INDIAN ASSOCIATION FOR HAEMOPHILIA AND ALLIED DISORDERS[1]

IAHAD Indian Association for Haemophilia and Allied Disorders

MINIMAL DATA FORM (MDF)

Patient ID:__________________

Demography & Diagnostic Information

Date of First Visit to HTC: __________________ Date of Birth: ___________ Factor Level (%) __________

Date of Diagnosis: __________________ Diagnosis Type: Haemophilia A/ Haemophilia B/ Others

Information given by: Father/Mother/Patient/Guardian

Data at Annual Followup

(Please complete the following section at registration into the registry and at each annual visit, for the preceding 12 month period)

Current Body Weight (Kg): ____________ Current Body Height (cm): __________ Inhibitor Assay (BU/ml): _________

Inhibitor Screen: Positive/Negative/Not tested/Not Applicable Assay method: Bethesda/Nijmegen

Target Joint: Yes/ No

Number of Bleeds (Past 12 months)

Joints: _____________ Muscles: _____________ CNS: ___________

Oral: _____________ Gastrointestinal: _____________ Urinary: ___________

Others (Specify): _____________

A. Hospital Care: Yes/No

Total Number of days: In-Patient: ____________ Out-Patient: _____________

B. Absence from Education/ Work: ____________ No. of days: _____________

Factor Replacement	
Factor Replacement/ Blood Products:	Yes/No/No Access
If Yes, Type of Replacement:	Episodic/ Prophylaxis/ Both
Episodic:	None/ Yes, for all bleeds/ Yes, for severe bleeds only/ Unknown
Total CFC used IU (Past 12 months):	
Administration:	Always at HTC/ Always at Home/ Both/Unknown
Prophylaxis:	None/Yes, intermittent/ Yes, continuous/ Unknown
Duration: *(Total number of weeks during past 12 months)*	

CFC/Blood Product	Brand Name/ Products	No. of times	Total units used
CFC			
Recombinant CFC			
Plasma derived CFC (EHL)			
FFP			
Cryoprecipitate			
Platelet			

Start Date	Stop Date/ Ongoing	Frequency Once per week/ Two times per week/ Three times per week/ Every other day/ Every two weeks/Other	Dose IU/Kg/Week	Reason	Administration Always at HTC/ Always at Home/ Both/ Unknown

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