

Haemophilia Quality Dashboard 2018/19



Indicator Reference Number	Domain	Theme	Measure	Rationale	Name of Indicator/ Description	Numerator	Denominator	Period Type	Frequency	Data Source Numerator	Data Source Denominator	Target	Interpretation Guidance	Notes	Reporting Periods			
															Q1	Q2	Q3	Q4
HAE07b	Domain 4: Ensuring that people have a positive experience of care	Clinical outcome	Patient survey results	Measure of patient perception of quality of care and to ensure patient involvement and consultation on services.	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 submitted data	Provider submitted data		Higher is better	Includes congenital Haemophilia A and Haemophilia B only; does not include other bleeding disorders or acquired haemophilia. Paediatric AND Adult patients to be included.				Apr 18 - Mar 19
HAE14	Domain 2: Enhancing quality of life for people with long term conditions	Clinical outcome	Patient activation and engagement	Patients on prophylaxis treatment (primarily these are 'severe' patients) are expected to make at least monthly submissions or records of data especially if using the Haemtrack™ digital interface. Note that younger paediatric patients will have their data reported by an adult, usually a parent.	Proportion of patients with Severe Haemophilia regularly reporting treatment administration and outcomes (bleeds), preferably using the Haemtrack™ digital interface, although other options do exist	From denominator, number of patients providing data relating to the self-administration of blood factor products, and data relating to the incidence of bleeding episodes and other related events, preferably via Haemtrack™	Number of patients with severe Haemophilia (Factor level <1%) seen by provider (*) during reporting period. * The provider 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.	Annual	Annual	Provider submitted data	Provider submitted data		Higher is better	Includes congenital Haemophilia A and Haemophilia B only; does not include other bleeding disorders or acquired haemophilia. Paediatric AND Adult patients to be included. Haemtrack™ returns, ideally electronic via the digital interfaces (smartphone App or PC), otherwise paper records transcribed by the service, or other bespoke paper records to the satisfaction of the service. Prophylaxis treatment: administration minimum frequency: once per week for standard half-life factors; once per fortnight for enhanced half-life factors; once per week for Emicizumab.				Apr 18 - Mar 19
HAE15	Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm	Clinical process	Patient review intervals	Patients with severe haemophilia should have a minimum of TWO documented clinical consultations each year.	Proportion of severe Haemophilia patients 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 severe Haemophilia (Factor level <1%) seen by provider (*) during reporting period. * The provider 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.	Annual	Annual	Provider submitted data	Provider submitted data		Higher is better	Includes congenital Haemophilia A and Haemophilia B only; does not include other bleeding disorders or acquired haemophilia. Paediatric AND Adult patients to be included. Annual review cycle: Rolling 14 month period using whole calendar months and discounting current month. For example, if current month is October 2017 the period in question is August 2016 to September 2017 inclusive. For purposes of the SSQD, please use as current month the month in which you are submitting the data. 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.				Apr 18 - Mar 19
HAE16	Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm	Clinical process	Extent of prophylactic treatment	Prophylaxis treatment for someone with severe haemophilia helps the blood to clot and minimises the likelihood of long-term joint damage.	Proportion of Severe Haemophilia patients prescribed a prophylactic treatment regimen	From denominator, number of patients prescribed a treatment regimen which is identified as being a prophylactic regimen	Number of patients with severe congenital Haemophilia A or B (Factor level <1%) seen by provider during (*) reporting period. * The provider 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.	Quarterly	Quarterly	Provider submitted data	Provider submitted data		Higher is better	Includes congenital Haemophilia A and Haemophilia B only; does not include other bleeding disorders or acquired haemophilia. Paediatric AND Adult patients to be included. Prophylactic regimen: administration minimum frequency: once per week for standard half-life factors; once per fortnight for enhanced half-life factors; once per week for Emicizumab.	Apr 18 - Jun 18	Jul 18 - Sep 18	Oct 18 - Dec 18	Jan 19 - Mar 19
HAE17	Domain 2: Enhancing quality of life for people with long term conditions	Clinical outcome	Joint health	The Haemophilia Joint Health Score (HJHS) is a validated measure of joint impairment. It provides information on joint health status over time, and therefore effectiveness of treatment in avoiding joint bleeds, which damage joints.	Proportion of patients with severe and moderate haemophilia with a joint score recorded at the most recent clinical review within the annual review cycle	Number of patients with a joint score recorded at the most recent annual review within the annual review cycle	Total number of severe (Factor level <1%) and moderate (Factor level >=1% and <5%) haemophilia patients seen by provider (*) during the reporting period. * The provider 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.	Annual	Annual	Provider submitted data	Provider submitted data		Higher is better	Includes congenital Haemophilia A and Haemophilia B only; does not include other bleeding disorders or acquired haemophilia. Paediatric AND Adult patients to be included. 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: Rolling 14 month period using whole calendar months and discounting current month. For example, if current month is October 2017 the period in question is August 2016 to September 2017 inclusive. For purposes of the SSQD, please use as current month the month in which you are submitting the data. 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.				Apr 18 - Mar 19

Data collection has been approved by the Review of Central Returns - ROCR
ROCR/OR/2230/001MAND