UK CF Registry
Annual Data Report 2009

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Preface

We are pleased to present the *Annual Data Report 2009*.

Since the introduction of the new web-based technology Port CF in 2007 there has been a steady increase in the proportion of registered patients for whom annual review data has been available; from 55% in 2007 to 82% in 2009. As the annual data reports are based solely on these data, higher reporting rates from as large and representative a sample of the patient population as possible allows us to be more confident in the validity and representativeness of our results.

The main objective of the Patient Registry is to drive up standards of clinical care throughout the UK. Broadly speaking, the findings are similar to those from the previous two years and are indicative of continuing high standards of care overall.

This year's report follows much the same format as last year's except we have incorporated rates of treatment for CF-related diabetes and details of patients who died in 2009. Another important change is the expansion of the centre-specific analyses. Now it is possible to identify individual centres and make comparisons between different models of care. We hope this will be helpful to both patients and clinicians. Comparisons must be made with caution, however, as centres differ in the number of patients they see and in the severity of their cases – factors which will influence, respectively, the variability in the data collected and any clinical outcomes.

This report encompasses all current models of delivering CF care. It refers to 'Centres' which comprise large multidisciplinary CF specialist teams, 'Networks' which reflect non-specialist CF services that provide local shared care in conjunction with the Centre, and finally 'Stand Alone' services that do not currently link in with any other CF service provider.

A notable feature in the summary table for 2009 is an increase in the number of reported deaths (141 in 2009 compared to 100 in 2008). This has translated into a slightly lower median predicted survival compared to 2008 although it is important to note that it is well within the confidence interval of the 2008 estimate. Detailed analyses over a longer time period would be required to determine whether this shift is a random fluctuation or not.

Benefitting from the detailed data compiled on Port CF, we have continually expanded our annual reports since 2007 to incorporate additional and detailed information on outcomes and services. It is anticipated that future reports will continue in this manner and, in particular, will incorporate trends over time where possible.

As always, we are appreciative of the hard work of those who participated in data collection/analysis: CF patients and their families who contributed information; care centre staff who diligently compile an ever-increasing amount of data; the CF Trust team who have the daunting task of managing the database and the biostatisticians at the National Heart and Lung Institute at Imperial College for providing the analysis and presenting the charts. The generosity and hard work of these groups have made this report possible, thus ensuring that those with CF, their carers and those seeking to expand our understanding of the disease have access to up-to-date and relevant information.

Dr Diana Bilton
Chair
CF Registry Steering Committee

Joanne Osmond
Director of Clinical Care
Cystic Fibrosis Trust

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Section 1: All UK Patients

1.1 Summary of the UK Cystic Fibrosis Registry

	2003	2004	2007	2008	2009
CF patients registered	6861	7046	8080[1]	8513[1]	9029[1]
CF patients with "complete" data; n(%)	4875 (71%)	5561 (79%)	4408[2] (55%)	6082[2] (71%)	7377[2] (82%)
Age in years; median	16	16	18[3]	18[3]	17[3]
Newly diagnosed patients	142	164	239[4]	235[4]	261[4]
Age at diagnosis in months; median	5	5	5[3]	4[3]	3[3,5]
Adults aged 16 yrs and over; %	50.8	51.4	56.7[3]	56.2[3]	55.1[3]
Males; %	53.8	53.4	53.9[3]	53.3[3]	53.1[3]
Genotyped; %	95	95	92.6[3]	93.7[3]	94.3[3]
Median predicted survival in years (95% Confidence interval)			35.2[6] (31.0, 42.6)	38.8[6] (34.2, 47.3)	34.4[6] (30.7, 37.0)
Total deaths reported	103	123	106	100	141
Age at death in years; median	24	26	24	27	27

Starting in 2007, data were entered on the newly established PortCF system. Definitions may not be consistent with previous years.

Notes:

[1] From 2007, this is calculated as the number of patients on the database who satisfied the following criteria:

- were born and diagnosed with CF prior to 1 January 2008/2009/2010; and
- had no recorded date of death before 1 January 2007/2008/2009

[2] "Complete" data refers to the minimum data required to produce the range of clinical outcomes presented in this report.

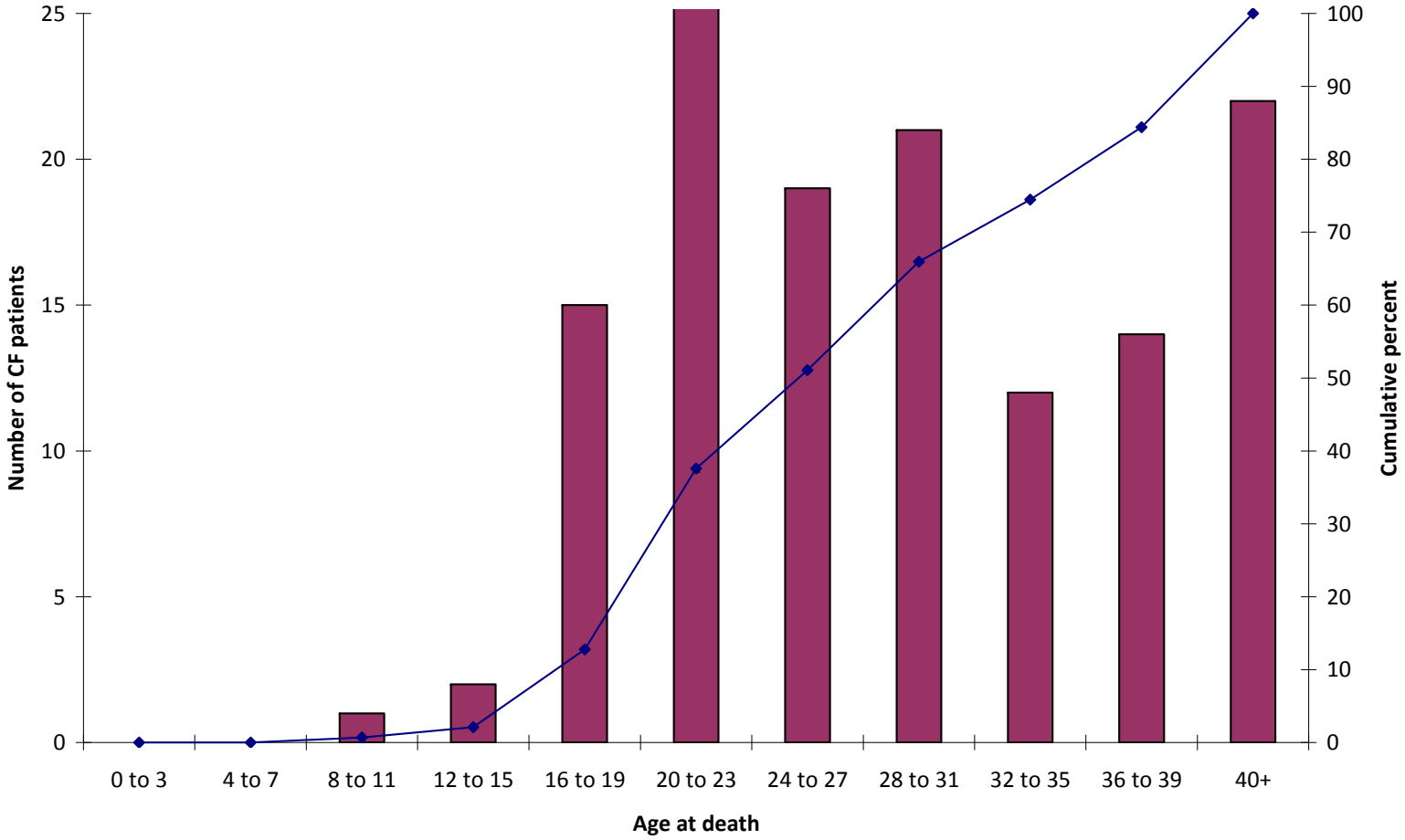
[3] Calculated for patients with "complete" data in that given year.

[4] Calculated for all patients registered.

[5] Five patients diagnosed prenatally had age at diagnosis set to 0 months.

[6] This represents the age beyond which half of the current UK CF Registry patients would be expected to live, given the ages of CF patients in the Registry and the mortality distribution of deaths in the same year.

1.2 Age distribution of deaths in 2009

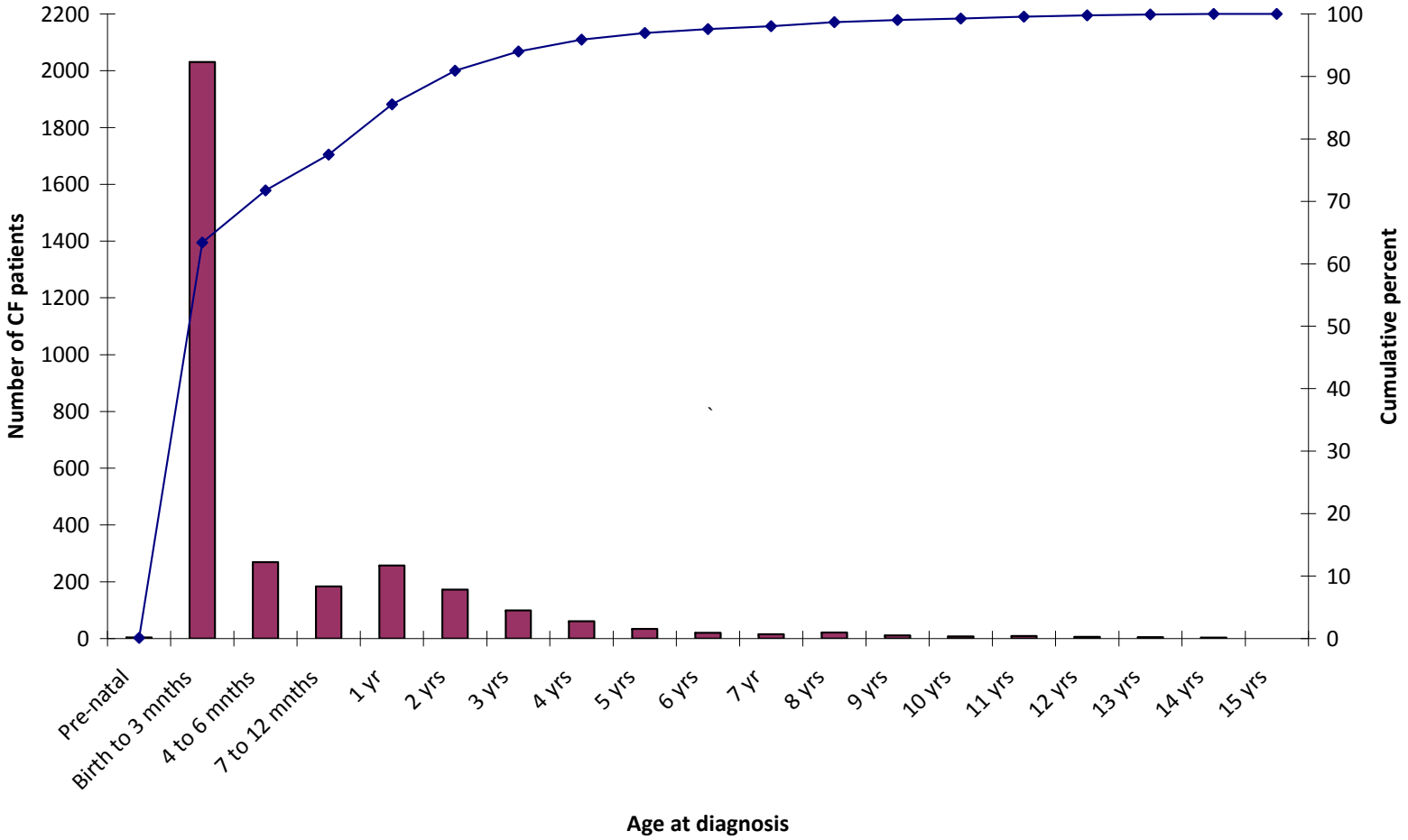


There were 141 recorded deaths in 2009. The median age at death was 27 years (min = 9 yrs; max = 82 years).

Analyses based on 7377 patients with complete* data at 2009 annual review

** "Complete" data refers to the minimum data required to produce the range of clinical outcomes presented in this report.*

1.3 Age at diagnosis and screening statistics among children



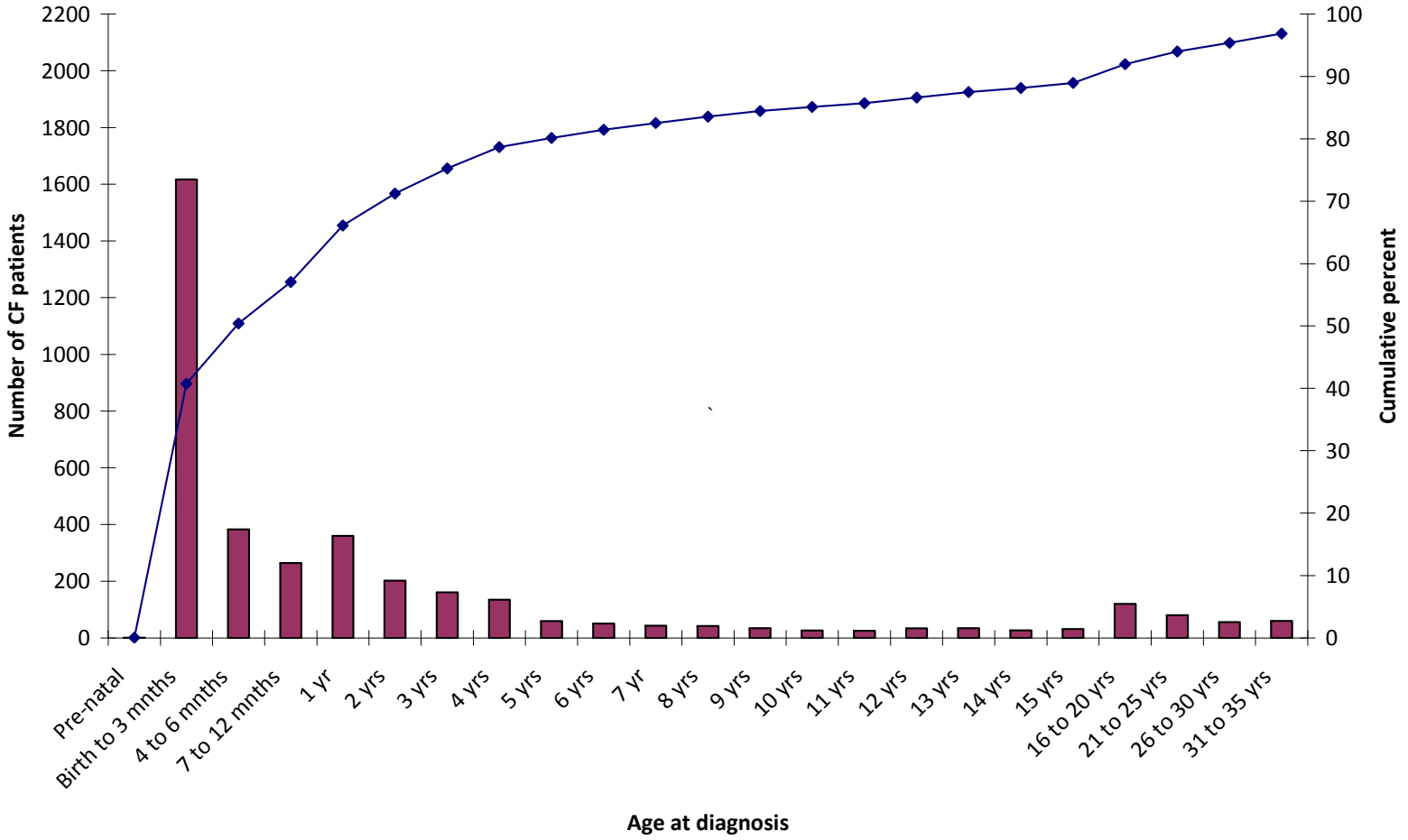
Date of diagnosis is available for 3210 of the 3312 children <16 years with annual review data. Four patients were diagnosed prenatally.

