Supplementary file 1: The SEEDS writing group

Agincourt HDSS, South Africa: Ryan Wagner, Rhian Twine, Myles Connor, F Xavier Gómez Olivé, Mark Collinson, Kathleen Kahn, Stephen Tollman; *Ifakara HDSS, Tanzania:* Honratio Masanja, Alexander Mathew (deceased); *Iganga-Mayuge HDSS, Uganda:* Angelina Kakooza, George Pariyo, Stefan Peterson, Donald Ndyomughenyi; *Kilifi HDSS, Kenya:* Fredrick Ibinda (deceased), Symon M Kariuki, Anthony K Ngugi, Rachael Odhiambo, Eddie Chengo, Martin Chabi, Evasius Bauni, Gathoni Kamuyu, Victor Mung'ala Odera (deceased), James O Mageto, Charles R Newton; *Kintampo HDSS, Ghana:* Ken Ae-Ngibise, Bright Akpalu, Albert Akpalu, Francis Agbokey, Patrick Adjei, Seth Owusu-Agyei; *London School of Hygiene and Tropical Medicine, UK:* Christian Bottomley, Immo Kleinschmidt; *King's College London, UK:* Victor C K Doku; *Swiss Tropical Institute, Switzerland:* Peter Odermatt; *University College London, UK:* Brian Neville (deceased), Josemir W Sander, Steve White; *National Institutes of Health, USA:* Thomas Nutman; *Centers for Disease Control and Prevention, USA:* Patricia Wilkins, John Noh.

Supplementary file 2: Factors investigated for an association with the epilepsy treatment gap in children and adults separately

Children	Adults
Age	Age
Sex	Sex
Mothers religious affiliation	Religion
Mothers marital status	Marital status
Mothers education level	Level of education
Mothers occupation	Occupation
Fathers education level	-
Fathers occupation	-
Mothers age at first birth	-
Sibling has seizures	Sibling has seizures
Snores more than three days per week	Snores more than three days per week
Place of birth (Home/hospital)	Place of birth (Home/hospital)
Presence of burn marks	Presence of burn marks
Sought traditional medicine	Sought traditional medicine
Previous hospitalisation	Previous hospitalisation
Learning difficulties	Learning difficulties
Neurological deficits	Neurological deficits
Frequent seizures	Frequent seizures
Focal seizures	Focal seizures
Status epilepticus	Status epilepticus

Supplementary file 3: Comparison of the characteristics of the people with epilepsy who gave versus those who did not give blood.

Characteristics	Sample assayed n=1303	Sample not assayed n=888	Univariate analysis		Multivariable analysis*	
			Odds ratio (95%CI)	p-vale	Odds ratio (95%CI)	p-vale
Sex: female	672 (51.6%)	454 (51.1%)	1.02 (0.86-1.21)	0.84	-	-
Sibling has seizures						
No	1156 (88.7%)	811 (91.3%)	1		1.12 (0.77-1.64)	
Yes	147 (11.3%)	77 (8.7%)	1.34 (0.99-1.81)	0.05	1	0.56
Snores more than three nights a week						
No	562 (45.4%)	415 (49.5%)	1		1	
Yes	677 (54.6%)	424 (50.5%)	1.18 (0.99-1.41)	0.07	1.04 (0.82-1.35)	0.68
Place of birth: home						
No	400 (31.5%)	365 (43.3%)	1		1	
Yes	869 (68.5%)	477 (56.7%)	1.66 (1.38-2.00)	<0.001	1.15 (0.88-1.55)	0.35
Burn marks						
No	1064 (81.8%)	776 (87.4%)	1		1	
Yes	236 (18.2%)	112 (12.6%)	1.54 (1.20-1.98)	<0.001	1.17 (0.84-1.66)	0.36
Sought traditional medicine						
No	305 (25.4%)	258 (33.0%)	1		1	
Yes	896 (74.6%)	525 (67.0%)	1.44 (1.18-1.77)	<0.001	1.06 (0.79-1.43)	0.71
Previous hospitalisation						
No	725 (56.0%)	512 (58.0%)	1			
Yes	569 (44.0%)	370 (42.0%)	1.09 (0.91-1.30)	0.35	-	-
Learning difficulties						
No	996 (76.7%)	691 (77.8%)	1		-	-
Yes	303 (23.3%)	197 (22.2%)	1.06 (0.86-1.32)	0.94		
Neurological deficits						
No	1123 (86.4%)	745 (83.9%)	1			
Yes	177 (13.6%)	143 (16.1%)	0.82 (0.64-1.05)	0.11	**0.70 (0.50-0.98)**	**0.03**
Frequent seizures						
No	571 (67.0%)	329 (62.9%)	1			
Yes	281 (33.0%)	194 (37.1%)	0.83 (0.66-1.06)	0.12	0.84 (0.65-1.09)	0.22
Focal seizures						
No	667 (51.2%)	543 (61.1%)	1			
Yes	636 (48.8%)	345 (38.9%)	1.50 (1.26-1.79)	<0.001	**1.38 (1.07-1.75)**	**0.02**
Status epilepticus						
No	905 (76.1%)	525 (73.9%)	1			
Yes	284 (23.9%)	185 (26.1%)	0.89 (0.72-1.11)	0.29		

