



Only symptoms and treatment BEFORE and AT diagnosis should be considered

1. Epistaxis

- 1.1 Have you ever had spontaneous epistaxis? ☐ Yes ☐ No or trivial (skip to 2)
- 1.2 Have the symptom ever required medical attention ? ☐ Yes ☐ No (resolve spontaneously; skip to 1.6)
- 1.3 If answer to 1.2 is yes, please specify
- ☐ Consultation only
 - ☐ Cauterization
 - ☐ Packing
 - ☐ Antifibrinolytics
 - ☐ Iron therapy
 - ☐ Treatment with desmopressin
 - ☐ Treatment with plasma
 - ☐ Treatment with platelet concentrate
 - ☐ Treatment with factor concentrates
 - ☐ Blood (RBC) transfusion
- 1.4 How many times in your life did you receive any of the above treatments (# 1.3)?
- ☐ 1 - 2
 - ☐ 3 to 5
 - ☐ 6 to 10
 - ☐ more than 10
- 1.5 At what age did you first have symptoms?
- ☐ Before 1 year
 - ☐ Between 1-5 years of age
 - ☐ Between 6-12 years of age
 - ☐ Between 13-25 years of age
 - ☐ After 25 years of age
- 1.6 Approximate number of episodes NOT requiring medical attention
- ☐ less than 1 per year
 - ☐ 1 per year
 - ☐ 2-5 every year
 - ☐ 1-3 every month
 - ☐ 1 every week
- 1.7 Duration of average single episode (min.) NOT requiring medical attention
- ☐ 1 minute or less
 - ☐ 1 - 10 minutes
 - ☐ more than 10 minutes

**2. Cutaneous bleeding (Bruising, ecchymoses, purpura, subcutaneous hematomas)**

- 2.1 Have you ever had any of the above cutaneous bleeding? ☐ Yes ☐ No or trivial skip to 3
- 2.2 Have the symptom ever required medical attention? ☐ Yes No ☐ skip to 2.6
- 2.3 If answer to 2.2 is yes, please specify
- ☐ Consultation only
 - ☐ Treatment with desmopressin
 - ☐ Treatment with plasma
 - ☐ Treatment with platelet concentrate
 - ☐ Treatment with factor concentrates
 - ☐ Blood (RBC) transfusion
- 2.4 How many times in your life did you receive any of the above treatments (# 2.3)?
- ☐ 1 - 2
 - ☐ 3 to 5
 - ☐ 6 to 10
 - ☐ more than 10
- 2.5 At what age did you first have symptoms?
- ☐ Before 1 year
 - ☐ Between 1-5 years of age
 - ☐ Between 6-12 years of age
 - ☐ Between 13-25 years of age
 - ☐ After 25 years of age
- 2.6 Approximate number of episodes NOT requiring medical attention
- ☐ less than 1 per year
 - ☐ 1 per year
 - ☐ 1-5 every six month
 - ☐ 1-3 every month
 - ☐ 1 every week
- 2.7 Type of bleeding
- ☐ Petechiae
 - ☐ Bruises
 - ☐ Hematomas
- 2.8 Location
- ☐ Exposed sites
 - ☐ Unexposed sites
 - ☐ Both
- 2.9 Common size
- ☐ ≤ 1 cm
 - ☐ >1 cm
 - ☐ Extensive (palm sized or larger)
- 2.10 How many bruises >1 cm in exposed areas in the most severe manifestation?
- ☐ ≤ 5
 - ☐ > 5
- 2.11 Location of petechiae
- ☐ Limited to lower limbs
 - ☐ Diffuse

