

Supplement Table 1: Skewness and number of extreme outliers in metric variables at baseline and in changes at follow-up, n = 36 to 335

Parameter	Baseline			Changes from baseline to follow-up		
	n	Skewness	Number of extreme outliers [#]	n	Skewness	Number of extreme outliers [#]
Overall well-being, KINDL-AB	335	-0.504	0	109	-0.010	0
Physical well-being, KINDL-AB	335	-0.062	0	113	-0.324	0
Psychological well-being, KINDL-AB	335	-0.699	0	117	0.019	0
Family-related well-being, KINDL-AB	304	-1.386	0	99	-0.408	0
Friend-related well-being, KINDL-AB	321	-0.995	5	108	-0.173	1
Education / work-related well-being, KINDL-AB	227	-1.182	0	60	-1.808	2
EQ-IV	241	-1.693	0	90	0.025	3
EQ-VAS	248	-0.959	0	96	-0.247	1
SF-36, Physical functioning	136	-0.952	0	38	0.839	2
SF-36, Physical role functioning	133	-0.525	0	36	0.201	0
SF-36, Bodily pain	135	-0.246	0	37	-0.013	0
SF-36, General health perceptions	134	-0.199	0	38	0.037	0

SF-36, Vitality	136	-0.460	0	38	-0.069	0
SF-36, Social role functioning	134	-1.066	0	36	0.033	0
SF-36, Emotional role functioning	132	-0.956	0	36	0.604	0
SF-36, Mental health	136	-0.692	0	38	0.194	0

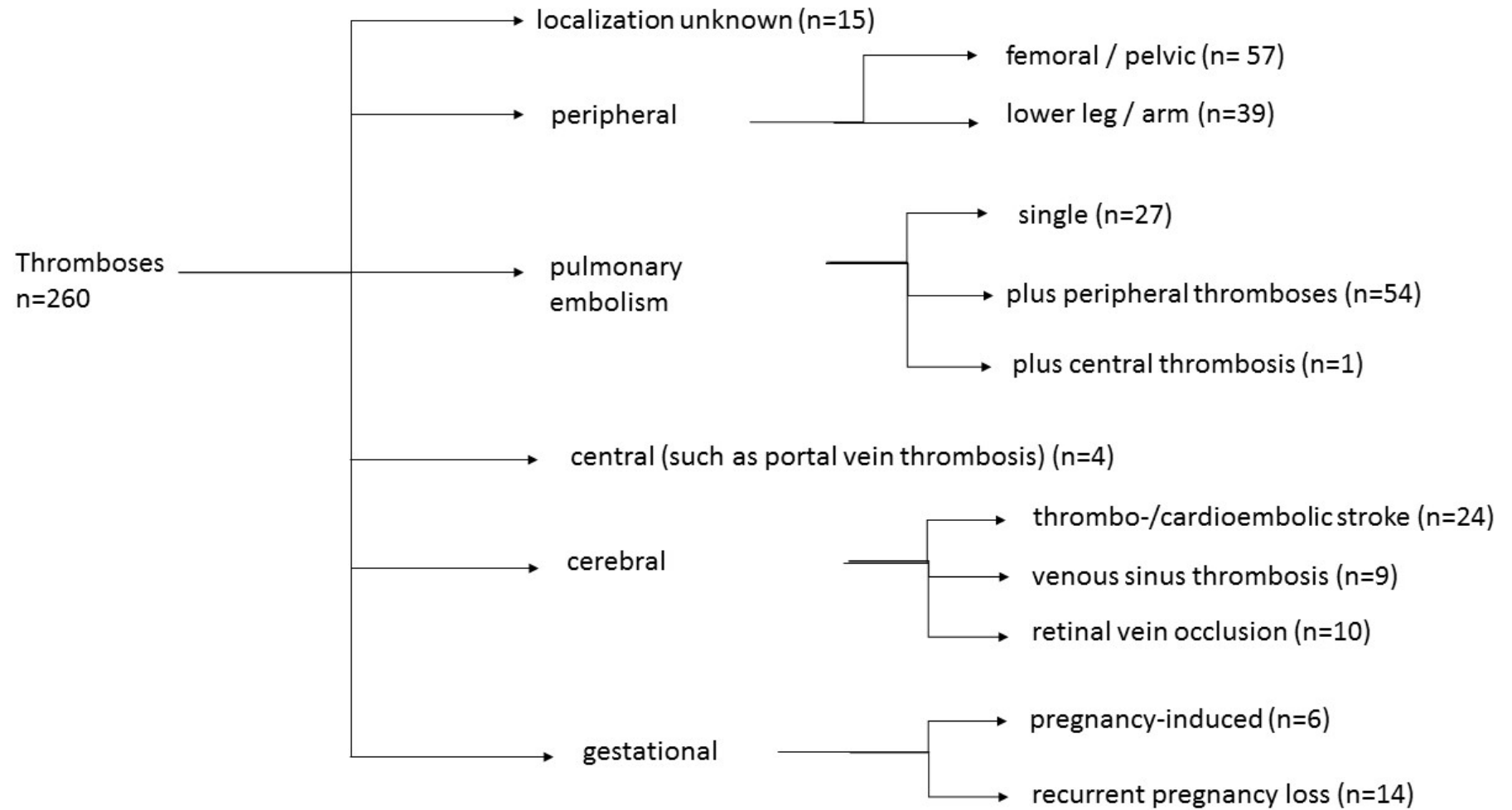
KINDL-AB = adult brief version of the revised KINDL questionnaire; EQ-IV = EQ-5D-3L Index value of the EQ-5D-3L questionnaire; EQ-VAS = EQ-5D visual analogue scale; SF-36 = Short Form (36) Health Survey; # = values more than 3 times the inter-quartile range (IQR) distant from the median.