Age at diagnosis	**n(%)**
Pre-natal	4 (0.1)
Birth – 3 months	2031 (63.3)
4-6 months	269 (8.4)
7-12 months	184 (5.7)
1 yr	257 (8.0)
2 yrs	173 (5.4)
3 yrs	99 (3.1)
4 yrs	61 (1.9)
5 yrs	34 (1.1)
6 yrs	20 (0.6)
7 yrs	15 (0.5)
8 yrs	21 (0.7)
9 yrs	11 (0.3)
10 yrs	8 (0.3)
11 yrs	9 (0.3)
12 yrs	6 (0.2)
13 yrs	5 (0.2)
14 yrs	3 (0.1)
15 yrs	0

The median (range) age at diagnosis is 1 month (0-14 years).

Of the 92 children with complete data born in 2009, 71 were identified by neo-natal screening.

1.4 Age at diagnosis and screening statistics among adults



Date of diagnosis is available for 3970 of the 4065 adults aged 16 yrs + with annual review data. One patient was diagnosed prenatally.

Age at diagnosis	n(%)
Pre-natal	1 (0.03)
Birth-3 months	1617 (40.7)
4-6 months	383 (9.7)
7-12 months	264 (6.7)
1 yr	360 (9.1)
2 yrs	202 (5.1)
3 yrs	161 (4.1)
4 yrs	135 (3.4)
5 yrs	59 (1.5)
6 yrs	51 (1.3)
7 yrs	43 (1.1)
8 yrs	42 (1.1)
9 yrs	35 (0.9)
10 yrs	26 (0.7)
11 yrs	25 (0.6)
12 yrs	34 (0.9)
13 yrs	35 (0.9)
14 yrs	27 (0.7)
15 yrs	31 (0.8)
16 – 20 yrs	120 (3.0)
21 – 25 yrs	80 (2.0)
26 – 30 yrs	56 (1.4)
31 – 35 yrs	60 (1.5)
36 – 40 yrs	39 (1.0)
41 yrs +	84 (2.1)

The median (range) age at diagnosis is 6 months (0-80 years).

Of the 4065 adults with complete data in 2009, 280 were diagnosed by neonatal screening.

24 adults were diagnosed in 2009.

1.5 Genotyping

6959 (94.3%) patients have been genotyped with a recorded value

DF508 Mutations; n (%)

Homozygous DF508	3728 (53.6%)
Heterozygous DF508	2642 (38.0%)
No DF508 or both unidentified	589 (8.5%)

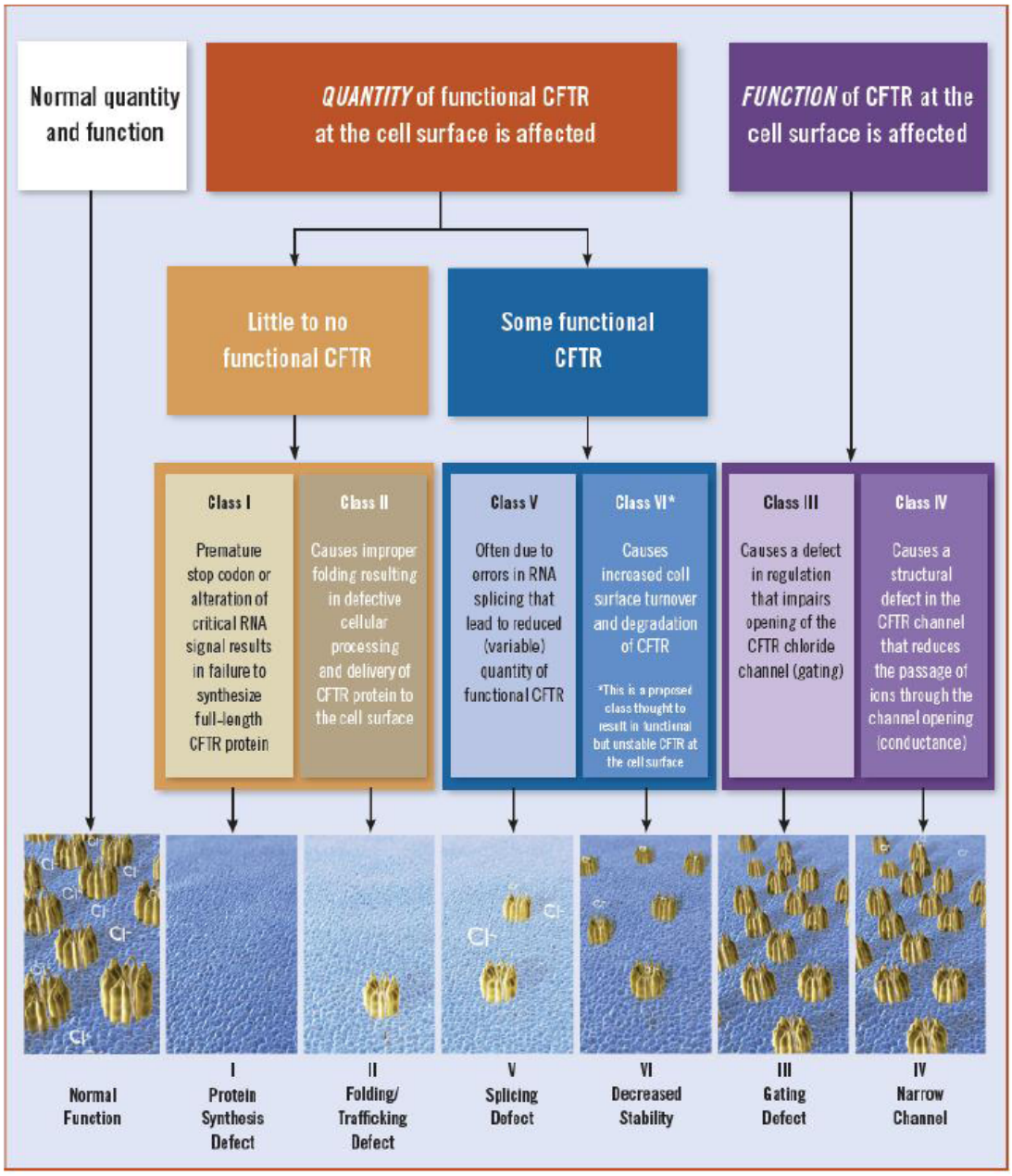
All mutations and their classes

All mutations

Current name	**New name**	**Class**	**N**	***(%)***
DF508	p.Phe508del	II	6370	*(91.5%)*
G551D	p.Gly551Asp	III	403	*(5.8%)*
R117H	p.Arg117His	IV	239	*(3.4%)*
G542X	p.Gly542X	I	230	*(3.3%)*
621+1G->T	c.489+1G>T	I	186	*(2.7%)*
N1303K	p.Asn1303Lys	II	94	*(1.4%)*
1898+1G->A	c.1766+1G>A	I	86	*(1.2%)*
1717-1G->A	c.1585-1G>A	I	85	*(1.2%)*
R560T	p.Arg560Thr	III	71	*(1.0%)*
DI507	p.Ile507del	II	70	*(1.0%)*
3659delC	c.3528delC	II	69	*(1.0%)*
R553X	p.Arg553X	I	59	*(0.9%)*
3849+10kbC->T	c.3717+10kbC>T	V	45	*(0.7%)*
E60X	p.Glu60X	I	44	*(0.6%)*
Q493X	p.Gln493X	I	43	*(0.6%)*
G85E	p.Gly85Glu	IV	42	*(0.6%)*
W1282X	p.Trp1282X	I	35	*(0.5%)*
1078delT	c.948delT	II	31	*(0.5%)*
2184delA	c.2052delA	II	27	*(0.4%)*
D1152H	p.Asp1152His	IV	24	*(0.3%)*
2789+5G->A	c.2657+5G>A	V	21	*(0.3%)*
V520F	p.Val520Phe	III	20	*(0.3%)*
R347P	p.Arg347Pro	IV	19	*(0.3%)*
R1162X	p.Arg1162X	I	16	*(0.2%)*
S549N	p.Ser549Asn	II	16	*(0.2%)*
A455E	p.Ala455Glu	V	14	*(0.2%)*
711+1G->T	c.579+1G>T	I	13	*(0.2%)*
R1158X	p.Arg1158X	I	10	*(0.1%)*
3120+1G->A	c.2988+1G>A	I	9	*(0.1%)*
R347H	p.Arg347His	IV	9	*(0.1%)*
R334W	p.Arg334Trp	IV	8	*(0.1%)*
1161delC	c.1029delC	I	6	*(0.1%)*
I148T	p.Ile148Thr	V	5	*(0.1%)*
L206W	p.Leu206Trp	unknown	5	*(0.1%)*

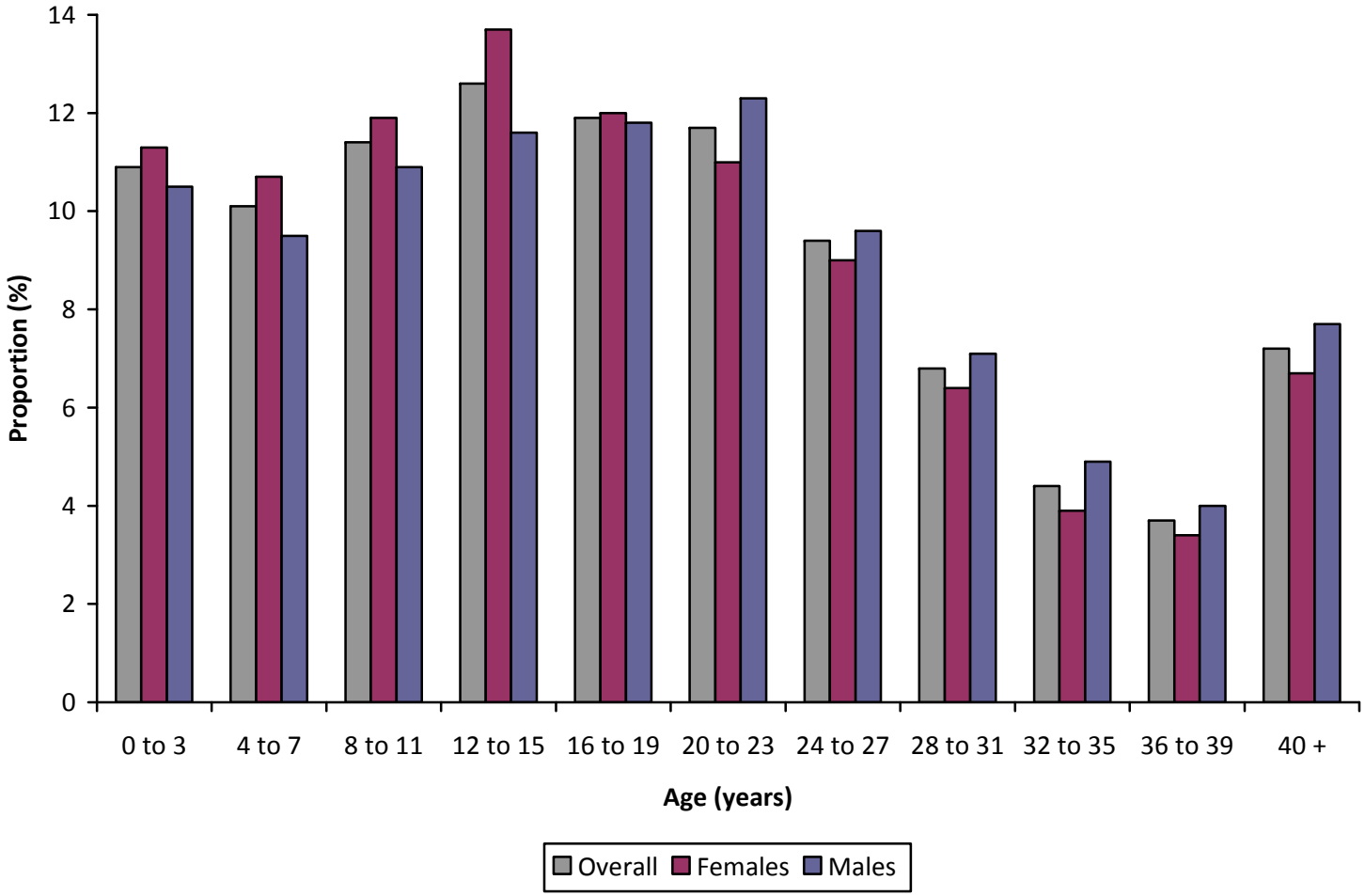
2183delAA->G	c.2051_2052delAAinsG	I	4	*(0.1%)*
A559T	p.Ala559Thr	unknown	4	*(0.1%)*
R352Q	p.Arg352Gln	unknown	4	*(0.1%)*
K710X	p.Lys710X	I	3	*(0.04%)*
3120G->A	c.2988G>A	V	2	*(0.03%)*
P574H	p.Pro574His	IV	2	*(0.03%)*
R1066C	p.Arg1066Cys	unknown	2	*(0.03%)*
R117C	p.Arg117Cys	IV/V	2	*(0.03%)*
R1283M	p.Arg1283Met	unknown	2	*(0.03%)*
S549R	p.Ser549Arg	II/III	2	*(0.03%)*
Y563D	p.Tyr563Asp	unknown	2	*(0.03%)*
1154insTC	c.1022_1023insTC	I	1	*(0.01%)*
1609delCA	c.1477_1478delCA	unknown	1	*(0.01%)*
1898+5G->T	c.1766+5G>T	V	1	*(0.01%)*
2869insG	c.2737_2738insG	I	1	*(0.01%)*
3272-26A>G	c.3140-26A>G	V	1	*(0.01%)*
3662delA	c.3530delA	unknown	1	*(0.01%)*
3849+4A->G	c.3717+4A>G	V	1	*(0.01%)*
574delA	c.442delA	unknown	1	*(0.01%)*
C524X	p.Cys524X	I	1	*(0.01%)*
G178R	p.Gly178Arg	unknown	1	*(0.01%)*
Q552X	p.Gln552X	I	1	*(0.01%)*
S1251N	p.Ser1251Asn	unknown	1	*(0.01%)*
S549I	p.Ser549Ile	unknown	1	*(0.01%)*
W1089X	p.Trp1089X	I	1	*(0.01%)*
Y1092X	p.Tyr1092X	I	1	*(0.01%)*
Other			*557*	*(8.0%)*
Not identified			*950*	*(13.7%)*

Cystic Fibrosis mutations and their functional effects



Courtesy of Vertex Pharmaceuticals Incorporated

1.6 Age distribution

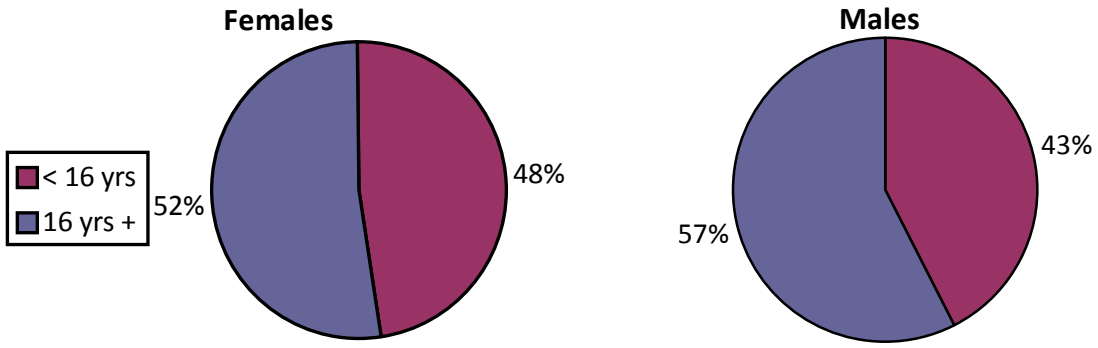


Age is calculated as the age at annual review encounter.