**3. Bleeding from minor wounds (not requiring stitches in the average patient)**

- 3.1 Have you ever had prolonged bleeding from minor wounds? ☐ Yes ☐ No or trivial skip to 4
- 3.2 Have the symptom ever required medical attention ? ☐ Yes ☐ No skip to 3.6
- 3.3 If answer to 3.2 is yes, please specify
- ☐ Consultation only
 - ☐ Surgical hemostasis
 - ☐ Treatment with desmopressin
 - ☐ Treatment with plasma
 - ☐ Treatment with platelet concentrate
 - ☐ Treatment with factor concentrates
 - ☐ Blood (RBC) transfusion
- 3.4 How many times in your life did you received any of the above treatments (# 3.3)?
- ☐ 1 - 2
 - ☐ 3 to 5
 - ☐ 6 to 10
 - ☐ more than 10
- 3.5 At what age did you first have symptoms?
- ☐ Before 1 year
 - ☐ Between 1-5 years of age
 - ☐ Between 6-12 years of age
 - ☐ Between 13-25 years of age
 - ☐ After 25 years of age
- 3.6 Approximate number of episodes NOT requiring medical attention
- ☐ less than 1 per year
 - ☐ 1 per year
 - ☐ 2-5 every year
 - ☐ 1-3 every month
 - ☐ 1 every week
- 3.7 Duration of average single episode (min.)
- ☐ 1 to 10 minutes
 - ☐ more than 10 minutes

**4. Hematuria**

4.1 Have you ever had hematuria ? ☐ Yes ☐ No skip to 5

4.2 If answer to 4.1 is yes, please specify

Presence of associated urologic disease

Yes ☐ (skip to 5)

No ☐

Specify:

- ☐ Stones
- ☐ Infection
- ☐ Kidney/ bladder disease

Please answer the following questions only for SPONTANEOUS symptoms (answer No to 4.1)

4.3 Have the symptom ever required medical attention ? Yes ☐ No ☐ skip to 4.7

4.4 If answer to 4.3 is yes, please specify

- ☐ Consultation only
- ☐ Surgery
- ☐ Iron therapy
- ☐ Treatment with desmopressin
- ☐ Treatment with plasma
- ☐ Treatment with platelet concentrate
- ☐ Treatment with factor concentrates
- ☐ Blood (RBC) transfusion

4.5 How many times in your life did you received any of the above treatments (# 4.4)?

- ☐ 1 - 2
- ☐ 3 to 5
- ☐ 6 to 10
- ☐ more than 10

4.6 At what age did you first have symptoms?

- ☐ Before 1 year
- ☐ Between 1-5 years of age
- ☐ Between 6-12 years of age
- ☐ Between 13-25 years of age
- ☐ After 25 years of age

4.7 Approximate number of episodes NOT requiring medical attention

- ☐ less than 1 per year
- ☐ 1 per year
- ☐ 1-5 every six month
- ☐ 1-3 every month
- ☐ 1 every week

**5. Gastrointestinal bleeding (Hematemesis, Melena, Hematochezia)**

5.1 Have you ever had gastrointestinal bleeding ? ☐ Yes ☐ No skip to 6

5.2 If answer to 5.1 is yes, please specify

Type of bleeding

- ☐ Hematemesis
☐ Melena
☐ Hematochezia

Presence of associated GI disease

Yes ☐ No ☐

Specify:

- ☐ Ulcer
☐ Portal hypertension
☐ Angiodysplasia

Please answer to the following questions only for SPONTANEOUS symptoms

5.3 Have the symptom ever required medical attention ? Yes ☐ No ☐ skip to 5.7

5.4 If answer to 5.3 is yes, please specify

- ☐ Consultation only
☐ Surgical haemostasis/antifibrinolytic
☐ Treatment with desmopressin
☐ Treatment with plasma
☐ Treatment with platelet concentrate
☐ Treatment with factor concentrates
☐ Blood (RBC) transfusion

5.5 How many times in your life did you received any of the above treatments (# 5.4)?

- ☐ 1 - 2
☐ 3 to 5
☐ 6 to 10
☐ more than 10

5.6 At what age did you first have symptoms?

- ☐ Before 1 year
☐ Between 1-5 years of age
☐ Between 6-12 years of age
☐ Between 13-25 years of age
☐ After 25 years of age

5.7 Approximate number of episodes NOT requiring medical attention

- ☐ less than 1 per year
☐ 1 per year
☐ 1-5 every six month
☐ 1-3 every month
☐ 1 every week

**6. Oral cavity bleeding** (Tooth eruption, spontaneous or after brushing/flossing, gum bleeding, bleeding after bites to lip & tongue)