*Multivariable analysis is adjusted for being a child.

Supplementary file 4: Characteristics of the study participants: children

Characteristics	Agincourt n=47	Ifakara n=131	Iganga-Maguye n=75	Kintampo n=88	All five sites combined n=570	p value‡
Childs age (median (IQR)	12.0 (7.0-14.5)	11.6 (7.3-15.0)	7.0 (5.0-12.0)	13.0 (10.8-15.0)	11.0 (7.0-14.8)	<0.001
Sex : Female	27 (57.4%)	64 (48.9%)	39 (52.0%)	51 (58.0%)	305 (53.5.0%)	0.69
Mothers marital status						
Married	18 (38.3%)	99 (75.6%)	66 (88.0%)	70 (79.5%)	440 (77.2%)	
Single/separated/divorced/windowed	29 (61.7%)	32 (24.4%)	9 (12.0%)	18 (20.5%)	130 (22.8%)	<0.001
Mothers education level						
Post primary	19 (57.6%)	1(1.4%)	14 (37.8%)	14 (66.7%)	207 (79.6%)	
≤ Primary school	14 (42.4%)	72 (98.6%)	23 (62.2%)	7 (33.3%)	53 (20.4%)	<0.001*
Mother's religious affiliation						
Christianity	12 (100%)	94 (76.4%)	32 (42.7%)	48 (69.6%)	330 (67.3%)	
Islam	0	29 (23.6%)	43 (57.3%)	21 (30.4%)	126 (25.7%)	
Traditionalist	0	0	0	0	34 (6.9%)	<0.001*
Mother's occupation						
Employed	2 (28.6%)	2 (2.2%)	7 (31.8%)	3 (4.8%)	38 (12.5%)	
Unemployed	5 (71.4%)	89 (97.8%)	15 (68.2%)	59 (95.2%)	265 (87.5%)	<0.001*
Father's education level						
≤ Primary school level	13 (50.0%)	69 (97.2%)	23 (76.7%)	10 (26.3%)	224 (71.1%)	
Post primary	13 (50.0%)	2 (2.8%)	7 (23.3%)	28 (73.7%)	91 (28.9%)	<0.001
Father's occupation						
Employed	9 (64.3%)	6 (8.1%)	16 (47.1%)	4 (6.0%)	98 (28.7%)	
Unemployed	5 (35.7%)	68 (91.9%)	18 (52.9%)	63 (94.0%)	243(71.3%)	<0.001*
Mothers age at first birth						
< 18 years	11 (28.2%)	26 (32.9%)	25 (52.1%)	41 (52.6%)	169 (41.4%)	
≥ 18 years	28 (71.8%)	53 (67.1%)	23 (47.9%)	37 (47.4%)	239 (58.6%)	0.02
Sibling has seizures						
Yes	43 (91.5%)	123 (93.9%)	64 (85.3%)	65 (73.9%)	506 (88.8%)	
No	4 (8.5%)	8 (6.1%)	11(14.7%)	23 (26.1%)	64 (11.2%)	<0.001*
Place of birth: home						
Yes	12 (26.1%)	52(40.9%)	23 (30.7%)	73 (83.9%)	359 (63.8%)	
No	34 (73.9%)	75 (59.1%)	52 (69.3%)	14 (16.1%)	204 (36.2%)	<0.001
Burn marks						
Yes	1 (2.1%)	14 (10.7%)	1(1.3%)	8 (9.2%)	60 (10.5%)	
No	46 (97.9%)	117 (89.3%)	74 (98.7%)	79 (90.8%)	509 (89.5%)	0.001*
Sought traditional medicine						
Yes	20 (71.4%)	87(77.0%)	37 (52.1%)	63 (75.0%)	359 (69.0%)	
No	8 (28.6%)	26 (23.0%)	34 (47.9%)	21 (25.0%)	161 (31.0%)	0.006
Previous hospitalisation						