1.7 Age and sex distribution

Age	Overall N=7377	Female N=3461	Male N=3916
0-3 yrs	801 (10.9)	390 (11.3)	411 (10.5)
4-7	742 (10.1)	370 (10.7)	372 (9.5)
8-11	838 (11.4)	411 (11.9)	427 (10.9)
12-15	931 (12.6)	475 (13.7)	456 (11.6)
16-19	877 (11.9)	414 (12.0)	463 (11.8)
20-23	861 (11.7)	380 (11.0)	481 (12.3)
24-27	690 (9.4)	313 (9.0)	377 (9.6)
28-31	502 (6.8)	223 (6.4)	279 (7.1)
32-35	325 (4.4)	135 (3.9)	190 (4.9)
36-39	276 (3.7)	118 (3.4)	158 (4.0)
40+	534 (7.2)	232 (6.7)	302 (7.7)
Median (range)	17 yrs (0 - 82 yrs)	16 yrs (0 – 82 yrs)	18 yrs (0 – 78yrs)

1.8 Age distribution by sex



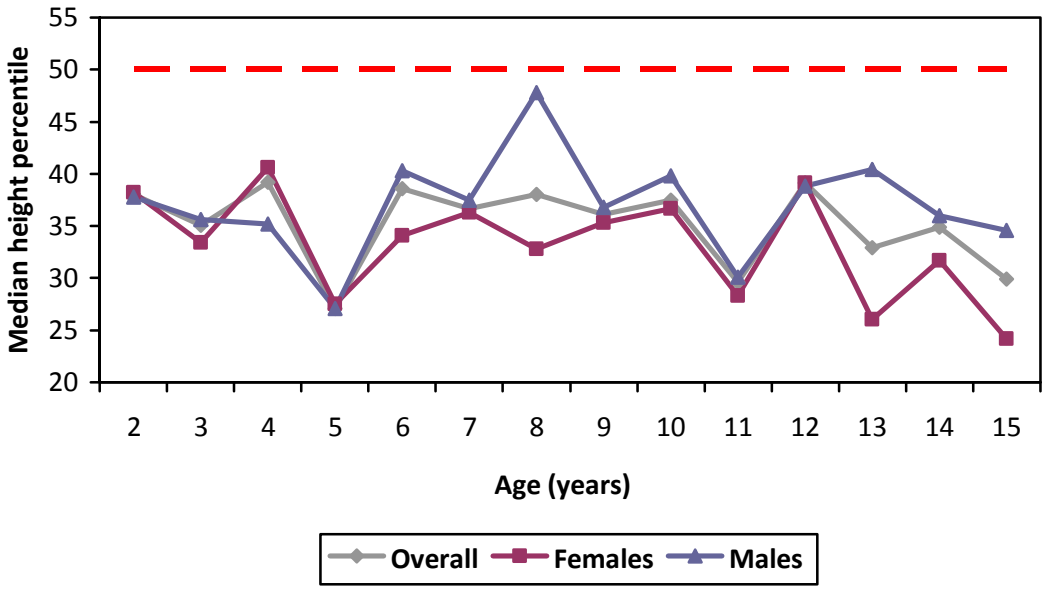
1.9 Employment status among adults aged 16 years and older

	Number of patients
Full-time working	1177
Part-time working	485
Student	761
Homemaker	176
Unemployed	740
"Disabled"	161
Retired	45
Unknown	226
No data	*392*

Note that these groups are not mutually exclusive.

Of the 3447 adults aged 16 years and older for whom an employment status questionnaire was completed (excluding "unknown"), 2370 (68.8%) reported being in work or study.

1.10 Median height percentiles among children (n=2819)

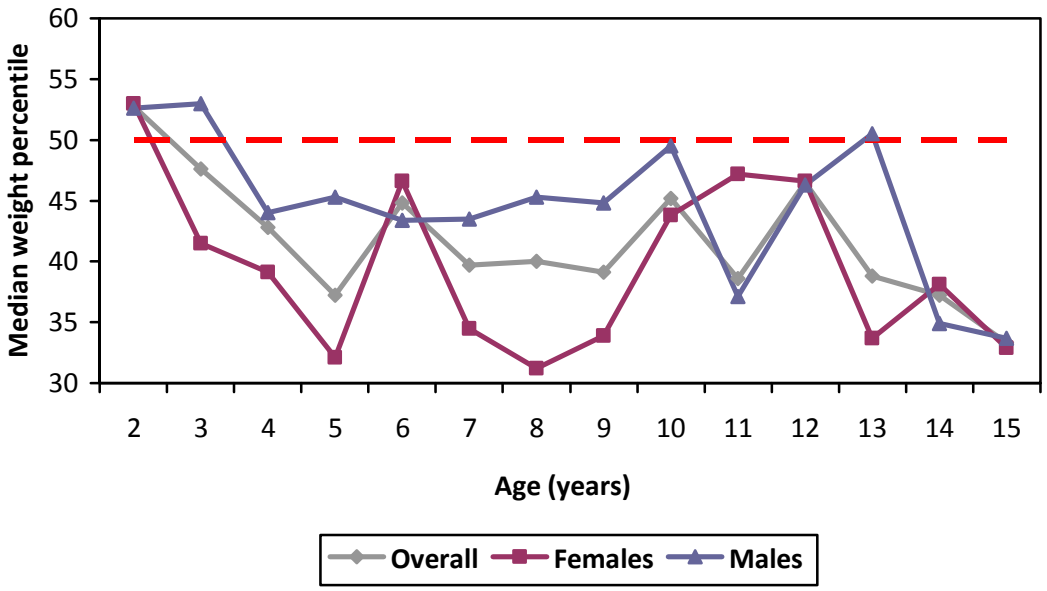


Age	Overall		Female		Male	
	N	Median (IQR)	N	Median (IQR)	N	Median (IQR)
2	221	38.0 (13.6, 69.5)	104	38.2 (16.0, 66.4)	117	37.8 (12.1, 74.8)
3	184	35.1 (16.0, 62.4)	88	33.4 (14.4, 57.0)	96	35.6 (16.2, 64.6)
4	186	39.2 (17.1, 62.7)	82	40.6 (18.1, 60.5)	104	35.2 (15.8, 69.3)
5	195	27.1 (13.3, 62.1)	100	27.5 (13.1, 59.6)	95	27.1 (13.3, 65.5)
6	176	38.6 (13.7, 58.4)	98	34.1 (16.0, 61.2)	78	40.3 (11.4, 57.4)
7	164	36.7 (20.0, 65.8)	79	36.3 (19.8, 69.2)	85	37.5 (20.0, 62.3)
8	203	38.0 (14.0, 64.7)	108	32.8 (10.6, 58.4)	95	47.8 (17.2, 75.1)
9	167	36.1 (11.4, 67.5)	87	35.3 (11.1, 57.7)	80	36.8 (14.2, 71.3)
10	230	37.5 (15.0, 66.6)	111	36.7 (12.3, 67.0)	119	39.8 (20.1, 64.5)
11	207	29.6 (11.3, 62.7)	92	28.3 (8.4, 73.4)	115	30.1 (14.7, 54.9)
12	216	39.1 (17.6, 67.4)	94	39.1 (15.9, 63.0)	122	38.8 (19.7, 67.7)
13	233	32.9 (10.5, 67.3)	127	26.0 (8.4, 58.0)	106	40.4 (18.0, 76.5)
14	235	34.9 (12.8, 62.1)	127	31.7 (14.8, 62.1)	108	36.0 (9.2, 62.1)
15	202	29.9 (7.4, 60.2)	100	24.2 (6.9, 55.3)	102	34.6 (8.7, 65.8)
Overall	2819	35.5 (13.9, 64.2)	1397	33.6 (12.8, 61.7)	1422	36.8 (14.8, 65.6)

N refers to the number of patients in each age/sex category who had non-missing height data

The red dotted line indicates the 50th percentile which is a marker used to target growth in children. The aim is to monitor and maintain growth as close to the 50th percentile as possible.

1.11 Median weight percentiles among children (n=2838)

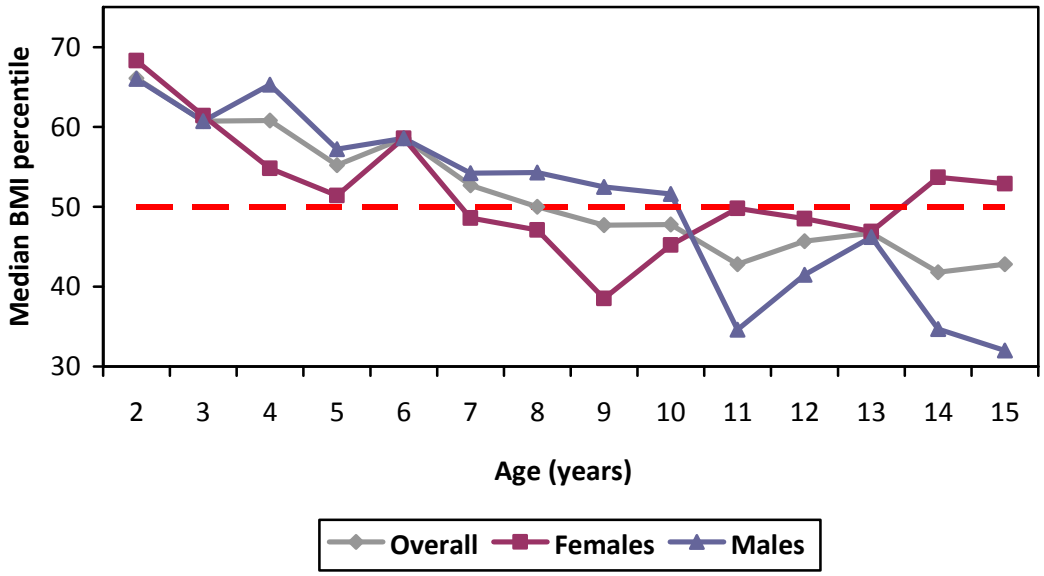


Age	Overall		Female		Male	
	N	Median (IQR)	N	Median (IQR)	N	Median (IQR)
2	228	52.8 (26.4, 78.0)	106	53.0 (31.3, 78.2)	122	52.6 (23.3, 78.8)
3	185	47.6 (23.6, 74.3)	89	41.5 (18.4, 70.2)	96	53.0 (26.5, 74.9)
4	187	42.8 (24.0, 66.7)	84	39.1 (22.4, 64.0)	103	44.0 (25.9, 70.8)
5	194	37.2 (15.5, 68.4)	99	32.1 (15.4, 64.1)	95	45.3 (15.5, 75.0)
6	176	44.8 (23.3, 62.1)	98	46.6 (21.3, 63.6)	78	43.4 (23.6, 57.5)
7	165	39.7 (18.0, 68.8)	79	34.5 (16.3, 68.7)	86	43.5 (22.6, 69.6)
8	203	40.0 (18.5, 70.9)	108	31.2 (15.8, 61.9)	95	45.3 (24.5, 78.9)
9	167	39.1 (16.3, 67.6)	87	33.9 (14.0, 59.9)	80	44.8 (17.4,74.6)
10	231	45.2 (15.7, 71.6)	111	43.8 (12.3, 74.9)	120	49.5 (21.4, 68.8)
11	208	38.6 (17.8, 66.3)	92	47.2 (18.0, 77.2)	116	37.1 (17.7, 56.6)
12	220	46.5 (18.9, 76.2)	97	46.6 (15.5, 73.1)	123	46.3 (19.2, 79.4)
13	234	38.8 (13.7, 71.9)	128	33.7 (10.9, 65.2)	106	50.5 (19.9, 76.9)
14	234	37.2 (14.1, 63.6)	127	38.1 (14.6, 66.7)	107	34.9 (14.0, 61.2)
15	206	33.3 (11.8, 62.5)	101	32.9 (11.4, 66.2)	105	33.7 (12.3, 61.4)
Overall	2838	41.9 (17.8, 69.6)	1406	39.3 (16.3, 67.8)	1432	44.3 (20.0, 70.8)

N refers to the number of patients in each age/sex category who had non-missing weight data

The red dotted line indicates the 50th percentile which is a marker used to target weight in children. The aim is to monitor and maintain weight as close to the 50th percentile as possible.

1.12 Median BMI percentiles among children (n=2809)

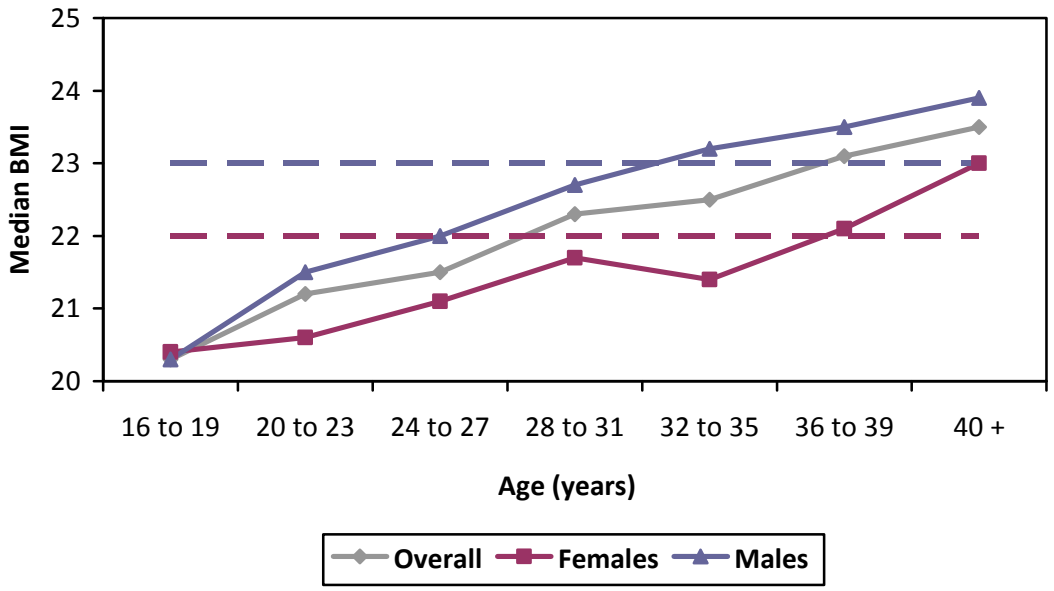


Age	Overall		Female		Male	
	N	Median (IQR)	N	Median (IQR)	N	Median (IQR)
2	221	66.1 (43.6, 83.8)	104	68.3 (45.8, 85.3)	117	66.0 (38.8, 83.0)
3	183	60.7 (39.8, 87.0)	88	61.4 (37.2, 86.5)	95	60.7 (40.9, 88.9)
4	185	60.8 (38.0, 81.9)	82	54.8 (38.8, 79.3)	103	65.3 (36.0, 83.0)
5	194	55.2 (29.1, 78.4)	99	51.4 (26.0, 76.7)	95	57.2 (33.2, 82.5)
6	175	58.6 (36.0, 75.2)	97	58.6 (36.1, 73.5)	78	58.6 (32.4, 77.3)
7	164	52.7 (27.7,71.8)	79	48.6 (24.6, 68.9)	85	54.2 (32.2, 74.6)
8	203	50.0 (26.0, 73.9)	108	47.1 (23.5, 73.5)	95	54.3 (27.5, 75.5)
9	167	47.7 (21.2, 63.9)	87	38.5 (19.6, 62.3)	80	52.5 (22.7, 67.7)
10	229	47.8 (23.2, 70.0)	111	45.2 (21.0, 71.2)	118	51.6 (23.6, 68.4)
11	205	42.8 (21.4, 66.0)	92	49.8 (28.5, 71.5)	113	34.6 (16.9, 61.1)
12	216	45.7 (20.6, 74.1)	94	48.5 (28.8, 72.7)	122	41.5 (19.0, 74.5)
13	232	46.7 (23.1,67.4)	126	46.9 (22.9, 67.7)	106	46.2 (24.1, 67.6)
14	233	41.8 (23.6, 66.1)	126	53.7 (27.6, 70.9)	107	34.7 (18.5, 55.4)
15	202	42.8 (19.9, 64.8)	100	52.9 (25.9, 66.4)	102	32.0 (17.5, 61.7)
Overall	2809	51.8 (26.3, 73.9)	1393	52.5 (28.0, 73.7)	1416	50.8 (24.4, 74.1)

N refers to the number of patients in each age/sex category who had non-missing BMI data

The red dotted line indicates the 50th percentile which is a marker used to target weight for height in children. The aim is to monitor and maintain weight for height as close to the 50th percentile as possible.