- 6.1 Have you ever had oral cavity bleeding ? ☐ Yes ☐ No or trivial skip to 7
- 6.2 Have the symptom ever required medical attention ? Yes ☐ No ☐ skip to 6.6
- 6.3 If answer to 6.2 is yes, please specify
- ☐ Consultation only
 - ☐ Surgical hemostasis (dental packing, suture, cauterization)
 - ☐ Antifibrinolytics
 - ☐ Treatment with desmopressin
 - ☐ Treatment with plasma
 - ☐ Treatment with platelet concentrate
 - ☐ Treatment with factor concentrates
 - ☐ Blood (RBC) transfusion
- 6.4 How many times in your life did you received any of the above treatments (# 6.3)?
- ☐ 1 - 2
 - ☐ 3 to 5
 - ☐ 6 to 10
 - ☐ more than 10
- 6.5 At what age did you first have symptoms?
- ☐ Before 1 year
 - ☐ Between 1-5 years of age
 - ☐ Between 6-12 years of age
 - ☐ Between 13-25 years of age
 - ☐ After 25 years of age
- 6.6 Approximate number of episodes NOT requiring medical attention
- ☐ less than 1 per year
 - ☐ 1 per year
 - ☐ 1-5 every six month
 - ☐ 1-3 every month
 - ☐ 1 every week
- 6.7 Duration of average single episode (min.)
- ☐ 1 to 10 minutes
 - ☐ more than 10 minutes

**7. Bleeding after Tooth/ Teeth extraction**

7.1 Have you ever had bleeding after tooth (teeth) extraction ? ☐ Yes ☐ No skip to 8

7.2 If answer to 7.1 is yes, please specify

Number of extractions

*Please fill in one of the following forms for **each** tooth extraction*

Age at extraction	<input type="text"/> <input type="text"/>	Type of extraction	<input type="checkbox"/> Deciduous <input type="checkbox"/> Permanent <input type="checkbox"/> Molar
Actions taken to prevent bleeding	<input type="checkbox"/> None <input type="checkbox"/> Antifibrinolytics <input type="checkbox"/> Desmopressin <input type="checkbox"/> Plasma or clotting factor concentrates <input type="checkbox"/> Platelet infusion		
	Bleeding after extraction?	Yes <input type="checkbox"/>	No <input type="checkbox"/>
	Actions taken to control bleeding	<input type="checkbox"/> None <input type="checkbox"/> Resuturing <input type="checkbox"/> Packing <input type="checkbox"/> Antifibrinolytics <input type="checkbox"/> Desmopressin <input type="checkbox"/> Plasma or clotting factor concentrates <input type="checkbox"/> Platelet infusion <input type="checkbox"/> Blood (RBC) transfusion	

**8. Bleeding after Surgery or Major Trauma**

8.1 Have you ever had bleeding after surgery or major trauma ? ☐ Yes ☐ No, skip to 9

8.2 If answer to 8.1 is yes, please specify

Number of interventions

Please fill in one of the following forms for **each** surgery or major trauma episode

Age at intervention/trauma	<input type="text"/> <input type="text"/>	Type of surgery	<input type="checkbox"/> Major-abdominal
			<input type="checkbox"/> Major-thoracic
		<input type="checkbox"/> Tonsillectomy/Adenoids	<input type="checkbox"/> Major-gynecology
		<input type="checkbox"/> Pharynx/Nose	<input type="checkbox"/> Other
Actions taken to prevent bleeding		<input type="checkbox"/> None	
		<input type="checkbox"/> Antifibrinolytics	
		<input type="checkbox"/> Desmopressin	
		<input type="checkbox"/> Plasma or clotting factor concentrates	
		<input type="checkbox"/> Platelet infusion	
Bleeding after intervention?	Yes <input type="checkbox"/>	No <input type="checkbox"/>	
Actions taken to control bleeding		<input type="checkbox"/> None	
		<input type="checkbox"/> Surgical hemostasis	
		<input type="checkbox"/> Antifibrinolytics	
		<input type="checkbox"/> Desmopressin	
		<input type="checkbox"/> Plasma or clotting factor concentrates	
		<input type="checkbox"/> Platelet infusion	
	<input type="checkbox"/> Blood (RBC) transfusion		

