Birmingham EB Severity Score Sheet (Adult)

Patient's name	DOB	Type of EB
Scorer's name		Date

^{*}See overleaf for detailed instructions

Score item	Measure	Max	Actual score
*Nails	Lost nails ÷ 4 Dystrophic nails ÷ 8	5	
*Area	½ x % damaged skin: blisters,erosions,scabs, healing skin,erythema,atrophic scarring; not dyspigmentation, or well-healed scars.	50	
*Mouth	0 = no mucosal involvement 1 = occasional blisters/erosions	5	
*Eyes	2 = frequent blisters 3 = persistent symptoms, early structural	5	
*Larynx	abnormality 4 = Moderate structural abnormality	5	
*Esophagus	5 = severe structural abnormality (see over for detailed scoring for each site)	5	
Scarring of hands	0 = no scarring 1 = Milia and atrophic scars 2 = Just detectable contractures or webbing 3 = obvious contractures, or proximal webbing 4 = Between 3 and 5 5 = Mitten formation with fingers all fused	5	
Skin Cancer (SCC)	Number of skin cancers +1 for local/regional/lymph node spread +2 for distant metastatic spread, up to maximum score 5	5	
Chronic wounds present for > 6/12	0 = none 1 = <1% body surface area (1% = palm size) 2 = 1-2% 3 = 2-5% 4 = 5-10% 5 = >10%	5	
Alopecia due to EB	0 = no alopecia from EB 1 = 1-19% scalp involvement 2 = 20-39% 3 = 40-59%, 4 = 60-79% 5 = 80-100%	5	
Nutritional compromise	0-5 (where 0 = normal and 5 = cachetic)	5	
TOTAL SCORE		100	

How to fill in the BEBS score sheet

Nails: enter number in each box and add up horizontally

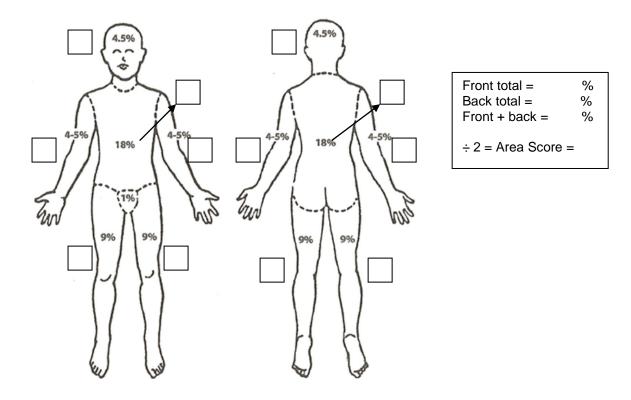
	R hand	L hand	R foot	L foot	Subtotals A	Subtotals B	Total score
lost nails	+	+	+	+	=	÷ 4 =	l
dystrophic nails	+	+	+	+	=	÷8=	/=
normal nails							
total	5	5	5	5			

Area:

Please shade in affected areas on the diagram, then work out percentage for each part and fill in the numbers in the adjacent boxes.

eg if half of the anterior trunk is affected, then put 9% in the box on anterior trunk.

Patient's palm size area corresponds to 1% of total body surface area



Mouth, Eyes, Larynx, Esophagus: detailed scoring

	Mouth	Eyes	Larynx	Esophagus
0	No problem from EB	No problem from EB	No problem from EB	No problem from EB
1	Occasional soreness	Occasional soreness	Occasional hoarseness	Occasional dysphagia
2	Frequent soreness	Frequent soreness	Frequent hoarseness	Frequent dysphagia
3	Persistent soreness Just detectable tongue tethering	Persistent soreness early visible external eye disease	Persistent hoarseness	Persistent dysphagia
4	Between 3-5	Between 3-5	Between 3-5	Between 3-5
5	Severe tongue tethering & microstomia	Bilateral sight- threatening eye disease	Life threatening laryngeal obstruction	Difficulty swallowing solids & liquid