours care, emergency management and the treatment of inhibitors.

Patient reviews should take place in accordance with this service specification within a multidisciplinary team.

As a minimum all patients with severe and moderate haemophilia and other bleeding disorders should have contact with their CCC at least once a year.

Patients with mild bleeding disorders do not require annual review, many have a structured telephone or video consultation and have open access to the CCC/HC service when they have an injury or need a procedure.

Patients with severe bleeding disorders and any patient on prophylaxis should be seen at least 6-monthly by the CCC MDT.

Children under 5 should be seen 3-4 times per year. Reviews of this group of patients should be done by the CCC team, either at the CCC or in out-reach clinics in any one of the HCs. In some cases, an additional review by the HC is needed for this patient group in conjunction with the CCC team.

Providers should also ensure complete, accurate and timely returns to the National Haemophilia Database.

The annual report of the UKHCDO data will be formally reviewed by the Commissioners and the All-Wales IBD Advisory Group.

2.3 Interdependencies with other services or providers

In addition to the specialised elements of care there are also a number of general services with varying levels of interdependency with haemophilia and other bleeding disorders.

Co-located services

Comprehensive Care Centres should have the following on-site services:

- A laboratory capable of carrying out all tests necessary for the definitive diagnosis of haemophilia and other bleeding disorders during routine working hours with 24 hour access to tests required for diagnosis of haemophilia and monitoring of its treatment e.g. factor VIII and IX , GP1b
- 24 hour access to a blood transfusion laboratory. Particularly for patients with inherited platelet disorders who may require platelet transfusion support and for the rare factor deficiencies where a specific factor concentrate does not exist and plasma may be required.
- 24 hour access to haemostatic agents (e.g. tranexamic acid, factor concentrates)

- Access to laboratories able to provide compatibility testing and matched components, including human leucocyte (HLA class I), human platelet (HPA) and red cell compatibility.

Interdependent services

Services which are required during the spell of care but where there is no absolute requirement for this service to be based on the same healthcare delivery site are as follows:

- Dental services.
- Access to consultant level care in HIV and hepatology.
- Psychology services
- Obstetric services, including reproductive counselling.
- Social care support.

Related services

There are a number of specialised services with a clear inter-dependency for specific patient sub-groups of those with haemophilia and other bleeding disorders as follows:

- Specialised services for women's health – this is relevant for gynaecology and maternity services and fetal medicine for women who are carriers or have a bleeding disorder
- Specialised services for liver, biliary and pancreatic medicine and surgery (adult) – this relates to access to hepatology for hepatitis-infected patients
- Medical genetic services
- Specialised services for children – important inclusions are anaesthesia and pain management, dentistry, vascular access services, neonatal intensive care, paediatric intensive care and paediatric surgery
- Specialised rheumatology services (all ages)
- Specialised pain management services (adult)
- Specialised orthopaedic services (adult).

Additionally, for the group of infected individuals there is a need for further inter-dependency with the following services:

- HIV/AIDS treatment and care and associated services

The service model needs to consider access arrangements for other specialised services, and the funding and quality assurance responsibilities lie with Health Boards where they are not commissioned by WHSSC.

2.4 Exclusion Criteria

Specialised services for haemophilia and other bleeding disorders specifically do not cover the following:

- The use of clotting factor for treatment of trauma or critical care or following surgery or as part of obstetric care (where the patient has no underlying bleeding disorder)
- General haemostasis and thrombosis services (including stroke services)
- Specialist haemostasis and thrombosis unrelated to haemophilia and bleeding disorders (e.g. liver disease)
- Anticoagulation treatment or the reversal of anticoagulant treatment.

2.5 Acceptance Criteria

The service outlined in this specification is for patients ordinarily resident in Wales, or otherwise the commissioning responsibility of the NHS in Wales. This excludes patients who whilst resident in Wales, are registered with a GP practice in England, but includes patients resident in England who are registered with a GP Practice in Wales.