Yes	6 (13.0%)	68 (52.3%)	5 (6.7%)	36 (41.4%)	265 (46.8%)	
No	40 (87.0%)	62 (47.7%)	70 (93.7%)	51 (58.6%)	301 (53.2%)	<0.001
Learning difficulties						
Yes	7 (14.9%)	15 (11.5%)	10 (13.3%)	19 (21.8%)	108 (19.0%)	
No	40 (85.1%)	116 (88.5%)	65 (86.7%)	68 (78.2%)	461 (81.0%)	0.01
Neurological deficits						
Yes	4 (8.5%)	11 (8.4%)	10 (13.3%)	10 (11.5%)	75 (13.2%)	
No	43 (91.5%)	120 (91.6%)	65 (86.7%)	77 (88.5%)	494 (86.8%)	0.12
Frequent seizures						
No	44 (95.7%)	113 (86.3%)	65 (86.7%)	72 (81.8%)	486 (85.4%)	
Yes	2 (4.3%)	18 (13.7%)	10 (13.3%)	16 (18.2%)	83 (14.6%)	0.001
Focal seizures						
No	34 (72.3%)	85 (64.9%)	53 (70.7%)	63 (71.6%)	302 (53.0%)	
Yes	13 (27.7%)	46 (35.1%)	22 (29.3%)	25 (28.4%)	268 (47.0%)	0.04
Status epilepticus						
No	28 (65.1%)	97 (92.4%)	43 (59.7%)	71 (87.7%)	363 (69.4%)	
Yes	15 (34.9%)	8 (7.6%)	29 (40.3%)	10 (12.3%)	160 (30.6%)	0.39

‡ p values for differences in distribution of characteristics across the five sites; * implies that a Fishers exact test was performed.

Supplementary file 5: Characteristics of the study participants: adults

Characteristics	Agincourt n=110	Ifakara n=133	Iganga-Maguye n=38	Kintampo n=179	All five sites combined† n=733	p value‡
Age (years):median (IQR)	38.0 (27.0-47.0)	29.7 (23.2-40.5)	30.5 (22.0-43.0)	26.0 (21.0-34.0)	29.0 (23.0-40.0)	<0.001
Sex : Female	60 (54.5)	58 (43.6%)	20 (52.6)	98 (54.7)	367 (50.1%)	0.26
Religion						
Christianity	25 (100%)	100 (80.0%)	25 (71.4%)	115 (75.2%)	440 (75.2%)	
Islam	0	23 (18.4%)	10 (28.6%)	34 (22.2%)	95 (16.2%)	
Traditionalist	0	2 (1.6%)	0	4 (2.6%)	50 (8.5%)	<0.001*
Marital status						
Married	30 (27.3%)	53 (40.8%)	12 (34.3%)	44 (25.3%)	222 (31.6%)	
Single/separated/divorced/windowed	80 (72.7%)	77 (59.2%)	23 (65.7%)	130 (74.7%)	480 (68.4%)	0.05
Level of education						
≤ Primary school	49 (62.0%)	64 (97.0%)	12 (52.2%)	6 (5.8%)	255 (62.8%)	
Post primary	30 (38.0%)	2 (3.0%)	11 (47.8%)	98 (94.2%)	151 (37.2%)	<0.001
Occupation						
Employed	2 (66.7%)	0	2 (25.0%)	1 (1.4%)	20 (8.1%)	
Unemployed	1 (33.3%)	75 (100%)	6 (75.0%)	71 (98.6%)	227 (92.9%)	<0.001*
Sibling has seizures						
Yes	5 (4.5%)	20 (15.0%)	4 (10.5%)	37 (20.7%)	83 (11.3%)	
No	105 (95.5%)	113(85.0%)	34 (89.5%)	142 (79.3%)	650 (88.7%)	<0.001*
Place of birth: home						
Yes	52 (49.0%)	75 (64.1%)	14 (36.8%)	154 (87.5%)	510 (72.2%)	
No	50 (51.0%)	42 (35.9%)	24 (63.2%)	22 (12.5%)	196 (27.8%)	<0.001
Burn marks						
Yes	25 (22.7%)	28 (21.1%)	6 (15.8%)	38 (21.5%)	176 (24.1%)	
No	85 (77.3%)	105 (78.9%)	32 (84.2%)	139 (78.5%)	555 (75.9%)	0.17
Sought traditional medicine						
Yes	60 (67.7%)	100 (84.7%)	24 (63.2%)	141 (83.9%)	537 (78.9%)	
No	30 (33.3%)	18 (15.3%)	14 (36.8%)	27 (16.1%)	144 (21.1%)	0.001
Previous hospitalization						
Yes	25 (22.9%)	55 (41.7%)	5 (13.2%)	63 (35.2%)	304 (41.8%)	
No	84 (77.1%)	77 (58.3%)	33 (86.8%)	116 (64.8%)	424 (58.2%)	<0.001
Learning difficulties						
Yes	37 (33.6%)	15 (11.3%)	10 (26.3%)	54 (30.7%)	195 (26.7%)	
No	73 (66.4%)	118 (88.7%)	28 (73.7%)	122 (69.3%)	535 (73.3%)	<0.001
Neurological deficits						
Yes	25 (22.7%)	7 (5.3%)	9 (23.7%)	17 (9.6%)	102 (14.0%)	
No	85 (77.3%)	126 (94.7%)	29 (76.3%)	160 (90.4%)	629 (86.0%)	<0.001
Frequent seizures						
Yes	7 (6.4%)	14(10.5%)	3 (7.9%)	20 (11.2%)	78 (10.6)	

