

Measure Number	Theme	Measure	Description & Provenance	Name of KPI	Numerator	Denominator	Period Type	Frequency	Data Source Numerator	Data Source Denominator	Data presentation	Target	Interpretation Guidance	Construction	Data Quality Concerns	Error Measurement	Notes_1
HAE03	Domain 2: Enhancing quality of life for people with long term conditions	Number of patients who are able to manage their condition using home treatment.	Proportion of patients with severe haemophilia registered as receiving home treatment .		Number of patients in denominator who access the majority of their maintenance products at home	Total number of registered patients with severe haemophilia (factor concentration <1%)	Quarterly	Quarterly	Local registers	Local registers	Run chart	to be decided	higher is better				
HAE05a	Domain 3: Helping people to recover from episodes of ill health or following injury	Factor usage by centre	Mean factor VIII usage per kilogram body weight (or ideal body weight) per patient aged under 18 years with severe bleeding disorder and no inhibitors		Sum total for all patients in denominator of their individual number of units of Factor VIII used per kg body weight	Number of patients aged under 18 years registered & on treatment with severe factor VIII disorder (factor concentration <1%), but no inhibitors	Quarterly	Quarterly	Returns to NHD	Returns to NHD	Table/Run Chart	to be decided	higher is better				
HAE05b	Domain 3: Helping people to recover from episodes of ill health or following injury	Factor usage by centre	Mean factor VIII usage per kilogram body weight (or ideal body weight) per adult patient with severe bleeding disorder and no inhibitors		Sum total for all patients in denominator of their individual number of units of Factor VIII used per kg body weight	Number of adult patients registered & on treatment with severe factor VIII disorder (factor concentration <1%), but no inhibitors	Quarterly	Quarterly	Returns to NHD	Returns to NHD	Table/Run Chart	to be decided	higher is better				
HAE05c	Domain 3: Helping people to recover from episodes of ill health or following injury	Factor usage by centre	Mean factor IX usage per kilogram body weight (or ideal body weight) per patient aged under 18 years with severe bleeding disorder and no inhibitors		Sum total for all patients in denominator of their individual number of units of Factor IX used per kg body weight	Number of patients aged under 18 years registered & on treatment with severe factor IX disorder (factor concentration <1%), but no inhibitors	Quarterly	Quarterly	Returns to NHD	Returns to NHD	Table/Run Chart	to be decided	higher is better				
HAE05d	Domain 3: Helping people to recover from episodes of ill health or following injury	Factor usage by centre	Mean factor IX usage per kilogram body weight (or ideal body weight) per adult patient with severe bleeding disorder and no inhibitors		Sum total for all patients in denominator of their individual number of units of Factor IX used per kg body weight	Number of adult patients registered & on treatment with severe factor IX disorder (factor concentration <1%), but no inhibitors	Quarterly	Quarterly	Returns to NHD	Returns to NHD	Table/Run Chart	to be decided	higher is better				
HAE07a	Domain 4: Ensuring that people have a positive experience of care	Patient survey results	Measure of patients' perception of quality of care.		Number of Survey responses	Total number of patients surveyed	Annual	Annual	Survey	Survey	Run Chart	to be decided	higher is better				
HAE07b	Domain 4: Ensuring that people have a positive experience of care	Patient survey results	Measure of patients' perception of quality of care.		Number of patients reporting a good or excellent experience of care	Number of Survey responses	Annual	Annual	Survey	Survey	Run Chart	to be decided	higher is better				
HAE08	Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm	Patients are seen within the minimum recommended intervals	% of severe patients attending for review every six months at a minimum		Number of patients in denominator attending at least 6 monthly during the previous year	Number of patients with severe disease (factor concentration <1%) registered and treated at the centre	Annual	Annual	Local clinic returns on weekly basis for all patients attending	Local clinic returns on weekly basis for all patients attending	% chart	to be decided	higher is better				
HAE10	Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm	Number of joint bleeds	Number of breakthrough bleeds in patients with severe disease who are treated on a prophylactic regime.		Number of patients in denominator who experience ≥ 1 joint bleed within a 3 month period	Number of patients on register with severe haemophilia A/B (factor concentration <1%) and are on a prophylactic regime	Quarterly	Quarterly	Haemtrack or clinic returns	Haemtrack or clinic returns	Table/Run Chart	to be decided	lower is better				
HAE13	Enhancing quality of life for people with long term conditions	Proportion of severe and moderate patients who have a joint score recorded	Initially, baseline data may need to be collected before can be used to monitor average disease progression.		Number of patients in denominator who have a joint score recorded	Total number of haemophilia A/B patients over 4 years old seen in clinic with severe and moderate disease (Factor concentration <5%) in reporting period	Annual	Annual	Stratified by age and severity ? Tool. ?Use modified paediatric haemophilia joint score	Stratified by age and severity ? Tool. ?Use modified paediatric haemophilia joint score	run chart	to be decided	higher is better				
HAE14	Domain2:	Percentage of accurate treatment records collected.	Number of complete treatment records for patients with severe haemophilia A and B		Number of patients in denominator where the trust has a populated record of factor usage and bleeding events	Total number of registered patients with severe haemophilia (factor concentration <1%)	Quarterly	Quarterly	Haemtrack or clinic returns	Haemtrack or clinic returns	Table/Run Chart	to be decided	higher is better				