2.6 Patient Pathway

Initial referral will be due to a suspected or known bleeding disorder and could come from a GP or as a referral to tertiary care from an acute trust. Either route could follow clinical presentation, laboratory investigations showing abnormal coagulation or could be due to genetic diagnosis and/or family studies.

2.7 Service providers

Comprehensive Care Centres

- Cardiff Haemophilia Centre
  University Hospital Wales
  Heath Park Way
  Cardiff
  CF14 4XW

- The Roald Dahl Haemostasis and Thrombosis Centre
  Royal Liverpool University Hospital
  Prescot Street
  Liverpool
  L7 8XP

- Liverpool Paediatric Haemophilia Centre
  Alder Hey Children's Hospital
  Eaton Road
  Liverpool
  L12 2AP

Haemophilia Centres

- Abergavenny Haemophilia Centre
  Nevill Hall Hospital
  Brecon Road
  Abergavenny
  NP7 7EG

- Swansea Haemophilia Centre
  Singleton Hospital
  Sketty
  Swansea
  SA2 8QA

- Bangor Haemophilia Centre
  Alaw Unit
  Ysbyty Gwynedd
  Penrhosgarnedd
  Bangor
  LL57 2PW

In order to deliver care close to a patient's home, other hospitals will provide care, for example as emergency out of hours treatment or for minor surgery or child birth. These services should be delivered in coordination with a supervising CCC.

2.8 Exceptions

If the patient does not meet the criteria for treatment as outlined in this policy, an Individual Patient Funding Request (IPFR) can be submitted for consideration in line with the All Wales Policy: Making Decisions on Individual Patient Funding Requests. The request will then be considered by the All Wales IPFR Panel.

If the patient wishes to be referred to a provider outside of the agreed pathway, an IPFR should be submitted.

Further information on making IPFR requests can be found at: Welsh Health Specialised Services Committee (WHSSC) | Individual Patient Funding Requests

3. Quality and Patient Safety

Providers must work to written quality standards and provide monitoring information to the lead commissioner. The quality management systems must be externally audited and accredited.

The centre must enable the patients, carers and advocates informed participation and to be able to demonstrate this. Provision should be made for patients with communication difficulties and for children, teenagers and young adults.

3.1 National Standards

All guidelines published by the United Kingdom Haemophilia Centres Doctors' Organisation.

Social Services and Well-Being Act 2014. Working Together to Safeguard People.

Safeguarding Children and Young People: Roles and competencies for healthcare staff | RCPCH

Transition from children's to adults' services for young people using health or social care services. NICE Guideline (NG43), February 2016.

3.2 Other quality requirements

- the provider will have a recognised system to demonstrate service quality and standards
- the service will have detailed clinical protocols setting out nationally (and local where appropriate) recognised good practice for each treatment site
- the quality system and its treatment protocols will be subject to regular clinical and management audit
- the provider is required to undertake regular patient surveys and develop and implement an action plan based on findings

4. Performance monitoring and information requirements

4.1 Performance Monitoring

WHSSC will be responsible for commissioning services in line with this document. This will include agreeing appropriate information and procedures to monitor the performance of organisations.

For the services defined in this policy the following approach will be adopted:

- Service providers to evidence quality and performance controls
- Service providers to evidence compliance with standards of care

WHSSC will conduct performance and quality reviews on an annual basis.

4.2 Key Performance Indicators

The providers will be expected to monitor against the full list of Quality Indicators derived from the service description components described in Section 2.2.

The provider should also monitor the appropriateness of referrals into the service and provide regular feedback to referrers on inappropriate referrals, identifying any trends or potential educational needs.

In particular, the provider will be expected to monitor against the following target outcomes:

- Number of breakthrough bleeds experienced by patients on prophylactic treatment
- Number and percentage of children (0-15 years) without inhibitors with a joint score of less than 4
- Number and percentage of children (0-15 years) with inhibitors with a joint score of less than 4
- Proportion of all patients with a moderate or severe bleeding disorder having contact with their CCC at least annually
- Proportion of Hepatitis C positive patients who have been assessed by a hepatologists
- An annual patient experience survey

4.3 Date of Review

This document is scheduled for review before 2025, where we will check if any new evidence is available.