**9. Menorrhagia**

- 9.1 Have you ever had very heavy menstrual bleeding (menorrhagia)? ☐ Yes ☐ No or trivial skip to 10
- If answer to 9.1 is yes, please specify
- ☐ Changing pads/tampons more frequently than every 2 hours
- ☐ Bleeding more than 7 days
- ☐ Clot and flooding
- Impairment of daily activities (work, housework, exercise, social activities): ☐ Never or rarely ☐ Most menses
- 9.2 Have the symptom ever required medical attention ? ☐ Yes ☐ No skip to 9.6
- 9.3 If answer to 9.2 is yes, please specify
- a ☐ Consultation only
- b ☐ Pictorial Bleeding Score _____ Assessment
- c ☐ Antifibrinolytic therapy
- d ☐ Iron therapy
- e ☐ Hormonal therapy
- f ☐ Combined antifibrinolytics & Hormonal therapy
- g ☐ Hysterectomy / endometrial ablation / D & C
- h ☐ Treatment with desmopressin
- ☐ Treatment with plasma
- ☐ Treatment with platelet concentrate
- ☐ Treatment with factor concentrates
- i ☐ Blood (RBC) transfusion
- l ☐ Hospital admission and emergency treatment
- 9.4 How many times in your life did you received any of the above treatments (# 9.3 a-l)? ☐ 1 - 2 ☐ 3 to 5 ☐ 6 to 10 ☐ more than 10
- 9.5 At what age did you first have symptoms? ☐ At menarche ☐ Between 14-25 years of age ☐ After 25 years of age
- 9.6 Have you had time off work/school for menorrhagia? ☐ < twice a year ☐ > twice a year
- 9.7 Duration of menorrhagia ☐ Since menarche ☐ > 12 months ☐ < 12 months
- 9.8 Have you had acute menorrhagia requiring emergency treatment/hospital admission ☐ Yes ☐ No How many times: _____

**10. Post-partum hemorrhage**

- 10.1 Number of successful pregnancies (live births)
- 10.2 Have you ever had post-partum haemorrhage? ☐ Yes ☐ No or trivial skip to 11
- 10.3 Did it occur ☐ In the first 24 hours after delivery (Primary)
☐ Between 24 hours and 6 weeks postpartum (Secondary)
☐ Both Primary and Secondary
- 10.4 How long did vaginal discharge (lochia) last? ☐ < 6 weeks
☐ > 6 weeks
- 10.5 Did it require changing pads/tampons more frequently than every 2 hours? ☐ Yes ☐ No
- 10.6 Did this bleeding cause delay of hospital discharge/ readmission to hospital? ☐ Yes ☐ No
- 10.7 Have the symptom ever required medical treatment? ☐ Yes ☐ No
- 10.8 If answer to 10.7 is yes, please specify ☐ Consultation only /oxytocin i.v. infusion
☐ Additional uterotonic medications
☐ Iron therapy
☐ Antifibrinolytic therapy
☐ Treatment with desmopressin
☐ Treatment with plasma
☐ Treatment with platelet concentrate
☐ Treatment with factor concentrates
☐ Blood (RBC) transfusion
☐ Any procedure requiring examination under anaesthesia
☐ Uterine balloon/package to tamponade the uterus
☐ Any procedure requiring critical care or surgical intervention (includes: hysterectomy, internal iliac artery ligation, uterine artery embolization, uterine brace sutures)
- 10.9 Number of deliveries that required any of the above treatments (# 10.8)?

**11. Muscle hematomas (spontaneous)**

- 11.1 Have you ever had muscle hematomas? ☐ Yes ☐ No or trivial skip to 12
- If yes, was it spontaneous or after trauma? ☐ Yes, spontaneous ☐ No, trauma-related
- 11.2 Have the symptom ever required medical attention ? ☐ Yes ☐ No skip to 11.6
- 11.3 If answer to 11.2 is yes, please specify
- ☐ Consultation only
 - ☐ Surgical draining
 - ☐ Treatment with desmopressin
 - ☐ Treatment with plasma
 - ☐ Treatment with platelet concentrate
 - ☐ Treatment with factor concentrates
 - ☐ Blood transfusion
- 11.4 How many times in your life did you receive any of the above treatments (# 11.3)?
- ☐ 1 - 2
 - ☐ 3 to 5
 - ☐ 6 to 10
 - ☐ more than 10
- 11.5 At what age did you first have symptoms?
- ☐ Before 1 year
 - ☐ Between 1-5 years of age
 - ☐ Between 6-12 years of age
 - ☐ Between 13-25 years of age
 - ☐ After 25 years of age
- 11.6 Approximate number of episodes NOT requiring medical attention
- ☐ less than 1 per year
 - ☐ 1 per year
 - ☐ 1-5 every six month
 - ☐ 1-3 every month
 - ☐ 1 every week

