

WBDR Minimal & Extended Data Set
Developed by the WBDR Steering Committee, 2019

*minimal data set fields

Data field	Measurement, Format and Definitions	Baseline visit	Follow-up visits (every clinic visit is a follow up visit)
Date of birth*	dd-mon-yyyy	X	
Sex*	(Drop down list) Male Female Other Unknown	X	
Country of residence*	Drop down list (all countries)	X	
Date of diagnosis*	dd-mon-yyyy	X	
Hemophilia, type*	(Drop down list) A B Unknown	X	

Hemophilia, severity*#	(Drop down list) Mild Moderate Severe Unknown	X	
Hemophilia, factor level at diagnosis*#	Free text (integer)	X	
Bleeding history*	(Drop down list) Has had ≥ 1 bleed in lifetime Has never had a bleed Unknown	X	
Inhibitor history*	(Drop down list) Inhibitor in the past Currently has an inhibitor Never had an inhibitor Unknown	X	
Treatment history*	(Drop down list) Has received treatment in the past Never received treatment Unknown	X	

Blood group	(Drop down list) A B O AB Unknown	X	
Genetic testing	Date of genetic testing (dd-MON-yyyy) DNA variant (drop down list) <ul style="list-style-type: none"> • Intron 22 inversion • Interon 1 inversion • Other • Not done • Unknown DNA variant type (Drop down list) <ul style="list-style-type: none"> • Inversion • Large structural variant (≥ 50 bp) • Nonsense • Frameshift • Small insertion or deletion • Slice • Missence • Synonymous • Promoter UTR • Other • Unknown 	X	

<p>Bleeding event assessment*</p> <p><i>Bleeding events since last visit.</i></p>	<p>Total number of bleeds the patient has experienced since the last clinic visit</p> <p>Number of bleeds per location</p> <p>Number of bleeds that were spontaneous vs traumatic</p>	<p>X</p>	<p>X</p>
<p>Inhibitor assessments*</p> <p><i>Inhibitor testing since last visit.</i></p>	<p>Date of test (dd-mon-yyyy) Type of test (Drop down list)</p> <ul style="list-style-type: none"> • Bethesda • Nijmegen-Bethesda • Mixing study (aPTT test) • Unknown • Other <p>Titre value (Free text)</p>	<p>X</p>	<p>X</p>
<p>Target joints*#</p> <p><i>Number of target joints</i></p>	<p>Free text</p>	<p>X</p>	<p>X</p>
<p>Hospital admissions*</p> <p><i>Number of hospitalizations since last visit</i></p>	<p>Start date (dd-mon-yyyy) Number of days hospitalized (Free text) Reason for hospitalization (Drop down list)</p> <ul style="list-style-type: none"> • Hemophilia related (Multiselect: Intracranial bleeding, Psoas muscle bleeding, Other muscle bleeding, Joint bleeding, Soft tissue bleeding, Other bleeding, Thromboembolic event, Surgery, Other) • Non-hemophilia related 	<p>X</p>	<p>X</p>

<p>Treatments*</p> <p><i>All treatments since last visit</i></p>	<p>Start date (dd-mon-yyyy)</p> <p>Indication (drop down list)</p> <ul style="list-style-type: none"> • Prophylaxis • On demand • ITI • Surgery • Trauma with no known bleed • Selective bleed prevention • Other • Unknown <p>Drug name (Drop down list)</p> <p>Dose (Free text)</p> <p>Unit (Drop down list)</p> <ul style="list-style-type: none"> • IU • Mg • BU/ml • Other <p>Number of intakes (Free text)</p> <p>Time unit (drop down list)</p> <p>End date (dd-MON-yyyy)</p> <p>Reason for stopping treatment (drop down list)</p>	<p>X</p>	<p>X</p>
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<p>Adverse events</p> <p><i>All AEs since last visit</i></p>	<p>Date of onset (dd-mon-yyyy) Event (Drop down list)</p> <ul style="list-style-type: none"> • Infection • Allergic reaction including anaphylaxis • Thromboembolic event • Thrombotic microangiopathy • Lack of efficacy • Injection site rejection • Other <p>Date of resolution (dd-mon-yyyy) Interventions (Free text)</p>	<p>X</p>	<p>X</p>
<p>Height Weight BMI</p>	<p>Free text</p>	<p>X</p>	<p>X</p>
<p>Co-morbidities</p>	<p>Date (dd-mon-yyyy) HIV status (drop down list)</p> <ul style="list-style-type: none"> • Positive • Negative • Testing not done • Unknown <p>HCV status Date of diagnosis (dd-mon-yyyy) Date HCV resolved (dd-mon-yyyy) Has the patient been diagnosed with any other disease? (check all)</p> <p><input type="checkbox"/> Respiratory disease <input type="checkbox"/> Cardiovascular disease <input type="checkbox"/> Hypertension <input type="checkbox"/> Kidney disease <input type="checkbox"/> Cancer <input type="checkbox"/> Diabetes <input type="checkbox"/> Osteoarthritis <input type="checkbox"/> Osteoporosis</p> <p><input type="checkbox"/> Rheumatoid arthritis <input type="checkbox"/> Obesity <input type="checkbox"/> Anxiety <input type="checkbox"/> Depression <input type="checkbox"/> Other</p>	<p>X</p>	<p>X</p>

<p>Employment, education, marital status</p>	<p>Date (dd-mon-yyyy)</p> <p>Employment status (drop down list)</p> <ul style="list-style-type: none"> • Employed full-time • Employed part-time (due to hemophilia) • Employed part-time • Not employed (due to hemophilia) • Not employed • Long term sick leave (due to hemophilia) • Long term sick leave • Student • Retired (due to hemophilia) • Retired • Other <p>Years of education (Free text)</p> <p>Marital status (Drop down list)</p> <ul style="list-style-type: none"> • Married/Living together • Separated/Divorced • Widow • Single • Prefer not to answer 	<p>X</p>	<p>X</p>
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Mortality*	Date of death (dd-mon-yyyy) Primary cause of death (drop down list) <ul style="list-style-type: none"> • Intracranial hemorrhage • Bleeding (excluding intracranial) • Thromboembolic event • HIV • Liver disease • Cancer • Infection including pneumonia • Cardiac • Other, specify • Unknown 	X	X
Quality of life (EQ-5D-5L)	Date (dd-mon-yyyy)	X	X
Functional scales	Haemophilia Joint Health Score (HJHS) Joint disease Range of motion (ROM) WFH Score (Gilbert) Functional Independence Score for Haemophilia (FISH)	X	X
*denotes minimal data set # definition as per Blanchette 2014			