If an update is carried out the policy will remain extant until the revised policy is published.

5. Equality Impact and Assessment

The Equality Impact Assessment (EQIA) process has been developed to help promote fair and equal treatment in the delivery of health services. It aims to enable Welsh Health Specialised Services Committee to identify and eliminate detrimental treatment caused by the adverse impact of health service policies upon groups and individuals for reasons of race, gender re-assignment, disability, sex, sexual orientation, age, religion and belief, marriage and civil partnership, pregnancy and maternity and language (Welsh).

This policy has been subjected to an Equality Impact Assessment.

The Assessment demonstrates the policy is robust and there is no potential for discrimination or adverse impact. All opportunities to promote equality have been taken.

6. Putting Things Right

6.1 Raising a Concern

Whilst every effort has been made to ensure that decisions made under this policy are robust and appropriate for the patient group, it is acknowledged that there may be occasions when the patient or their representative are not happy with decisions made or the treatment provided.

The patient or their representative should be guided by the clinician, or the member of NHS staff with whom the concern is raised, to the appropriate arrangements for management of their concern.

If a patient or their representative is unhappy with the care provided during the treatment or the clinical decision to withdraw treatment provided under this policy, the patient and/or their representative should be guided to the LHB for NHS Putting Things Right. For services provided outside NHS Wales the patient or their representative should be guided to the NHS Trust Concerns Procedure, with a copy of the concern being sent to WHSSC.

6.2 Individual Patient Funding Request (IPFR)

If the patient does not meet the criteria for treatment as outlined in this policy, an Individual Patient Funding Request (IPFR) can be submitted for consideration in line with the All Wales Policy: Making Decisions on Individual Patient Funding Requests. The request will then be considered by the All Wales IPFR Panel.

If an IPFR is declined by the Panel, a patient and/or their NHS clinician has the right to request information about how the decision was reached. If the patient and their NHS clinician feel the process has not been followed in accordance with this policy, arrangements can be made for an independent review of the process to be undertaken by the patient's Local Health Board. The ground for the review, which are detailed in the All Wales Policy: Making Decisions on Individual Patient Funding Requests (IPFR), must be clearly stated

If the patient wishes to be referred to a provider outside of the agreed pathway, and IPFR should be submitted.

Further information on making IPFR requests can be found at: Welsh Health Specialised Services Committee (WHSSC) | Individual Patient Funding Requests

Annex i Codes

Code Category	Code	Description
ICD-10	D66	Hereditary Factor VIII deficiency
ICD-10	D67	Hereditary Factor IX deficiency
ICD-10	D68	Von Willebrand's disease
ICD-10	D682	Hereditary deficiency of other clotting factors
ICD-10	D683	Haemorrhagic disorder due to circulating anticoagulation
ICD-10	D689	Coagulation defect, unspecified
ICD-10	D691	Qualitative platelet defects
ICD-10	D699	Haemorraghic condition, unspecified

Annex ii Abbreviations and Glossary

Abbreviations

CCC Comprehensive Care Centre

HC Haemophilia Centre

IPFR Individual Patient Funding Request

NEQAS UK National External Quality Assessment Scheme

UKAS United Kingdom Accreditation Service

UKHCDO United Kingdom Haemophilia Centre Doctors' Organisation

WHSSC Welsh Health Specialised Services Committee

Glossary

Individual Patient Funding Request (IPFR)

An IPFR is a request to Welsh Health Specialised Services Committee (WHSSC) to fund an intervention, device or treatment for patients that fall outside the range of services and treatments routinely provided across Wales.

Welsh Health Specialised Services Committee (WHSSC)

WHSSC is a joint committee of the seven local health boards in Wales. The purpose of WHSSC is to ensure that the population of Wales has fair and equitable access to the full range of Specialised Services and Tertiary Services. WHSSC ensures that specialised services are commissioned from providers that have the appropriate experience and expertise. They ensure that these providers are able to provide a robust, high quality and sustainable services, which are safe for patients and are cost effective for NHS Wales.