1.13 Median BMI values among adults (n=3888)

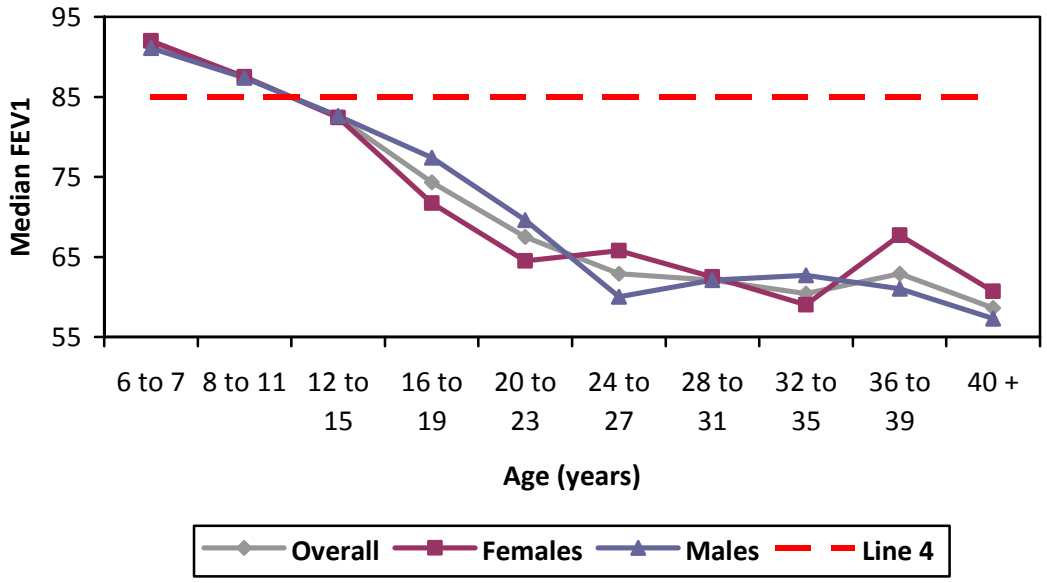


Age	Overall		Female		Male	
	N	Median (IQR)	N	Median (IQR)	N	Median (IQR)
16-19	852	20.3 (18.6, 22.2)	399	20.4 (18.8, 22.2)	453	20.3 (18.4, 22.2)
20-23	828	21.2 (19.3, 23.1)	368	20.6 (18.9, 22.5)	460	21.5 (19.6, 23.5)
24-27	656	21.5 (19.7, 23.4)	292	21.1 (19.5, 22.8)	364	22.0 (20.0, 24.0)
28-31	477	22.3 (20.5, 24.7)	210	21.7 (20.0, 24.2)	267	22.7 (20.7, 25.0)
32-35	309	22.5 (20.6, 24.9)	126	21.4 (19.6, 23.7)	183	23.2 (21.2, 25.1)
36-39	263	23.1 (21.3, 25.3)	113	22.1 (19.9, 24.5)	150	23.5 (21.8, 25.6)
40+	503	23.5 (21.2, 26.0)	220	23.0 (20.8, 25.4)	283	23.9 (21.9, 26.4)
Overall	3888	21.7 (19.7, 23.9)	1728	21.2 (19.4, 23.3)	2160	22.1 (20.0, 24.3)

N refers to the number of patients in each age/sex category with non-missing BMI data

The purple dotted line indicates a BMI of 22 which is a marker used to target BMI in adult women; the blue dotted line indicates a BMI of 23 which is a marker used for adult men.

1.14 Median FEV_1 (% predicted) among patients aged 6 years and older (n=5636)



Age	Overall		Female		Male	
	N	Median (range)	N	Median (range)	N	Median (range)
6-7	282	91.7 (78.8, 102.3)	144	92.0 (79.5, 101.3)	138	91.1 (78.3, 102.7)
8-11	735	87.5 (75.1, 97.5)	367	87.5 (74.4, 97.6)	368	87.4 (76.2, 97.0)
12-15	824	82.5 (69.1, 94.7)	418	82.4 (66.5, 95.8)	406	82.6 (71.3, 92.8)
16-19	828	74.3 (58.6, 91.5)	393	71.7 (56.1, 89.0)	435	77.4 (61.6, 93.2)
20-23	816	67.5 (49.0, 85.9)	363	64.5 (48.0, 84.8)	453	69.6 (49.6, 86.0)
24-27	630	62.9 (44.0, 82.5)	278	65.8 (47.5, 84.7)	352	60.0 (41.5, 79.6)
28-31	470	62.1 (44.1, 80.6)	205	62.5 (46.5, 81.3)	265	62.1 (42.6, 80.3)
32-35	301	60.4 (44.7, 78.8)	121	59.0 (45.1, 78.9)	180	62.7 (43.1, 78.8)
36-39	255	62.9 (41.8, 78.9)	111	67.7 (40.9, 81.8)	144	61.0 (41.8, 77.7)
40+	495	58.6 (38.5, 79.3)	214	60.7 (39.5, 79.3)	281	57.3 (37.7, 81.0)
Overall	5636	74.0 (54.2, 90.4)	2614	74.1 (54.8, 91.2)	3022	74.0 (53.4, 90.0)

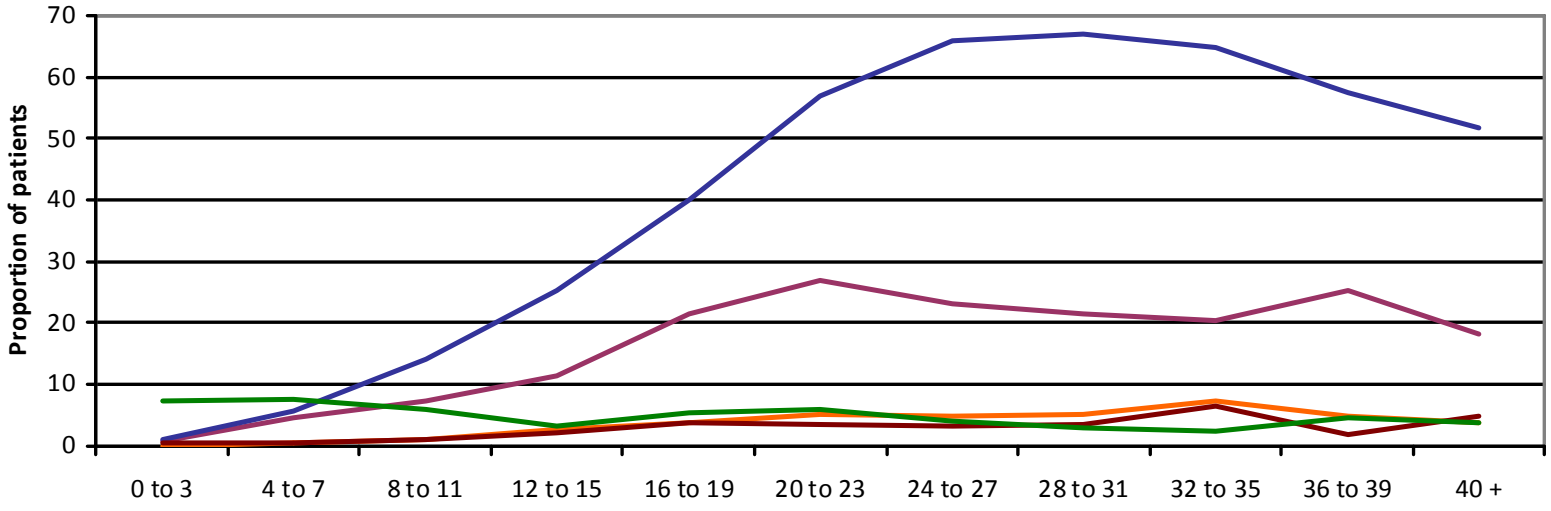
N refers to the number of patients in each age/sex category among those with non-missing FEV_1 % predicted data

In previous reports median FEV_1 % predicted has been reported for patients aged 8 years and older. However, a consensus among CF paediatricians has resulted in a report for FEV_1 % predicted for patients aged 6 years and older, based on their view that the majority of 6 year olds are able to produce reliable lung function measurements.

The dotted line in this figure illustrates a target FEV_1 % predicted of 85%, anything above this indicates normal or near-normal lung function values.

The aim of good CF care is to preserve normal lung function for as long as possible among the paediatric population and to maintain stable lung function in adulthood. This is important for the latter as lung function at 50% and above will facilitate all of the normal activities of daily living including attendance at work and college.

1.15 Lung infections



N in age band	801	742	838	931	877	861	690	502	325	276	534
N cultures taken	730	688	795	870	833	757	621	445	283	219	462

Chronic *S.aureus*; n=1000 (15.2%) — Chronic *P.aeruginosa*; n=2402 (36.0%) — *B.cepacia*; n=210 (3.1%)

MRSA; n=170 (2.5%) — *H.influenzae*; n=343 (5.1%)

Chronic infection with *S. aureus* or *P. aeruginosa* was identified from annual review. Data on *B.cepacia*, MRSA and *H.influenzae* were collected from culture results at annual review.

Current treatments and good cross-infection measures mean that we can aim to reduce the number of people with CF transferring from paediatric to adult care with chronic *Pseudomonas aeruginosa* infection, and currently the aim is for less than 30% of paediatric patients to be chronically infected at the time of transfer. A future aim is to see this reduce to less than 20%.

Lung Infections

	Age (yrs)											Overall
	0-3	**4-7**	**8-11**	**12-15**	**16-19**	**20-23**	**24-27**	**28-31**	**32-35**	**36-39**	**40+**	
N patients in age band	*801*	*742*	*838*	*931*	*877*	*861*	*690*	*502*	*325*	*276*	*534*	*7377*
N cultures taken at clinic	*730*	*688*	*795*	*870*	*833*	*757*	*621*	*445*	*283*	*219*	*462*	*6703*
Chronic *S.aureus*; n(%)	6 (0.9)	31 (4.5)	54 (7.2)	96 (11.4)	170 (21.4)	203 (27.0)	143 (23.2)	96 (21.6)	57 (20.4)	58 (25.2)	86 (18.1)	1000 (15.2)
Chronic *P.aeruginosa*; n(%)	8 (1.1)	40 (5.7)	110 (14.1)	217 (25.2)	321 (40.1)	433 (56.9)	407 (65.9)	299 (66.9)	185 (64.9)	134 (57.5)	248 (51.8)	2402 (36.0)
***B.cepacia*; n(%)**	0	3 (0.4)	9 (1.1)	24 (2.8)	31 (3.7)	39 (5.2)	31 (5.0)	23 (5.2)	21 (7.4)	11 (5.0)	18 (3.9)	210 (3.1)
MRSA; n(%)	3 (0.4)	4 (0.6)	9 (1.1)	18 (2.1)	31 (3.7)	26 (3.4)	19 (3.1)	15 (3.4)	18 (6.4)	4 (1.8)	23 (5.0)	170 (2.5)
***H.influenza*; n(%)**	53 (7.3)	53 (7.7)	47 (5.9)	28 (3.2)	45 (5.4)	44 (5.8)	25 (4.0)	13 (2.9)	7 (2.5)	10 (4.6)	18 (3.9)	343 (5.1)

Age is calculated as age at annual review

1.16 Complications identified in 2009

	Overall (n=7377)	<16 years (n=3312)	≥16 years (n=4065)
Nontuberculous mycobacteria or atypical mycobacteria; *n(%)*	223 (3.0%)	41 (1.2%)	182(4.5%)
Cirrhosis with no portal hypertension; *n(%)*	104 (1.4%)	23 (0.7%)	81 (2.0%)
Cirrhosis with portal extension; *n(%)*	136 (1.8%)	27 (0.8%)	109 (2.7%)
Gallbladder disease requiring surgery; *n(%)*	33 (0.4%)	3 (0.1%)	30 (0.7%)
Nasal polyps requiring surgery; *n(%)*	293 (4.0%)	60 (1.8%)	233 (5.7%)
Pneumothorax requiring chest tube; *n(%)*	48 (0.7%)	2 (0.1%)	46 (1.1%)
Cancer confirmed by histology; *n(%)*	16 (0.2%)	2 (0.1%)	14 (0.3%)
Fibrosing colonopathy/ colonic stricture; *n(%)*	4 (0.1%)	2 (0.1%)	2 (0.05%)
ABPA; *n(%)*	612 (8.3%)	227 (6.9%)	385 (9.5%)
Port inserted or replaced; *n(%)*	446 (6.0%)	155 (4.7%)	291 (7.2%)

1.17 CF-related diabetes

	Overall* (n=7048)	<16 years * (n=3139)	≥16 years * (n=3909)
Treatment for CF-related diabetes; n(%)	1153 (16.4 %)	105 (3.3 %)	1048 (26.8 %)

***** *Treatment for CF-related diabetes was enquired about in an annual review questionnaire which was completed by 7048 of the 7377 patients with "complete" annual review encounter data. For this reason the number of patients in each age group differs to section 1.16.*

1.18 Transplants

Of those with complete data in 2009, 143 patients were evaluated and 79 accepted onto the transplant list.

25* patients received transplants: 19 bilateral lung
5 liver
2 kidney

** One patient received two transplants*

1.19 Other therapy

	Overall (n=7377)	**<16 years (n=3312)**	**≥16 years (n=4065)**
NIV; n(%)	209 (3.2)	83 (2.8)	126 (3.5)
Long-term oxygen; n(%)	420 (6.3)	93 (3.1)	327 (8.9)
Among those who had long-term oxygen therapy:			
Continuously	86 (20.5)	8 (8.6)	78 (23.9)
Nocturnal+exertion	100 (23.8)	19 (20.4)	81 (24.8)
PRN	65 (15.5)	12 (12.9)	53 (16.2)
With exacerbation	169 (40.2)	54 (58.1)	115 (35.2)

1.20 Feeding

	Overall (n=7377)	**<16 years (n=3312)**	**≥16 years (n=4065)**
Any supplemental feeding; n(%)	2188 (32.0)	818 (26.3)	1370 (36.7)
Nasogastric Tube	100 (4.6)	26 (3.2)	74 (5.4)
Gastrostomy Tube / Button	447 (20.4)	172 (21.0)	275 (20.1)
Jejunal	5 (0.2)	3 (0.4)	2 (0.1)
TPN	0	0	0

1.21 Days on IV antibiotics

Age	Home		Hospital		Total	
	N (%)	Median (IQR)	N (%)	Median (IQR)	N (%)	Median (IQR)
0-3	42 (5.8)	10 (7, 18)	214 (29.7)	14 (8, 20)	222 (30.8)	14 (11, 25)
4-7	114 (16.1)	20 (11, 31)	237 (33.5	14 (7, 23)	267 (37.8)	14 (14, 37)
8-11	168 (21.2)	21 (14, 42)	258 (32.5)	14 (7, 28)	309 (39.0)	28 (14, 47)
12-15	259 (29.6)	28 (14, 42)	382 (43.7)	14 (8, 35)	462 (52.8)	28 (14, 56)
16-19	283 (34.6)	25 (14, 42)	374 (45.8)	16 (10, 35)	461 (56.4)	28 (14, 54)
20-23	350 (42.8)	21 (14, 42)	414 (50.7)	16 (10, 39)	531 (65.0)	29 (14, 55)
24-27	273 (41.5)	28 (14, 42)	314 (47.7)	17 (10, 34)	422 (64.1)	30 (14, 56)
28-31	221 (46.1)	26 (14, 42)	209 (43.6)	14 (7, 33)	303 (63.3)	28 (15, 56)
32-35	112 (36.7)	28 (14, 55)	111 (36.4)	16 (7, 36)	159 (52.1)	28 (14, 63)
36-39	100 (37.6)	22 (14, 47)	100 (37.6)	14 (7, 27)	148 (55.6)	27 (14, 56)
40+	164 (32.5)	22 (13, 42)	183 (36.2)	14 (8, 34)	247 (48.9)	28 (14, 57)
Overall	2086 (30.1)	24 (14, 42)	2796 (40.3)	14 (8, 30)	3531 (50.9)	28 (14, 53)