**12. Hemarthrosis**

- 12.1 Have you ever had hemarthrosis ? ☐ Yes ☐ No or trivial skip to 13
- If yes, was it spontaneous or after trauma? ☐ Yes, spontaneous ☐ No, trauma-related
- 12.2 Have the symptom ever required medical attention ? ☐ Yes ☐ No skip to 12.6
- 12.3 If answer to 12.2 is yes, please specify
- ☐ Consultation only
- ☐ Surgical draining
- ☐ Treatment with desmopressin
- ☐ Treatment with plasma
- ☐ Treatment with platelet concentrate
- ☐ Treatment with factor concentrates
- ☐ Blood transfusion
- 12.4 How many times in your life did you receive any of the above treatments (# 11.3)?
- ☐ 1 - 2
- ☐ 3 to 5
- ☐ 6 to 10
- ☐ more than 10
- 12.5 At what age did you first have symptoms?
- ☐ Before 1 year
- ☐ Between 1-5 years of age
- ☐ Between 6-12 years of age
- ☐ Between 13-25 years of age
- ☐ After 25 years of age
- 12.6 Approximate number of episodes NOT requiring medical attention
- ☐ less than 1 per year
- ☐ 1 per year
- ☐ 1-5 every six month
- ☐ 1-3 every month
- ☐ 1 every week



13. CNS bleeding (spontaneous)

- 13.1 Have you ever had cranial or spinal bleeding? ☐ Yes ☐ No or trivial skip to 14
- If yes, was it spontaneous or after trauma? ☐ Yes, spontaneous ☐ No, trauma-related
- 13.2 If answer to 13.1 is yes, please specify
- Type of bleeding ☐ Subdural
☐ Intracerebral
☐ Subarachnoid
- Was the diagnosis made by ☐ CT scan
☐ MRI
☐ Angiography
- 13.3 Type of treatment
- ☐ Consultation
- ☐ Surgical draining
- ☐ Treatment with plasma, platelet or factor concentrates
- 13.4 At what age did you have CNS bleeding?
- ☐ Before 1 year
☐ Between 1-5 years of age
☐ Between 6-12 years of age
☐ Between 13-25 years of age
☐ After 25 years of age



14 Other bleedings

14.1 Have you ever had one of the following?

Excessive umbilical stump bleeding ☐ Yes ☐ No

Cephalohematoma ☐ Yes ☐ No

Bleeding at circumcision ☐ Yes ☐ No

Venipuncture bleeding ☐ Yes ☐ No

Suction Bleeding ☐ Yes ☐ No

Ovulation bleeding(in women) ☐ Yes ☐ No

14.2 Have one of these symptoms ever required medical attention? ☐ Yes ☐ No

14.3 If answer to 12.2 is yes, please specify ☐ Consultation only
☐ Antifibrinolytics
☐ Surgery
☐ Treatment with desmopressin
☐ Treatment with plasma
☐ Treatment with platelet concentrate
☐ Treatment with factor concentrates
☐ Blood (RBC) transfusion

14.4 How many times in your life did you receive any of the above treatments (# 12.3) for this symptom?
☐ 1 - 2
☐ 3 to 5
☐ 6 to 10
☐ more than 10