No	103 (93.6%)	119 (89.5%)	38 (92.1%)	159 (88.8%)	655 (89.4%)	0.51*
Focal seizures						
Yes	55 (50.0%)	40 (30.1%)	18 (47.4%)	69 (38.5%)	368 (50.2%)	
No	55 (50.0%)	93 (69.9%)	20 (52.6%)	110 (61.5%)	365 (49.8%)	<0.001
Status epilepticus						
Yes	21 (21.4%)	2 (2.1%)	17 (48.6%)	9 (5.3%)	21 (21.4%)	
No	77 (78.6%)	93 (97.9%)	18 (51.4%)	162 (94.7%)	77 (78.6%)	<0.001

‡ p values for differences in distribution of characteristics across the five sites; * implies that a Fishers exact test was performed.

Supplementary file 6: Cross classification of the reported AEDs and the detected AEDS among the PWE who reported taking AEDs

AED reported	AED detected						
	PB only	PH only	CB only	PB & PH	PB & CB	PH & CB	PB, PH & CB
Phenobarbital (PB) only	134	3	1	25	0	1	3
Phenytoin (PH) only	0	8	0	0	0	0	0
Carbamazepine (CB) only	2	1	8	0	0	4	0
PB & PH	22	6	0	24	2	1	1
PB & CB	10	1	6	0	7	0	7
PH & CB	0	0	0	0	0	1	0