Supplement Table 2: Response (n and % of all eligible) in association with socio-economic status variables, n=329 – 332 eligible

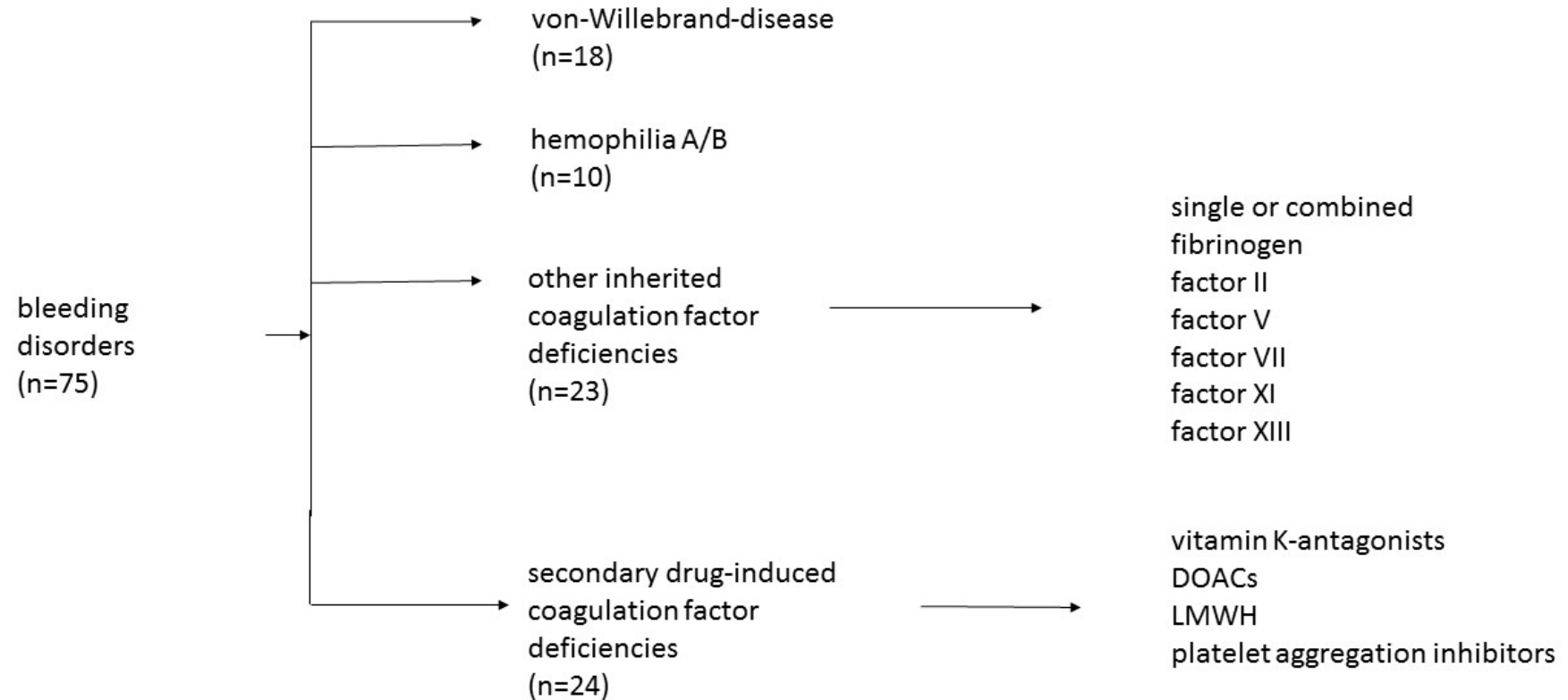
KINDL-AB item	Socio-economic status variable of all eligible		
	working (half- or fulltime) (n=177)	housewife or house husband, non-working, temporarily laid off OR unemployed, mini-job, (one-euro) community jobs, voluntary service (n=61)	retired / retired + mini job (n=94)
11: During the past week ... Doing the duties at school / in education / at the job was easy. (n=332 eligible)	165 (93.2%)	34 (55.7%)	28 (29.8%)
12: During the past week ... I found school / education / job interesting. (n=332 eligible)	165 (93.2%)	35 (57.4%)	25 (26.6%)
	Married, living with the partner (n=233)	Divorced, married but living separate, widowed (n=26)	Single (n=69)
7: During the past weeks ... I got on well with my partner. (n=328 eligible)	233 (100%)	19 (73.1%)	46 (66.7%)
8: During the past week ... I felt fine at home. (n=328 eligible)	233 (100%)	22 (84.6%)	52 (75.4%)

KINDL-AB = adult brief version of the revised KINDL questionnaire.

Supplement Figure 1: Diagnoses of patients with thrombophilia, n = 260



Supplement Figure 2: Diagnoses of patients with hereditary and acquired bleeding disorders, n = 75



DOAC = directly acting oral anticoagulants; LMWH = Low-molecular-weight heparin.

Supplement 3: KINDL-AB questionnaire, preliminary version, not yet validated in English

1. First of all, we would like to know something about your physical health...

<u>During the past week...</u>	never	seldom	some-times	often	all the time
1. ... I felt ill					
2. ... I was tired and worn-out					
3. ... I felt strong and full of energy					

2. ... then something about how you've been feeling ...

<u>During the past week...</u>	never	seldom	some-times	often	all the time
1. ... I had fun and laughed a lot					
2. ... I felt scared or unsure of myself					
3. ... I felt on top of the world					

3. The next questions are about your partner

<u>During the past week...</u>	never	seldom	some-times	often	all the time
1. ... I got on well with my partner					
2. ... I felt fine at home					

4. ... and then about your friends.

<u>During the past week...</u>	never	seldom	some-times	often	all the time
1. ... I was a "success" with my friends					
2. ... I got along well with my friends					

13. Last of all, we would like to know something about school / training / occupation

<u>During the past week...</u>	never	seldom	some-times	often	all the time
1. ... I mastered the duties at school / training / occupation					
2. ... I found school / training / occupation interesting					