N refers to the number of patients in each age category who had IV antibiotics

1.22 Nebulised drug treatment

Age	DNase treatment; n(%)
0-3 yrs	55 (6.9)
4-7	152 (20.5)
8-11	332 (39.6)
12-15	449 (48.2)
16-19	441 (50.3)
20-23	410 (47.6)
24-27	345 (50.0)
28-31	226 (45.0)
32-35	127 (39.1)
36-39	102 (37.0)
40+	194 (36.3)
Overall	2833 (38.4)

Antibiotic use among patients with chronic *Pseudomonas aeruginosa*

	Overall	**<16 years**	**≥16 years**
Patients with chronic pseudomonas	2620	457	2163
Tobramycin solution; n(%)	531 (20.3)	75 (16.4)	456 (21.1)
Other aminoglycoside; n(%)	58 (2.2)	12 (2.6)	46 (2.1)
Colistin; n(%)	1185 (45.2)	241 (52.7)	944 (43.6)
Promixin; n(%)	543 (20.7)	111 (24.3)	432 (20.0)
Chronic macrolide; n(%)	1576 (60.2)	190 (41.6)	1386 (64.1)
At least one of the above; n(%)	2248 (85.8)	392 (85.8)	1856 (85.8)

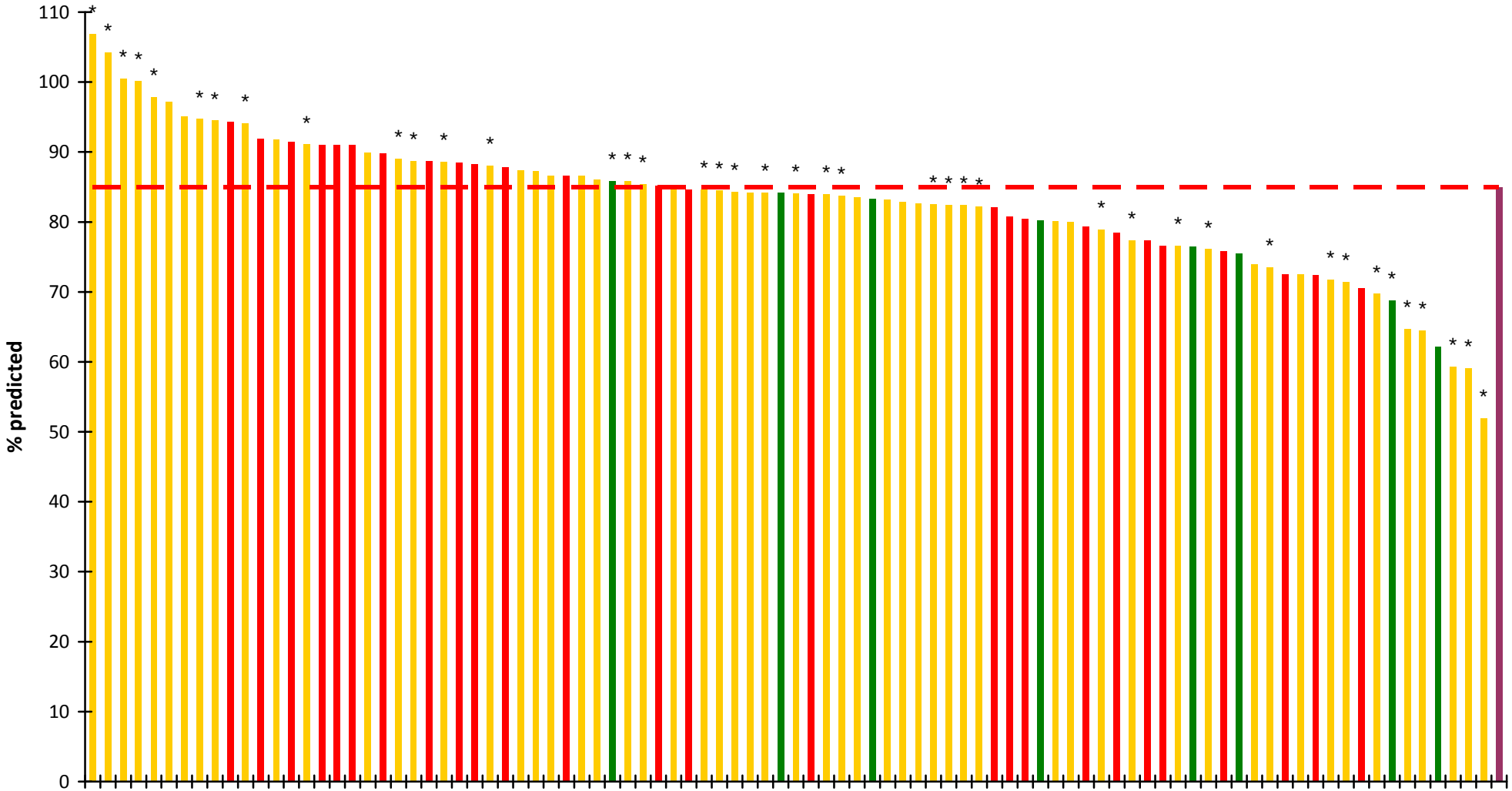
The consensus view in the UK is that 90% of patients chronically infected with *Pseudomonas aeruginosa* should be prescribed at least one of the above nebulised antibiotics.

Section 2: Analyses by paediatric care centre/clinic

(based on 3604 patients from paediatric care centres with complete* data at 2009 annual review)

** "Complete" data refers to the minimum data required to produce the range of clinical outcomes presented in this report.*

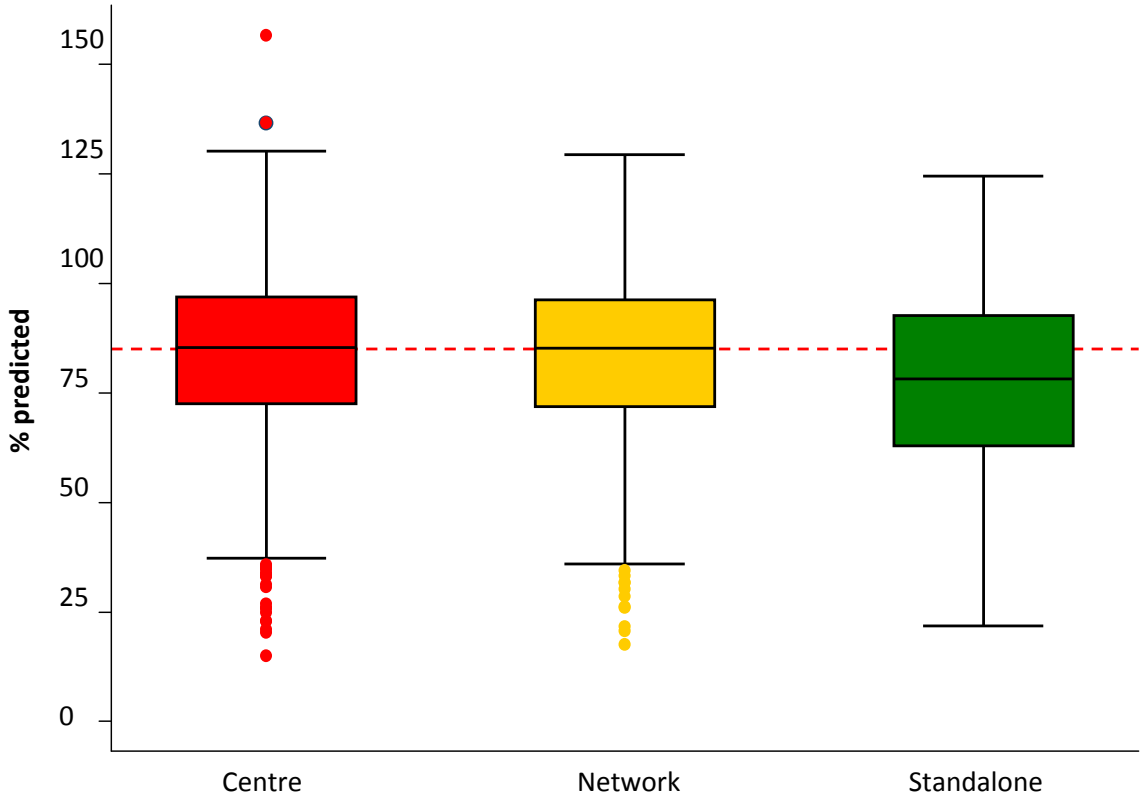
Figure 2.1.1 Median FEV_1 % predicted by paediatric centre/clinic – all centres, networks and stand-alone clinics



The median FEV_1 % predicted for paediatric centres/clinics is 85.0% predicted (min=15.0, max=156.6).

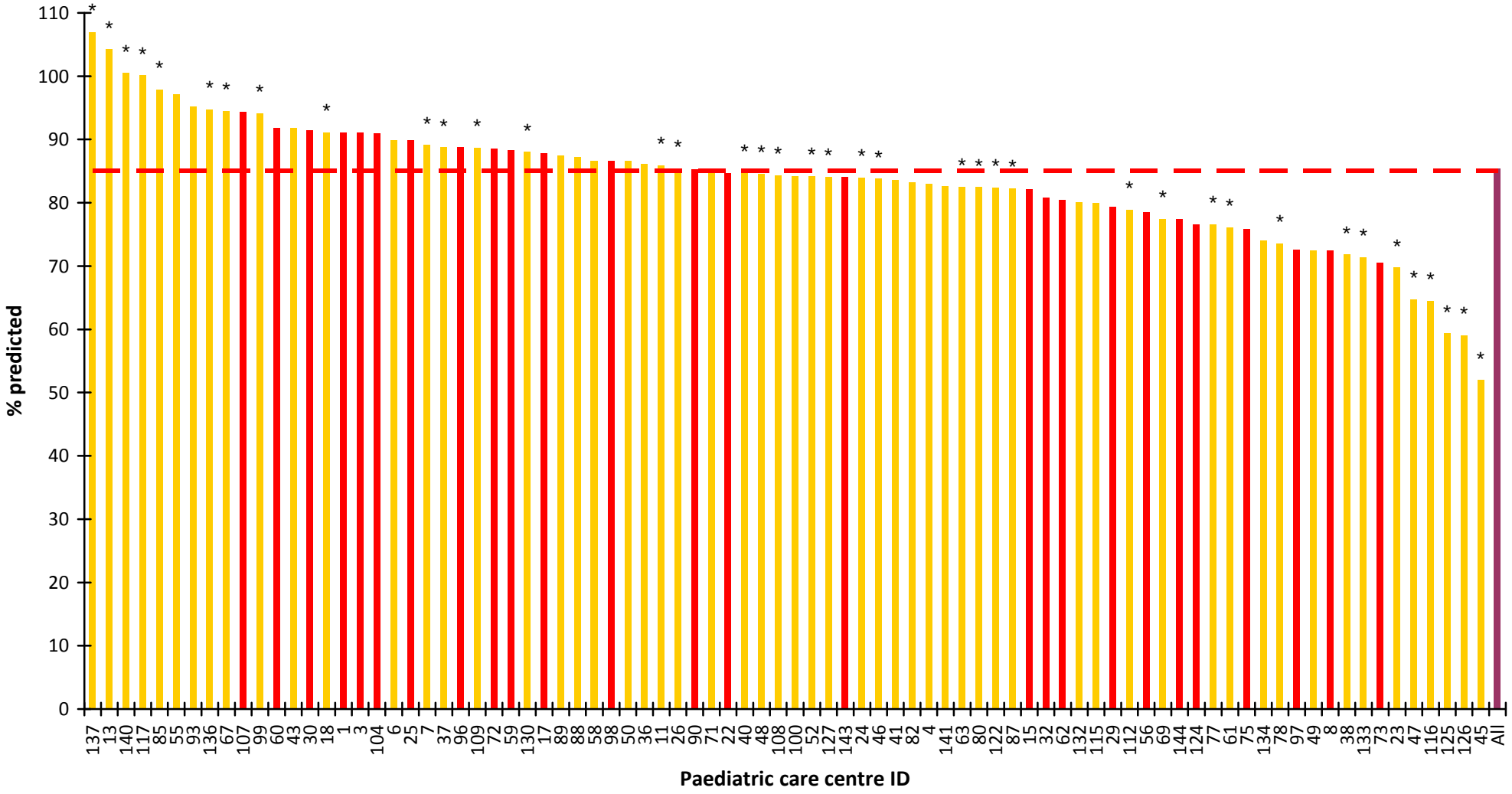
*Red: centres. Gold: network clinics. Green: stand-alone clinics. Plum: all. * Centre/clinic with a dataset submission of less than 20 patients*

Figure 2.1.2 Distribution of FEV_1 % predicted by paediatric model of care



The median FEV_1 % predicted for paediatric centres/clinics is 85.0% predicted (min=15.0, max=156.6).
Red: centres. Gold: network clinics. Green: stand-alone clinics.

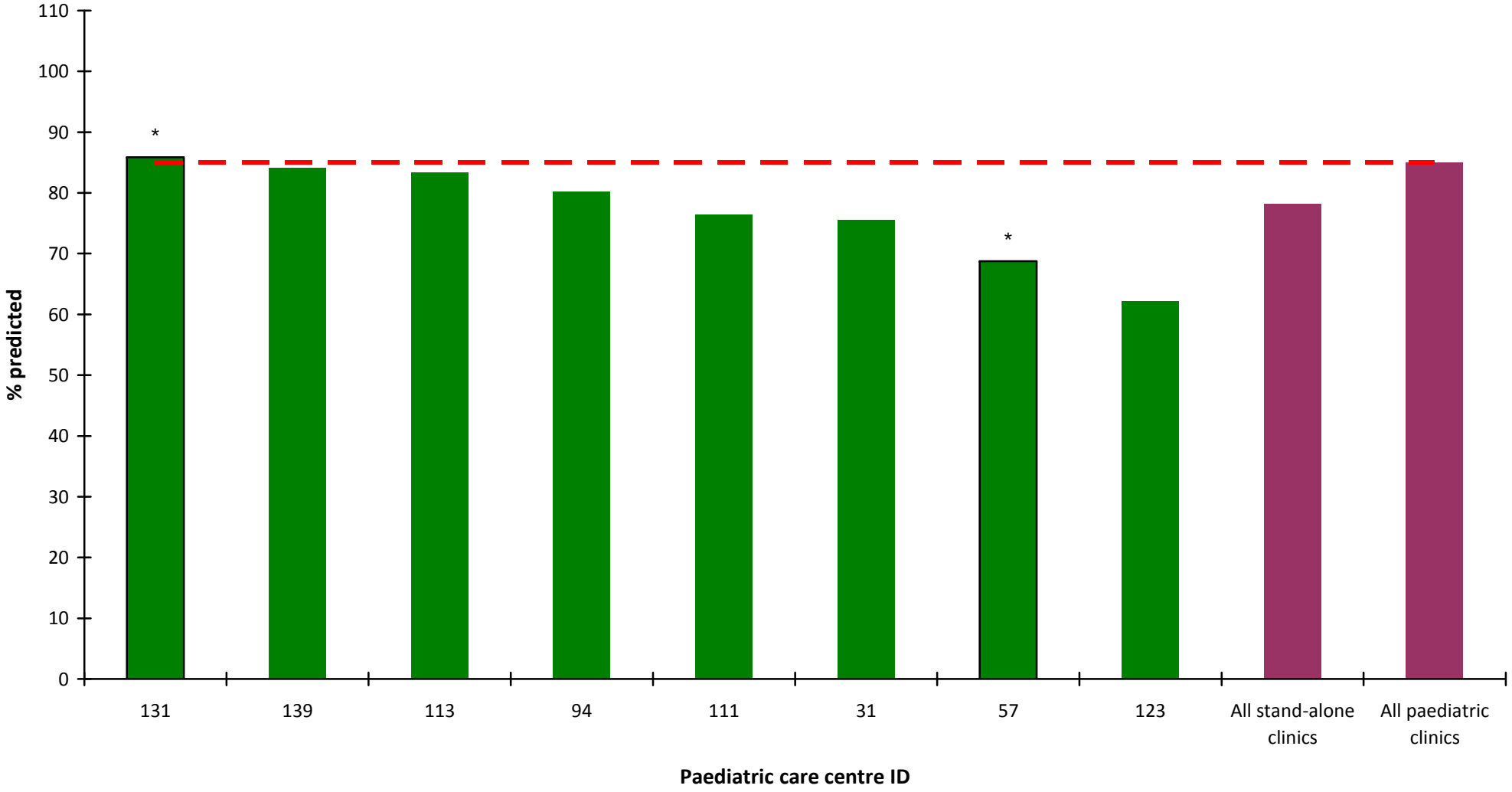
Figure 2.1.3 Median FEV_1 % predicted by paediatric centre/clinic – all centres and networks



The median FEV1 % predicted for paediatric centres and networks is 85.4% predicted (min=15.0, max=156.6).