Supplementary file 7: Magnitude of site specific non-adherence to AEDs
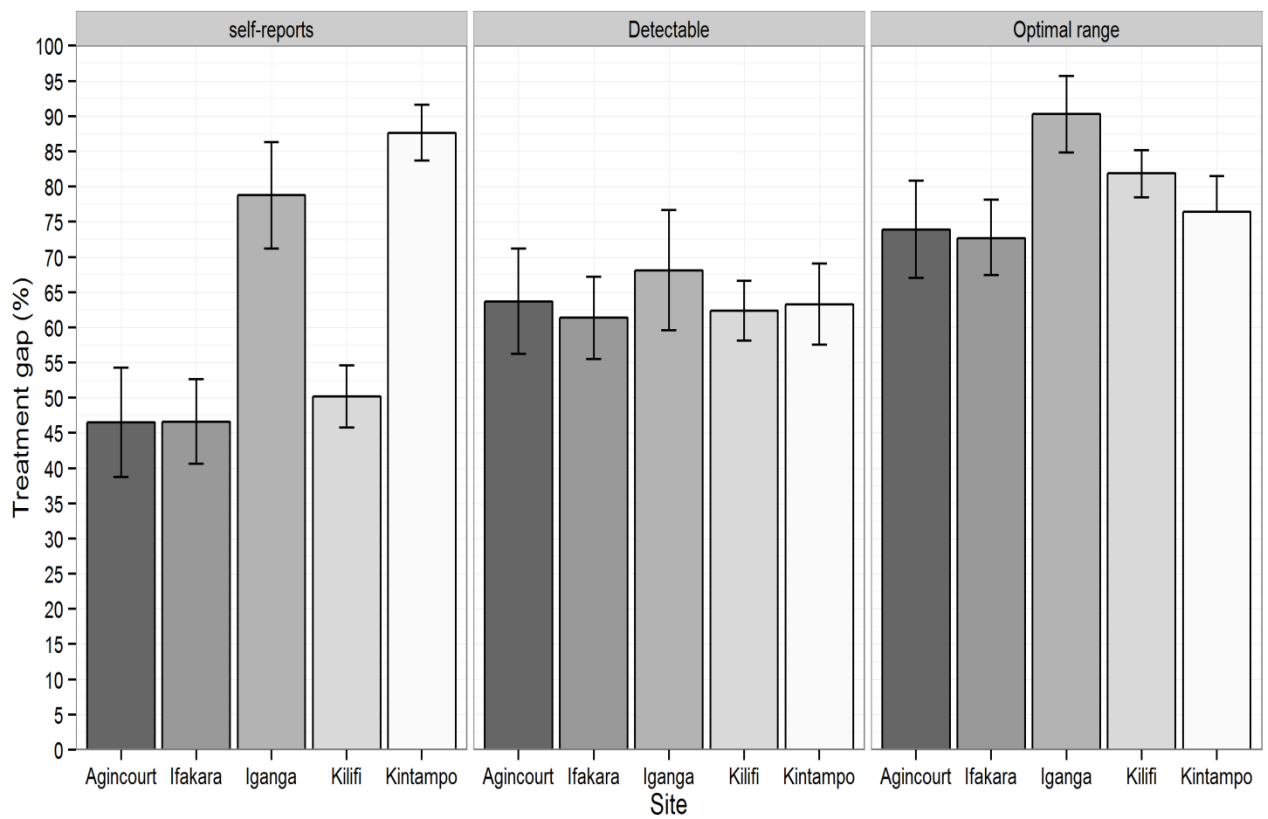
A graphical representation of the non-adherence to AEDs for each of the five sites based on self-reports, and as measured by detectable and optimal levels of anti-epileptic drugs in the blood.

Supplementary file 8: Magnitude of age specific non-adherence of AEDs
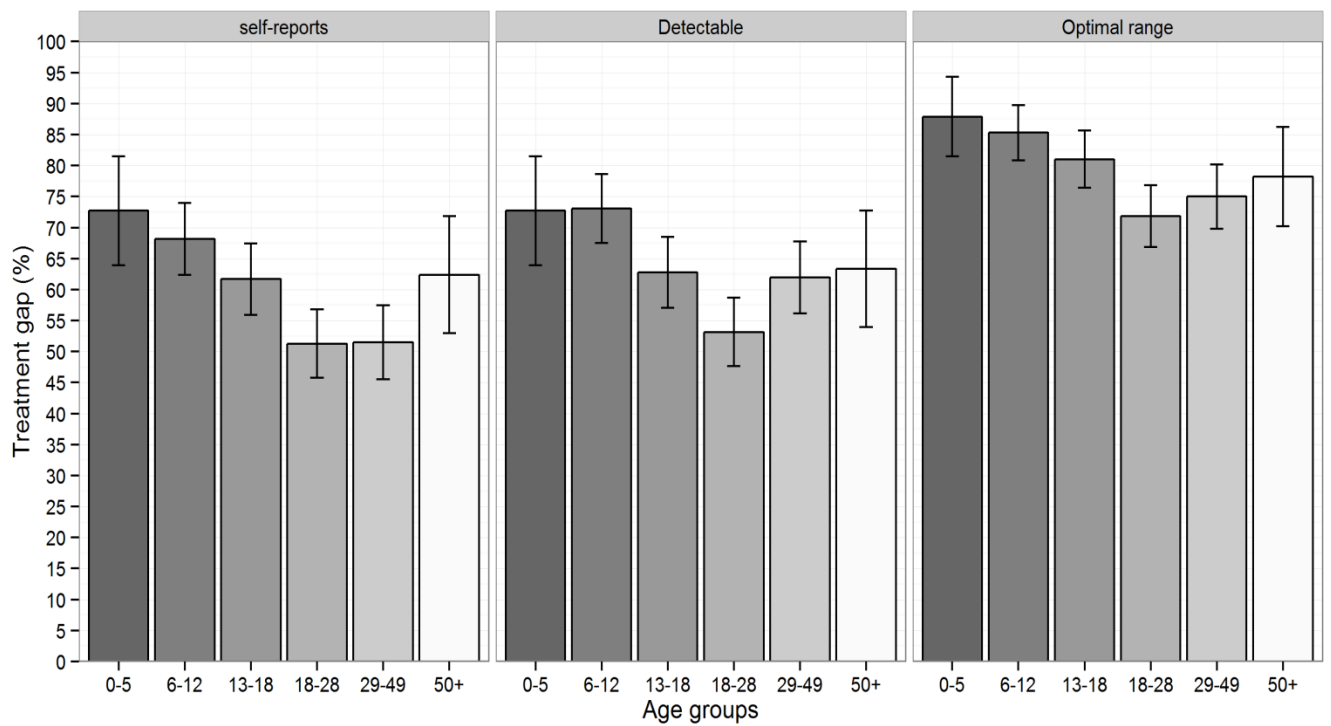
A graphical representation of the non-adherence to AEDs by age groups based on self-reports, and as measured by detectable and optimal levels of anti-epileptic drugs in the blood.

