

SECTION 3.1: DEMOGRAPHY & DIAGNOSTIC INFORMATION

Patient ID: _____

Patient Information

Name: _____
 Hospital No: _____
 Phone 1: _____ Phone 2: _____
 Country: _____ Contact Address: _____
 E-Mail: _____

Treater Information

Name of Haemophilia Treatment Center (HTC): _____
 Physician responsible: _____
 Institution: _____
 Primary E-Mail: _____ Office Address: _____
 Secondary E-Mail: _____
 Phone: _____
 Fax: _____
 Website: _____

Baseline Characteristics

Information given by: Father/Mother/Patient/Guardian
 Date of baseline data collection: _____ Measured activity date: _____
 Date of Birth: _____ Sex: Male/Female
 Severity: Severe <1%
 Moderate 1% - 5%
 Mild >5% - <40%
 Haemophilia Type: A
 B
 Result: % FVIII/IX _____% Lab or Hosp Name: _____
 Measured Clotting Factor Activity: Done/ Not tested/ Test Unavailable/ Unknown/ Not Applicable
 Blood Group: A/ B/ O/ AB/ Not tested Rh: Positive/ Negative
 Twin with same deficiency: Yes/ No HIV Status: Positive/ Negative/ Unknown
 HCV Antibody: Positive/ Negative/ Unknown HCV PCR: Positive/ Negative/ Unknown
 Haemophilia A: Yes/ No Intron 22 Inversion: Yes/ No/Unknown
 Mutation Known: Yes
 Planned, waiting for result
 Tested but unknown mutation
 Not tested
 Test unavailable

Mutation Comment: _____

Personal Details

Weight (Kg): _____ Height (cm): _____
 Highest Education completed: Pre-elementary/ Primary, Secondary/ If Primary/Secondary, enter grade 1-12: _____
 Technical School/ College degree/ If others, Specify: _____
 Advanced degree/ Others
 Employment Status: Employed Full-time/ Employed, If others, Specify: _____
 Part-time/ Not Employed/ Full time
 Student/ Retired/ Others

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HTC utilization

- Frequent (visits HTC at least once per year)
- Infrequent (visits HTC every 2-3 years)
- Rare (visits HTC every 4 or more years)
- First visit

Health Insurance

Health Insurance: Uninsured/ Government, Employer/ Private Insurance/ Others
If others, Specify: _____

Diagnostic Information

Date of Diagnosis: _____
Diagnosis: Haemophilia A/ Haemophilia B/ Others
If others, specify: _____
Name of Lab/ Hospital: _____

	Test (Done/Not Done/ Test not available/Unknown)	Result (Seconds)	Date
I. APTT (Activated partial thromboplastin time)			
1. Control / Normal Range			
2. Mixing Study (1/2 + 1/2)			
II. PT (Prothrombin time)			
1. Control / Normal Range			
2. Mixing Study (1/2 + 1/2)			
III. TT			
IV. Platelet Count			

Factor Assay	Test	Result (%)	Date
Factor assays done during coagulation workup	Yes/ No		
Factor VIII	Yes/ No		
Factor IX	Yes/ No		
VWF RCo and Ag	Yes/ No		
Fibrinogen	Yes/ No		
Others	Yes/ No		

Platelet Aggregometry Test	Test	Result (%)	Date
Platelet Aggregometry	Yes/ No/NA		
Ristocetin 1.5 mg/ml	Yes/ No/NA		
Ristocetin 0.5 mg/ml	Yes/ No/NA		
ADP	Yes/ No/NA		
Epinephrine	Yes/ No/NA		
Collagen	Yes/ No/NA		
Arachidonic Acid	Yes/ No/NA		

¹Adapted from WBDR/WFH (www.bleedingdisorderregistry.org)

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Inhibitor Status	Test	Result	Date
Inhibitor Status	Yes/ No		
Screen	Done/ Not Done/ Test not available/ Unknown	Positive/ Negative/ Unknown	
Bethesda Assay	Done/ Not Done/ Test not available/ Unknown	_____ BU/ml	
Nijmegen Modification	Done/ Not Done/ Test not available/ Unknown		

Comments