

Blood and Infection  
Blood Disorders  
Haemophilia (All Ages)

B05/S/a

Code	Metric	Numerator	Denominator	Period Type	Frequency	Data Source Numerator	Data Source Denominator	Target	Notes	Q1	Q2	Q3	Q4
HAE07b	Proportion of patients who responded reporting a 'good' or 'excellent' experience of care	Number of patients reporting a 'good' or 'excellent' experience of care	Number of Survey responses during the reporting period.	Annual	Annual	Provider	Provider		Includes all service users, any age, or their parents/carers, who have a specialised bleeding disorder such as haemophilia (A, B or acquired), & other rare bleeding disorders, of any severity (mild, moderate, severe, carrier) AND who have received an episode of care or intervention from the service in a preceding contiguous 12 month period.	N/A	N/A	N/A	Apr-22 - Mar-23
HAE14	Proportion of patients treated with prophylaxis factor replacement regimen who are regularly reporting treatment administration and outcomes (bleeds), e.g. using Haemtrack™	From denominator, number of patients providing data relating to the self-administration of a prophylaxis factor replacement therapy regimen, and data relating to the incidence of bleeding episodes and other related events, usually via Haemtrack™	Number of patients treated with a prophylaxis factor replacement regimen seen by provider during reporting period.	Annual	Annual	Provider	Provider		Includes all patients with an inherited bleeding disorder, any age, who are treated with a prophylaxis factor replacement regimen (including emicizumab) for whom data is submitted to the clinical team. This is usually done using a Haemtrack™ digital interface (smartphone App or PC), otherwise paper records transcribed by the service, or other paper records to the satisfaction of the service. The provider is that which holds the specialised commissioning contract for 'Specialist services for haemophilia and other related bleeding disorders (adults and children)' for patients at all sites and locations to which that contract relates.	N/A	N/A	N/A	Apr-22 - Mar-23
HAE15	Proportion of patients with a severe inherited bleeding disorder with at least two documented clinical reviews in each annual review cycle	From denominator, number of patients reviewed at least twice within each annual review cycle	Number of patients with a severe inherited bleeding disorder who are under the care of the service.	Annual	Annual	Provider	Provider		Includes all patients, any age, with a severe inherited bleeding disorder. Annual review cycle: Rolling 14 month period using whole calendar months and discounting current month. Clinical review delivered, led or overseen by the Haemophilia Service from a Comprehensive Care Centre to include medical, nursing and physiotherapy review as a minimum; any other review or consultation does not count as a clinical review for the purpose of the dashboard. The provider is that which holds the specialised commissioning contract for 'Specialist services for haemophilia and other related bleeding disorders (adults and children)' for patients at all sites and locations to which that contract relates.	N/A	N/A	N/A	Apr-22 - Mar-23

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HAE17	Proportion of patients of any age with severe or moderate haemophilia A or B with a joint score recorded at a clinical review within the most recent annual review cycle	Number of patients with a joint score recorded at at least one review within the most recent annual review cycle	Total number of severe and moderate haemophilia patients with an annual review recorded in the preceeding 14 months	Annual	Annual	Provider	Provider		Includes congenital Haemophilia A and Haemophilia B only; does not include other bleeding disorders or acquired haemophilia. Paediatric AND Adult patients. At least one joint score recorded within the limits defined in the Annual Review Cycle (Stratified by age and severity. Use modified paediatric haemophilia joint score). Annual review cycle is the most recent 14 month period excluding the current month. Clinical review delivered, led or overseen by the Haemophilia service from a Comprehensive Care Centre to include medical, nursing and physiotherapy review as a minimum; any other review or consultation does not count as a clinical review for the purpose of the dashboard. The responsible provider is that which holds the specialised commissioning contract for 'Specialist services for haemophilia and other related bleeding disorders (adults and children)' for patients at all sites and locations to which that contract relates.	N/A	N/A	N/A	Apr-22 - Mar-23
HAE18	Proportion of patients with a severe inherited bleeding disorder prescribed a prophylaxis factor replacement treatment regimen	From denominator, number of patients prescribed a treatment regimen which is identified as being a prophylaxis factor replacement regimen	Number of patients with a severe inherited bleeding disorder who are under the care of the service	Annual	Annual	Provider	Provider		Includes all patients with a severe inherited bleeding disorder, any age, who are treated with a prophylaxis factor replacement regimen (including emicizumab). The provider is that which holds the specialised commissioning contract for 'Specialist services for haemophilia and other related bleeding disorders (adults and children)' for patients at all sites and locations to which that contract relates.	N/A	N/A	N/A	Apr-22 - Mar-23
HAE19	Proportion of patients with a severe inherited bleeding disorder who have had an appointment with a physiotherapist who is a member of the Haemophilia Chartered Physiotherapists' Association within the preceeding 14 months	Number of patients who have received an episode of care with a physiotherapist who is a member of the HCPA	Number of patients, adult and paediatric, with a severe inherited bleeding disorder under the care of the service.	Annual	Annual	Provider	Provider		A physiotherapist must be a member of the HCPA in order to confirm that the care is provided by a physiotherapist who has special knowledge and interest in bleeding disorders. The episode of care could be part of haemophilia MDT clinic review including physiotherapy, or a separate referral or appointment to a physiotherapist. The time period relates to the preceeding 14 whole months excluding the current month.	N/A	N/A	N/A	Apr-22 - Mar-23
HAE20	Proportion of patients, or families of patients, with an inherited bleeding disorder who have received clinical psychology (or similar) support within the preceeding 14 months (primarily relating to the bleeding disorder)	Number of patients who have received a new psychological intervention or episode of care relating to their bleeding disorder	Number of patients, adult or paediatric, or their family members or carers, who have been referred for, or have otherwise received, a new psychology intervention or episode of care	Annual	Annual	Provider	Provider		A psychology intervention or episode of care can be an inter-clinic referral, and new referral to a dedicated psychology service or to a primary care based service or intervention. Referrals do not necessarily have had to have been made by the service, for example it could be made by a GP. The intervention or care provided or sought must be wholly or primarily related to the patient's bleeding disorder. The time period relates to the preceeding 14 whole months excluding the current month.	N/A	N/A	N/A	Apr-22 - Mar-23

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HAE21	Proportion of patients, or families of patients, with an inherited bleeding disorder who have been referred for social care (or similar) support within the preceeding 14 months	Number of patients who have received new social care support relating to their bleeding disorder	Number of patients, adult or paediatric, or their family members or carers, who have been referred for, or have otherwise received, new social care support relating to their bleeding disorder	Annual	Annual	Provider	Provider		Social care support will often manifest as a referral to an external provider, including charities and other non-NHS services, or it may relate to a provider service or it may even be integral to the haemophilia service. Social care support for children will often extend to work with a patient's school. Only referrals which relate wholly or primarily to the patient's bleeding disorder are to be counted. Referrals can be made by various parties, including GPs etc.	N/A	N/A	N/A	Apr-22 - Mar-23