Table 1. Bleeding score

SYMPTOMS (up to the time of diagnosis)	SCORE				
	0 ^s	1 ^s	2	3	4
Epistaxis	No/trivial	- > 5/year or - more than 10 minutes	Consultation only*	Packing or cauterization or antifibrinolytic	Blood transfusion or replacement therapy (use of hemostatic blood components and rFVIIa) or desmopressin
Cutaneous	No/trivial	For bruises 5 or more (> 1cm) in exposed areas	Consultation only*	Extensive	Spontaneous hematoma requiring blood transfusion
Bleeding from minor wounds	No/trivial	- > 5/year or - more than 10 minutes	Consultation only*	Surgical hemostasis	Blood transfusion, replacement therapy, or desmopressin
Oral cavity	No/trivial	Present	Consultation only*	Surgical hemostasis or antifibrinolytic	Blood transfusion, replacement therapy or desmopressin
GI bleeding	No/trivial	Present (not associated with ulcer, portal hypertension, hemorrhoids, angiodysplasia)	Consultation only*	Surgical hemostasis, antifibrinolytic	Blood transfusion, replacement therapy or desmopressin



Hematuria	No/trivial	Present (macroscopic)	Consultation only*	Surgical hemostasis, iron therapy	Blood transfusion, replacement therapy or desmopressin
Tooth extraction	No/trivial or none done	Reported in $\leq 25\%$ of all procedures, no intervention**	Reported in $>25\%$ of all procedures, no intervention**	Resuturing or packing	Blood transfusion, replacement therapy or desmopressin
Surgery	No/trivial or none done	Reported in $\leq 25\%$ of all procedures, no intervention**	Reported in $>25\%$ of all procedures, no intervention**	Surgical hemostasis or antifibrinolytic	Blood transfusion, replacement therapy or desmopressin
Menorrhagia	No/trivial	Consultation only* or - Changing pads more frequently than every 2 hours or - Clot and flooding or - PBAC score $>100^{\#}$	- Time off work/school $> 2/\text{year}$ or - Requiring antifibrinolytics or hormonal or iron therapy	- Requiring combined treatment with antifibrinolytics and hormonal therapy or - Present since menarche and > 12 months	- Acute menorrhagia requiring hospital admission and emergency treatment or - Requiring blood transfusion, Replacement therapy, Desmopressin, or - Requiring dilatation & curettage or endometrial ablation or hysterectomy)
Post-partum hemorrhage	No/trivial or no deliveries	Consultation only* or - Use of syntocin or - Lochia > 6 weeks	- Iron therapy or - Antifibrinolytics	- Requiring blood transfusion, replacement therapy, desmopressin or - Requiring examination under anaesthesia and/or the use of uterin balloon/package to tamponade the uterus	- Any procedure requiring critical care or surgical intervention (e.g. hysterectomy, internal iliac artery legation, uterine artery embolization, uterine brace sutures)
Muscle hematomas	Never	Post trauma, no therapy	Spontaneous, no therapy	Spontaneous or traumatic, requiring desmopressin or replacement therapy	Spontaneous or traumatic, requiring surgical intervention or blood transfusion



Hemarthrosis	Never	Post trauma, no therapy	Spontaneous, no therapy	Spontaneous or traumatic, requiring desmopressin or replacement therapy	Spontaneous or traumatic, requiring surgical intervention or blood transfusion
CNS bleeding	Never	-	-	Subdural, any intervention	Intracerebral, any intervention
Other bleedings [^]	No/trivial	Present	Consultation only*	Surgical hemostasis, antifibrinolytics	Blood transfusion or replacement therapy or desmopressin

In addition to the guidance offered by the table, it is mandatory to refer to the text for more detailed instructions.

[§] Distinction between 0 and 1 is of critical importance. Score 1 means that the symptom is judged as present in the patient's history by the interviewer but does not qualify for a score 2 or more

* Consultation only: the patient sought medical evaluation and was either referred to a specialist or offered detailed laboratory investigation

** Example: 1 extraction/surgery resulting in bleeding (100%): the score to be assigned is 2; 2 extractions/surgeries, 1 resulting in bleeding (50%): the score to be assigned is 2; 3 extractions/surgeries, 1 resulting in bleeding (33%): the score to be assigned is 2; 4 extractions/surgeries, 1 resulting in bleeding (25%): the score to be assigned is 1

[#] If already available at the time of collection

[^] Include: umbilical stump bleeding, cephalohematoma, cheek hematoma caused by sucking during breast/bottle feeding, conjunctival hemorrhage or excessive bleeding following circumcision or venipuncture. Their presence in infancy requires detailed investigation independently from the overall score



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