*Red: centres. Gold: network clinics. Plum: all. * Centre/clinic with a dataset submission of less than 20 patients.*

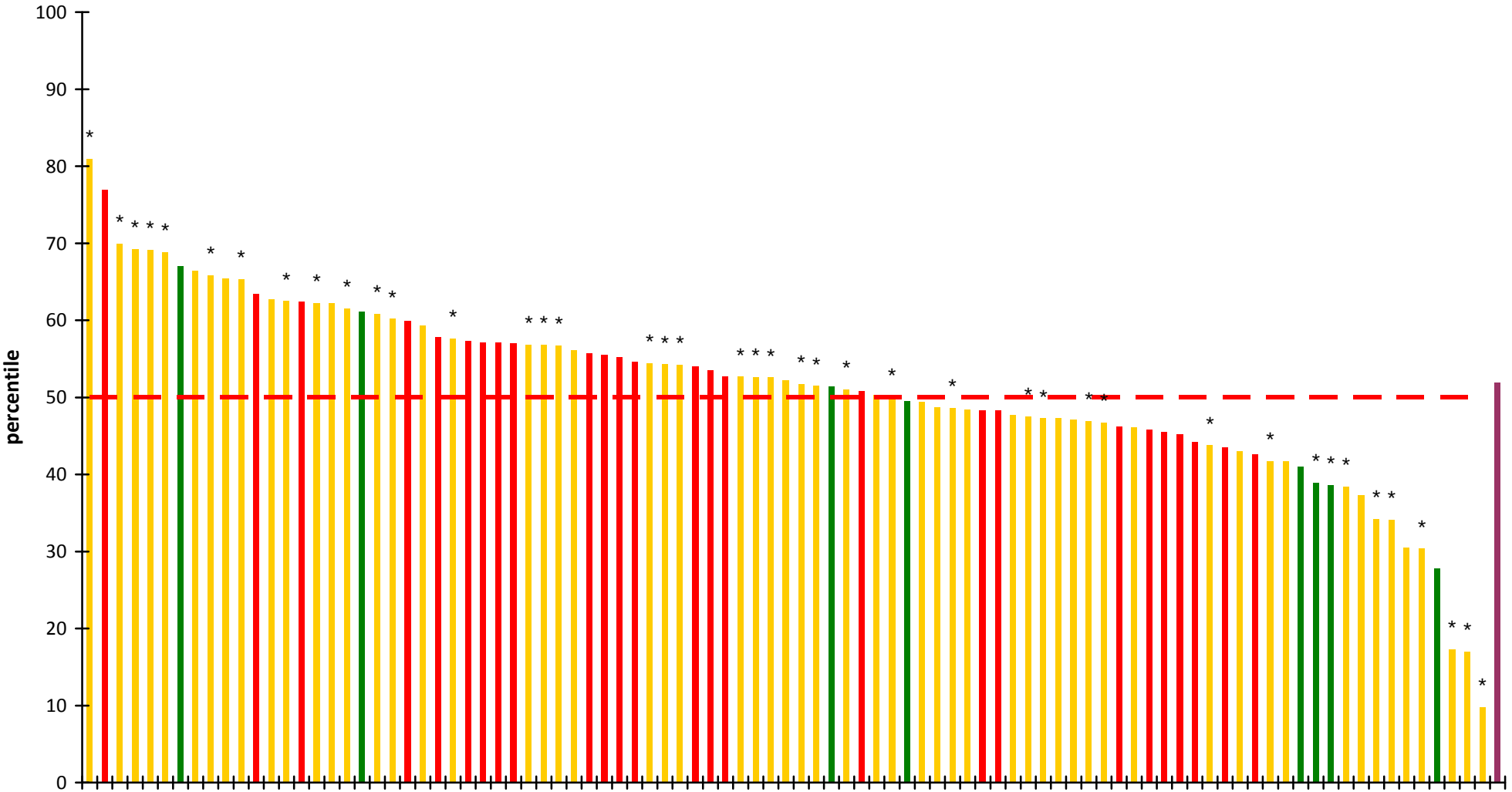
Figure 2.1.4 Median FEV_1 % predicted by paediatric stand-alone clinics



The median FEV1 % predicted for stand-alone paediatric clinics is 78.2% predicted (min=21.9, max=124.5).

*Green: stand-alone clinics. Plum: all. * Clinic with a dataset submission of less than 20 patients*

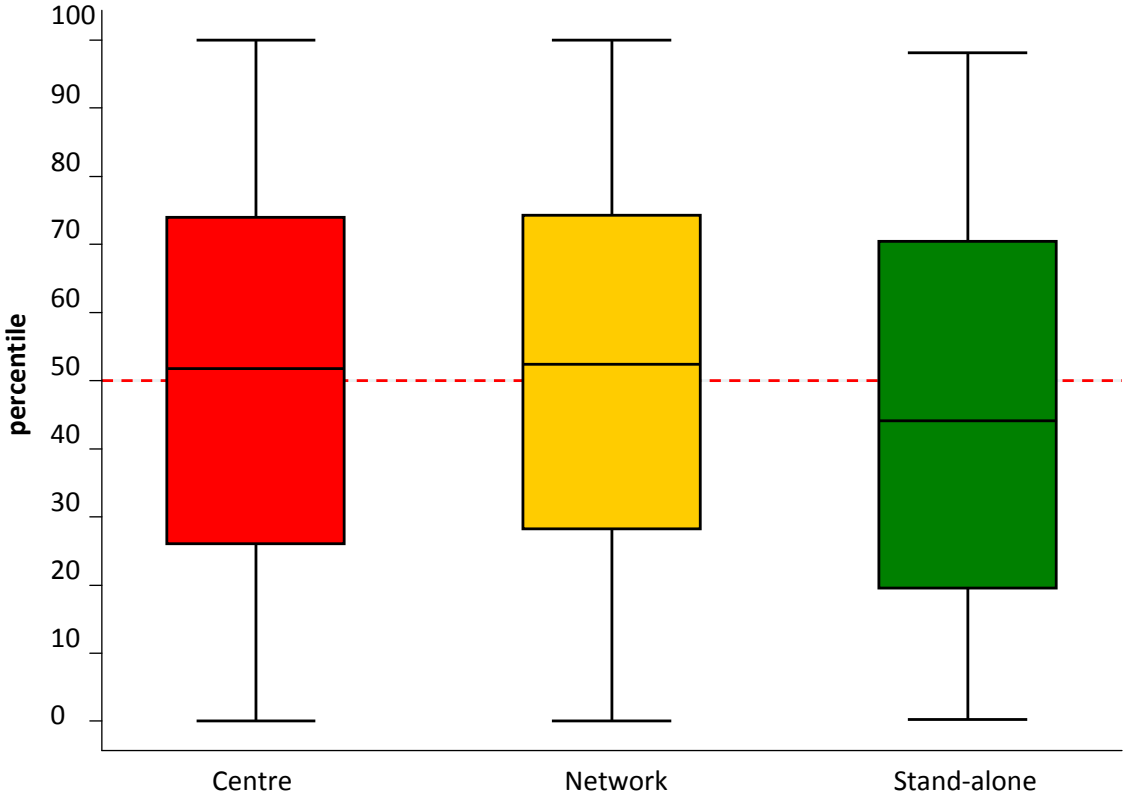
Figure 2.2.1 Median BMI percentile by paediatric centre/clinic – all centres, networks and stand-alone clinics



The median BMI percentile for paediatric centres/clinics is 51.8 (min=0, max=100).

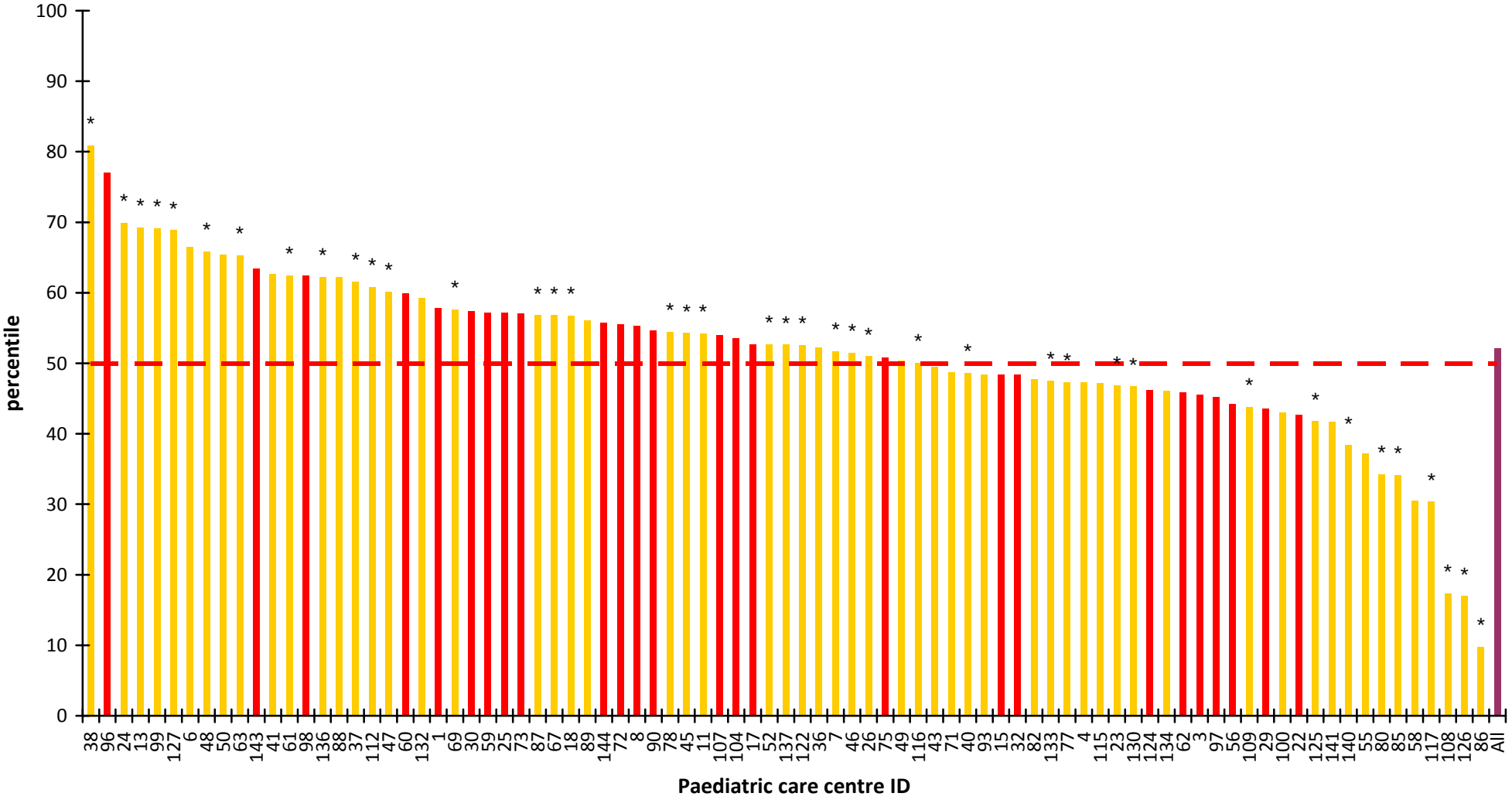
*Red: centres. Gold: network clinics. Green: stand-alone clinics. Plum: all. * Centre/clinic with a dataset submission of less than 20 patients*

Figure 2.2.2 Distribution of BMI percentiles by paediatric model of care



The median BMI percentile for paediatric centres/clinics is 51.8 (min=0, max=100).
Red: centres. Gold: network clinics. Green: stand-alone clinics.

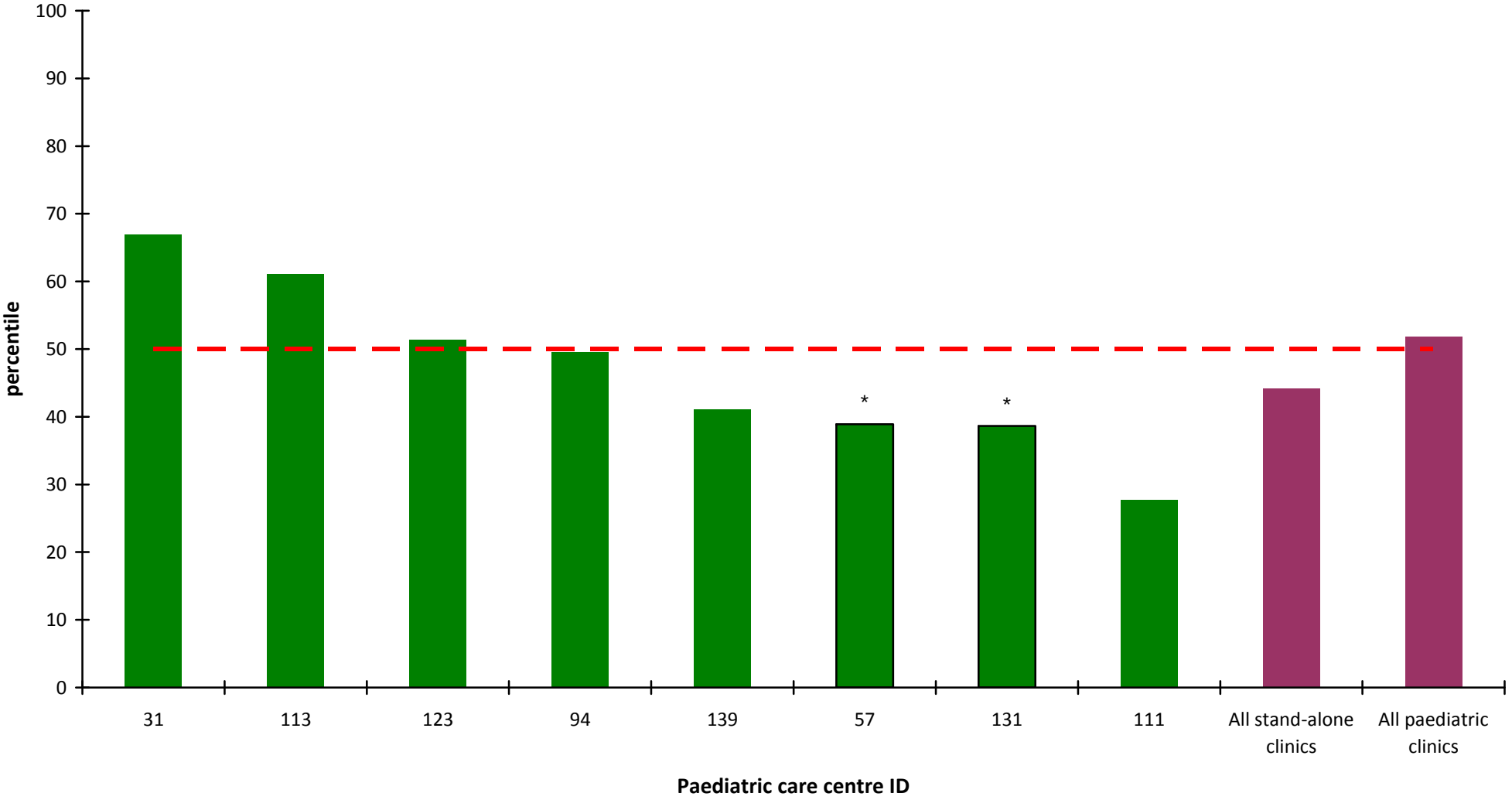
Figure 2.2.3 Median BMI percentile by paediatric centre/clinic – all centres and networks



The median BMI percentile for paediatric centres and networks is 52.1 (min=0, max=100).

