1. Introduction and Who Guideline applies to

This guideline is for staff managing people with inherited and acquired bleeding disorders, such as haemophilia and Von Willebrand disease.

2. Guideline Standards and Procedures

The Leicester Comprehensive Care centre manages a wide range of IABDs and whilst the management of acute bleeding and prophylactic concentrate therapy are the specific interventions there are a number of additional management aims that are of benefit in the holistic management of these conditions. This document outlines these topics and aims, and specific approaches where appropriate.

Antenatal and neonatal care. Reproductive counselling may should be offered to all patients with an inherited bleeding disorder in order to discuss heritability and management of pregnancies. The timing of these discussions should be assessed by clinicians in the haemostasis unit in order to be age appropriate; and may be offered outside of routine clinic reviews on request by potentially affected individuals or couples. The management of pregnancy for those with IABDs or carriers of bleeding disorders should be in the setting of the joint Haematology Obstric clinic (aka HOBS). A separate gyuideline exists to describe this service.

Chronic joint disease. The aim of prophylactic therapy in severe haemophilia is to prevent long term joint damage, which may manifest with joints causing chronic pain, reduced range of movement or reduced function. Patients receiving prophylaxis should have a physiotherapy assessed Haemophilia Joint Health Score documented on an annual basis in an attempt to identify problems as early as possible.

For those in whom irreversiblejoint damage as occurred, the following services are available:

Orthopaedic clinic – to see an orthopaedic surgeon and physiotherapist

Physiotherapy

Analgesia reviews – this might include paracetamol, codeine/tramadol, COX-2 selective NSAID (celecoxib), neuropathic analgesia, joint injection. If basic measures are not successful from the routine bleeding disorders clinic, referral may be made to the UHL pain clinic.

Psychology – a separate referral from the haemophilia team would be required for this

Comorbidity screening and healthy living opportunities

PWH may suffer with other medical disorders, and haemophilia/IABDs may complicate the management. Examples would include the need for factor therapy for dental work or complex decisions regarding antithrombotic therapy in ischaemic heart disease. As a result, opportunities for health screening should be taken where possible in order to anticipate and manage other health issues.

Specifically, the following should be considered at routine clinic review:

pulse check,

blood pressure measurement

smoking and alcohol history

dental care

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planned procedures

new medical problems and new medications

iron deficiency

cardiovascular screening blood tests e.g. cholesterol

other blood screening tests e.g. renal function, liver function, PSA

health promotion e.g. healthy eating, exercise, attendance at screening clinic (bowel, breast), vaccinations

Infectious diseases. Historically there has been an increased prevalence of blood borne viral infections in PWH and IABDs. Primarily this affected individuals who were transfused blood products between c1970-1990, with a major infectious agents being HIV and hepatitis C. Many patients died of these conditions, however there are survivors. Those with HIV are now managed in the UHL infectious disease unit and should be receiving ant-retroviral therapy and monitoring. Patients with hepatitis C should have been offered antiviral therapy and it is expected that the majority of those with hepatitis C will have received effective eradication therapy as of 2019.

3.Education and Training

Nil

4. Monitoring Compliance

What will be measured to monitor compliance	How will compliance be monitored	Monitoring Lead	Frequency	Reporting arrangements
Clinic measurements	Notes audit	MDT lead	Annual	MDT
Clinic documentation	Clinic letters	MDT lead	Annual	MDT
Patient satisfaction	Friends and family/complaints	MDT lead	Annual	MDT

5. Supporting References (maximum of 3)

UKHCDO Inherited and acquired bleeding disorders quality standards.UKHCDO

6. Key Words

Haemophilia, Von Willebrand disease

CONTACT AND REVIEW DETAILS	
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Details of Changes made during review:	