Supplementary file 9: Characteristics associated with being a child among people with epilepsy who did not have optimal levels of anti-epileptic drugs in blood.

Characteristics			Univariable analysis		Multivariable analysis	
	Children (n=484)	Adults (n=541)	Odds ratio (95% CI)	p value	Odds ratio (95% CI)	p value
Sex: female	262 (54%)	272 (50.3%)	1.23 (0.95-1.55)	0.12	1.06 (0.79-1.45)	0.62
Sibling has seizures						
No	432 (89.3%)	484 (89.5%)	1			
Yes	52 (10.7%)	57 (10.5%)	1.10 (0.75-1.62)	0.69	-	-
Place of birth: home						
No	174 (36.4%)	134 (25.7%)	1		1	
Yes	304 (63.6%)	388 (74.3%)	0.68 (0.49-0.92)	**0.01**	0.79 (0.55-1.09)	0.16
Burn marks						
No	436 (90.1%)	421 (78.1%)	1		1	
Yes	48 (9.9%)	118 (21.9%)	0.39 (0.27-0.57)	**<0.001**	**0.41 (0.28-0.63)**	**<0.001**
Sought traditional medicine						
No	140 (31.7%)	117 (23.3%)	1		1	
Yes	302 (68.3%)	385(76.7%)	0.68 (0.50-0.92)	**0.02**	0.75 (0.53-1.03)	0.08
Previous hospitalisation						
No	267 (55.5%)	320 (59.7%)	1			
Yes	214 (44.5%)	216 (40.3%)	1.25 (0.97-1.64)	**0.10**	-	-
Learning difficulties						
No	402 (83.1%)	400 (74.3%)	1		1	
Yes	82 (16.9%)	138 (25.7%)	0.59 (0.43-0.81)	<0.001	**0.63 (0.44-0.89)**	**0.01**
Neurological deficits						
No	420 (86.8%)	462 (85.7%)	1			
Yes	64 (13.2%)	77(14.3%)	0.92 (0.65-1.30)	0.62	-	-
Frequent seizures						
No	416(86.1%)	480 (88.7%)	1			
Yes	67(13.9%)	61 (11.3%)	1.25 (0.86-1.84)	0.24	1.26 (0.82-1.92)	0.26
Focal seizures						
No	259 (53.5%)	269 (49.7%)	1			
Yes	225 (46.5%)	272 (50.3%)	0.83 (0.63-1.10)	0.16	0.84 (0.61-1.12)	0.23
Status epilepticus						
No	304 (68.6%)	393 (80.2%)	1		1	
Yes	139(31.4%)	97 (19.8%)	1.82 (1.33-2.53)	<0.001	**1.98 (1.40-2.88)**	**<0.001**

*lack of previous hospitalisation was associated with lack of burn marks and was therefore not entered in the multivariable model. IQR = interquartile range; CI= confidence interval.