*Red: centres. Gold: network clinics. Plum: all. * Centre/clinic with a dataset submission of less than 20 patients*

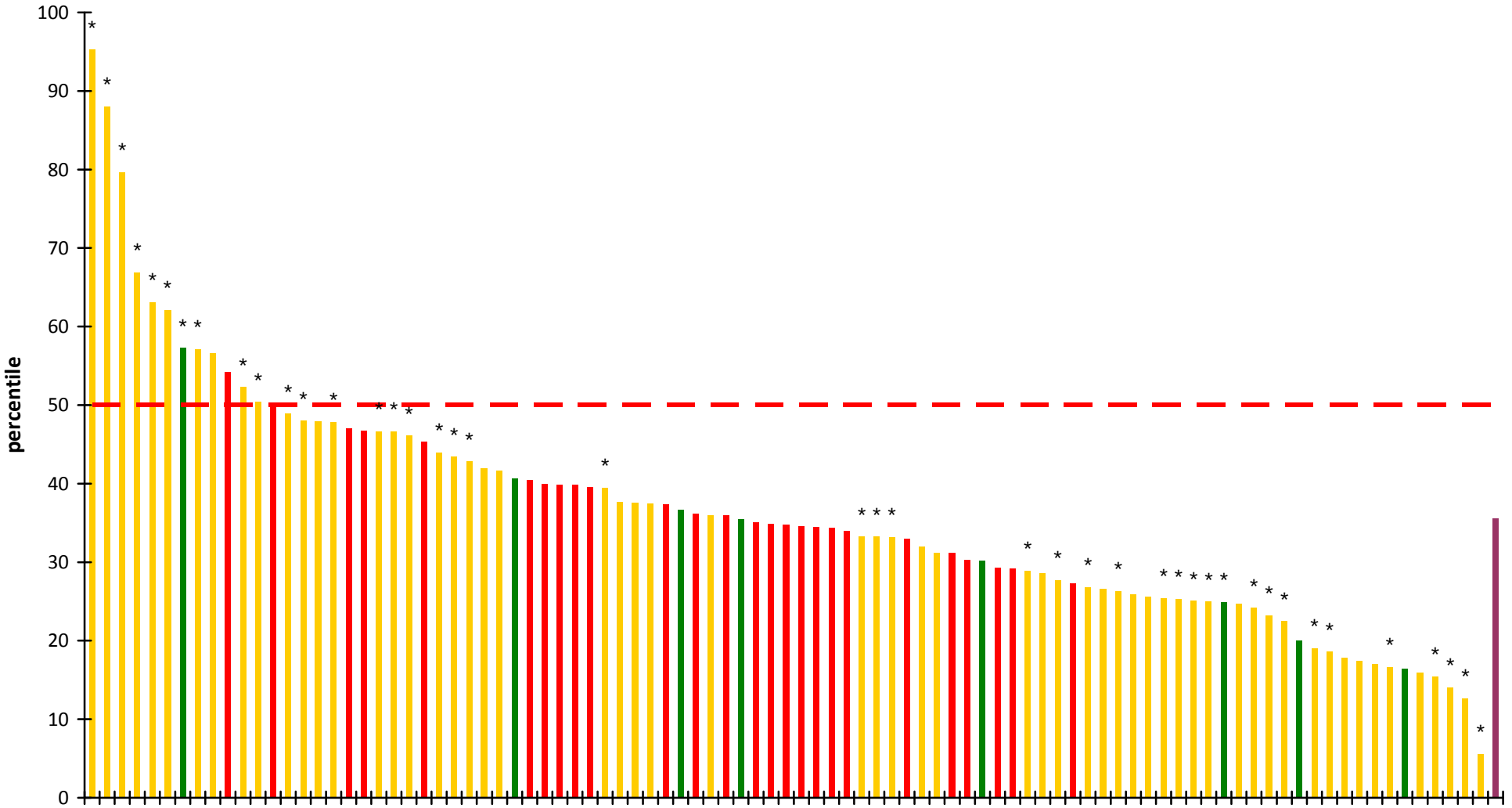
Figure 2.2.4 Median BMI percentile by paediatric stand-alone clinics



The median BMI percentile for stand-alone paediatric clinics is 44.1 (min=0.3, max=98.1).

*Green: stand-alone clinics. Plum: all. * Clinic with a dataset submission of less than 20 patients*

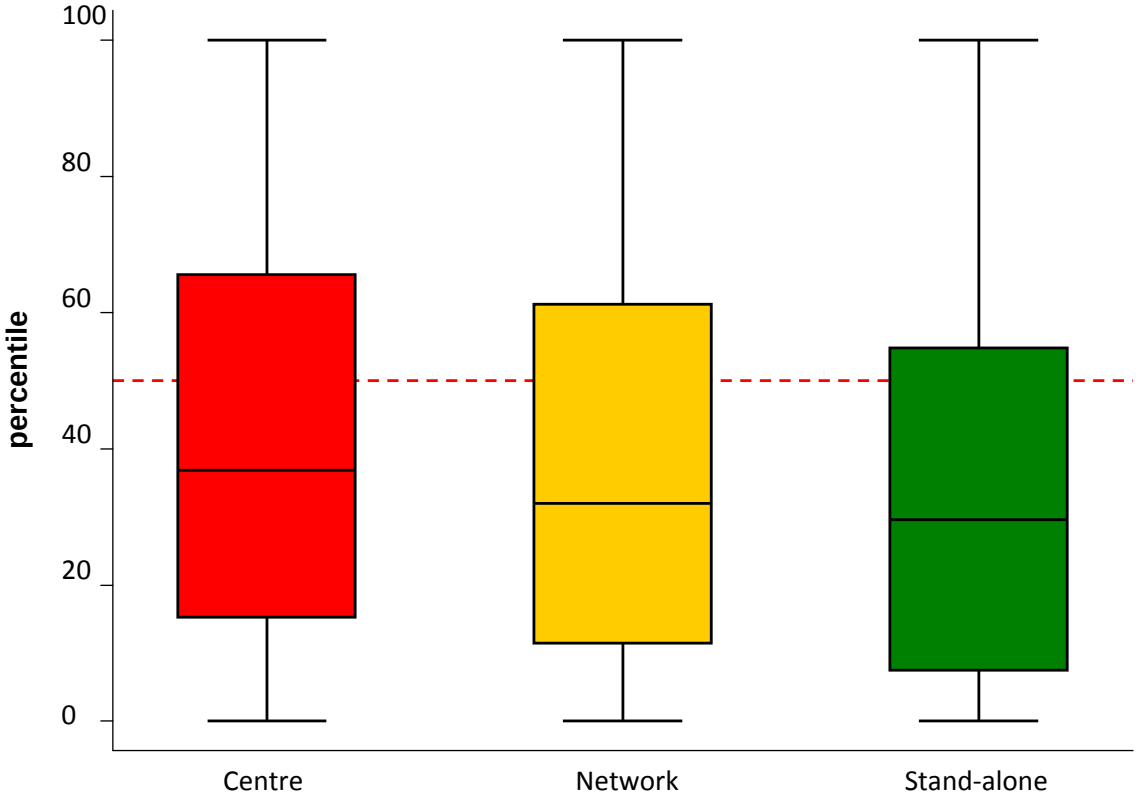
Figure 2.3.1 Median height percentile by paediatric centre/clinic – all centres, networks and stand-alone clinics



The median height percentile for paediatric centres/clinics is 35.5 (min=0, max=100).

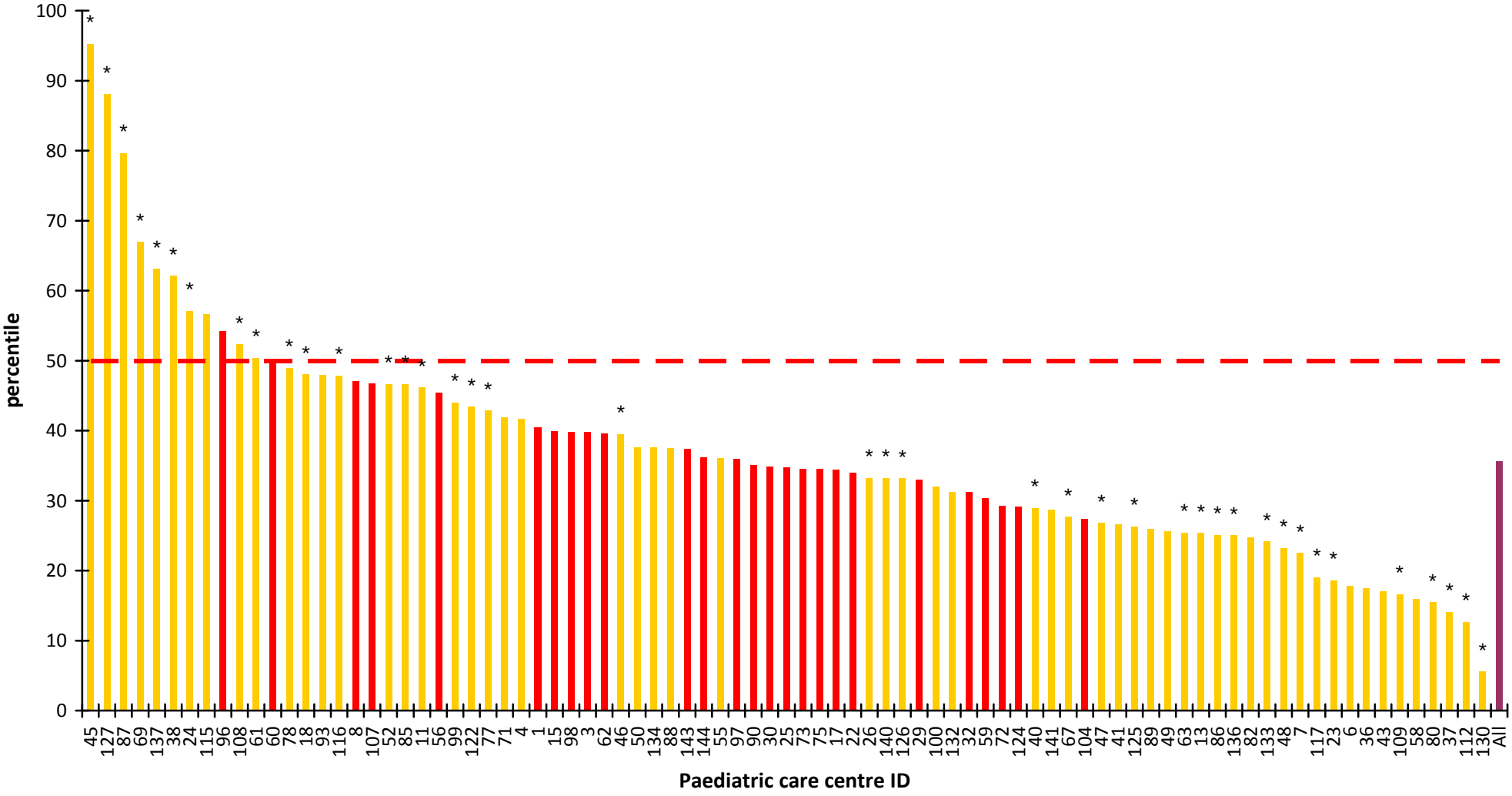
*Red: centres. Gold: network clinics. Green: stand-alone clinics. Plum: all. * Centre/clinic with a dataset submission of less than 20 patients*

Figure 2.3.2 Distribution of height percentiles by paediatric model of care



The median height percentile for paediatric centres/clinics is 35.5 (min=0, max=100).
Red: centres. Gold: network clinics. Green: stand-alone clinics.

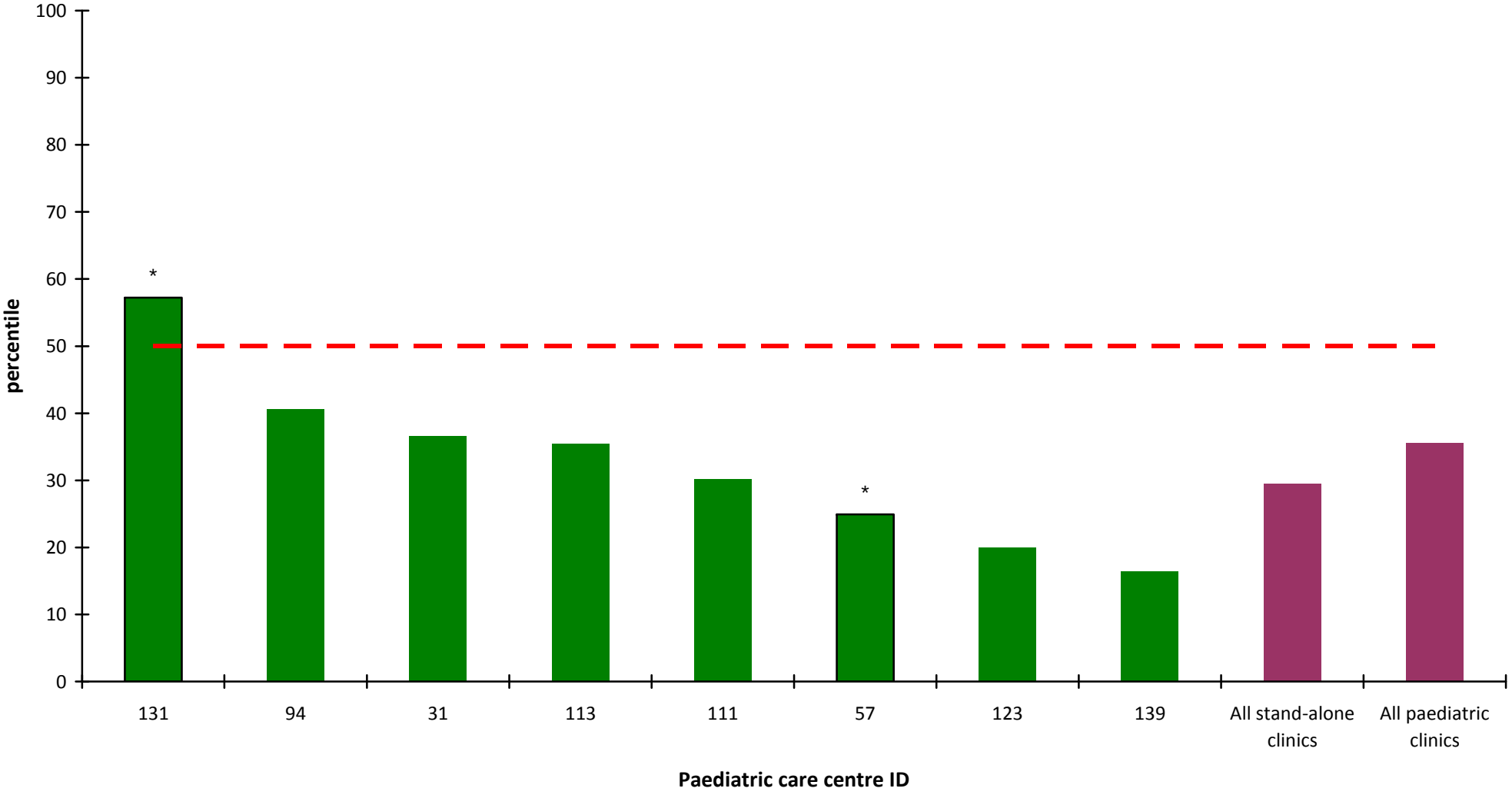
Figure 2.3.3 Median height percentile by paediatric centre/clinic – all centres and networks



The median height percentile for paediatric centres and network clinics is 35.6 (min=0, max=100).

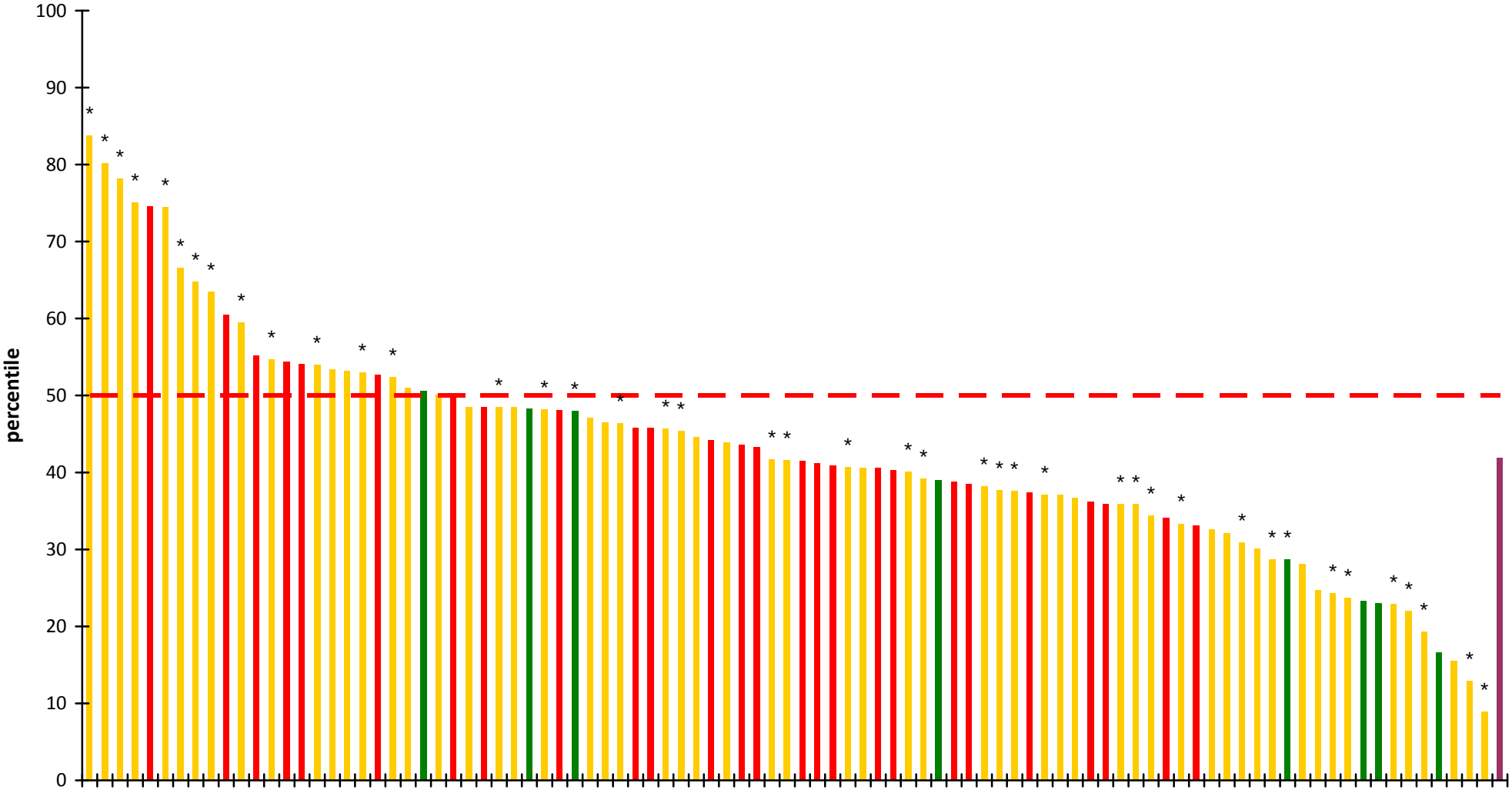
*Red: centres. Gold: network clinics. Plum: all. * Centre/clinic with a dataset submission of less than 20 patients*

Figure 2.3.4 Median height percentile by paediatric stand-alone clinics



The median height percentile for stand-alone paediatric clinics is 29.6 (min=0.1, max=100).
*Green: stand-alone clinics. Plum: all. * Clinic with a dataset submission of less than 20 patients*

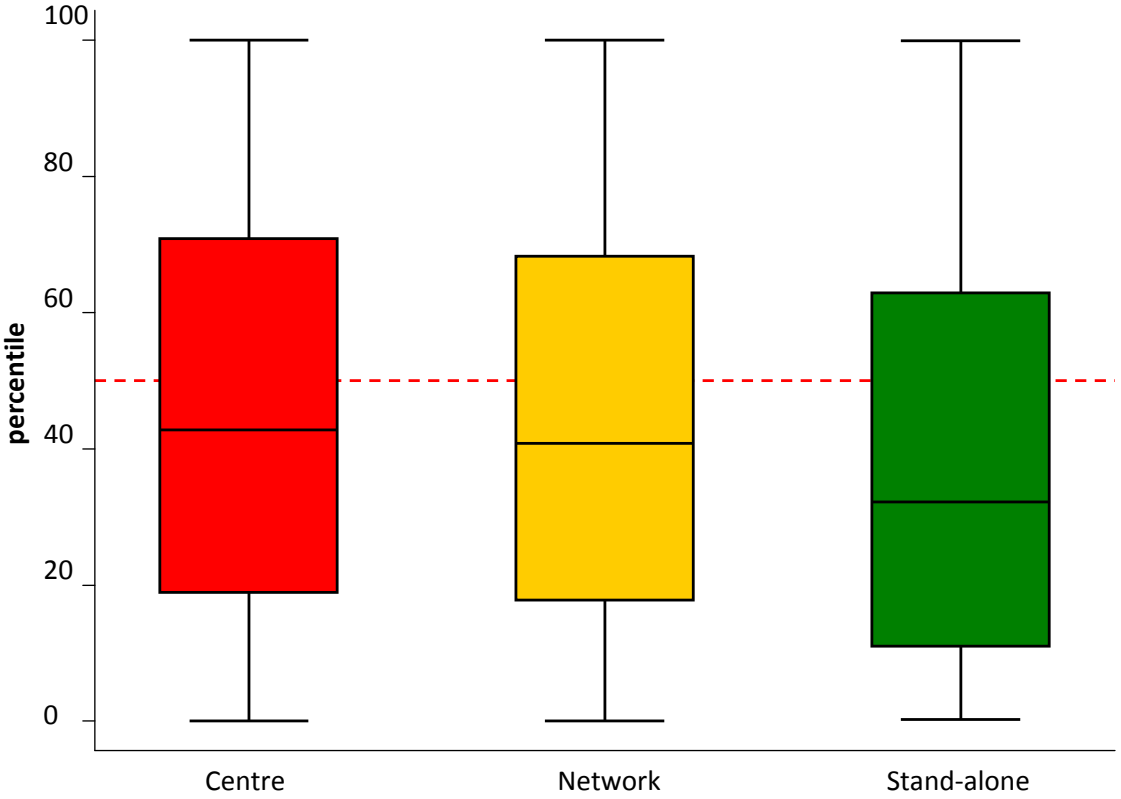
Figure 2.4.1 Median weight percentile by paediatric centre/clinic – all centres, networks and stand-alone clinics



The median weight percentile for paediatric centres/clinics is 41.9 (min=0, max=100).

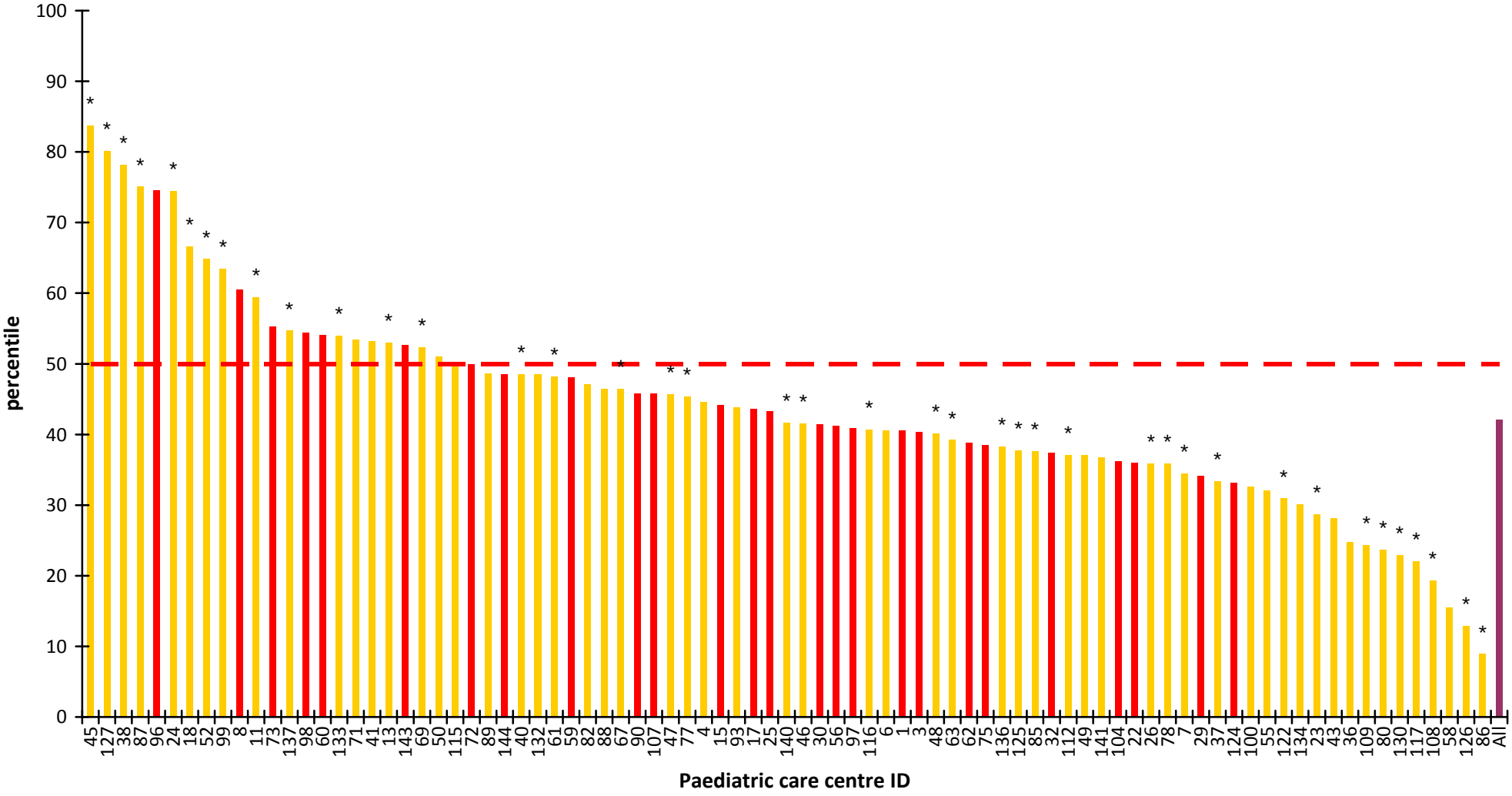
*Red: centres. Gold: network clinics. Green: stand-alone clinics. Plum: all. * Centre/clinic with a dataset submission of less than 20 patients*

Figure 2.4.2 Distribution of weight percentiles by paediatric model of care



The median weight percentile for paediatric centres/clinics is 41.9 (min=0, max=100).
Red: centres. Gold: network clinics. Green: stand-alone clinics.

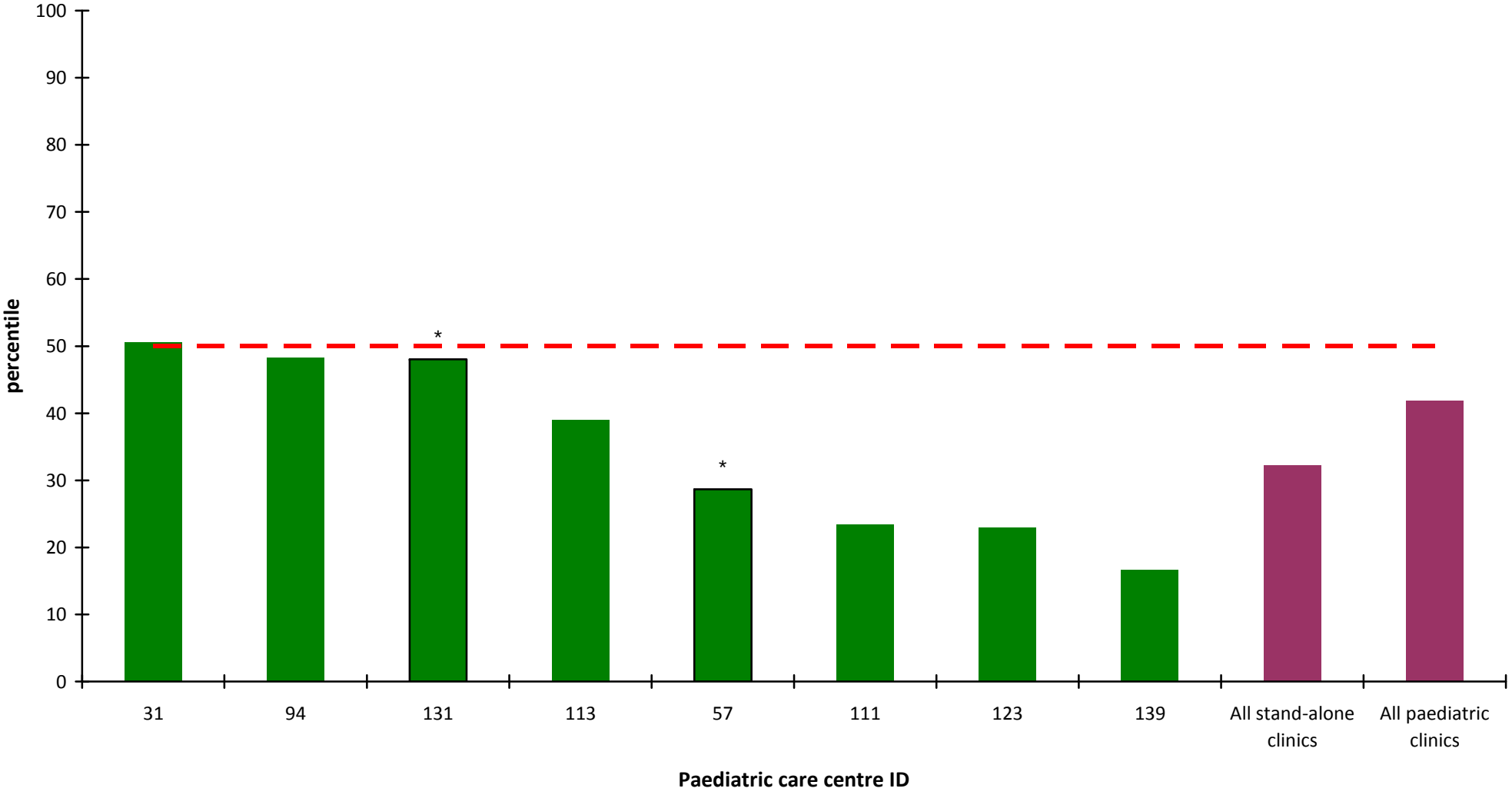
Figure 2.4.3 Median weight percentile by paediatric centre/clinic – all centres and networks



The median weight percentile for paediatric centres and network clinics is 42.2 (min=0, max=100).

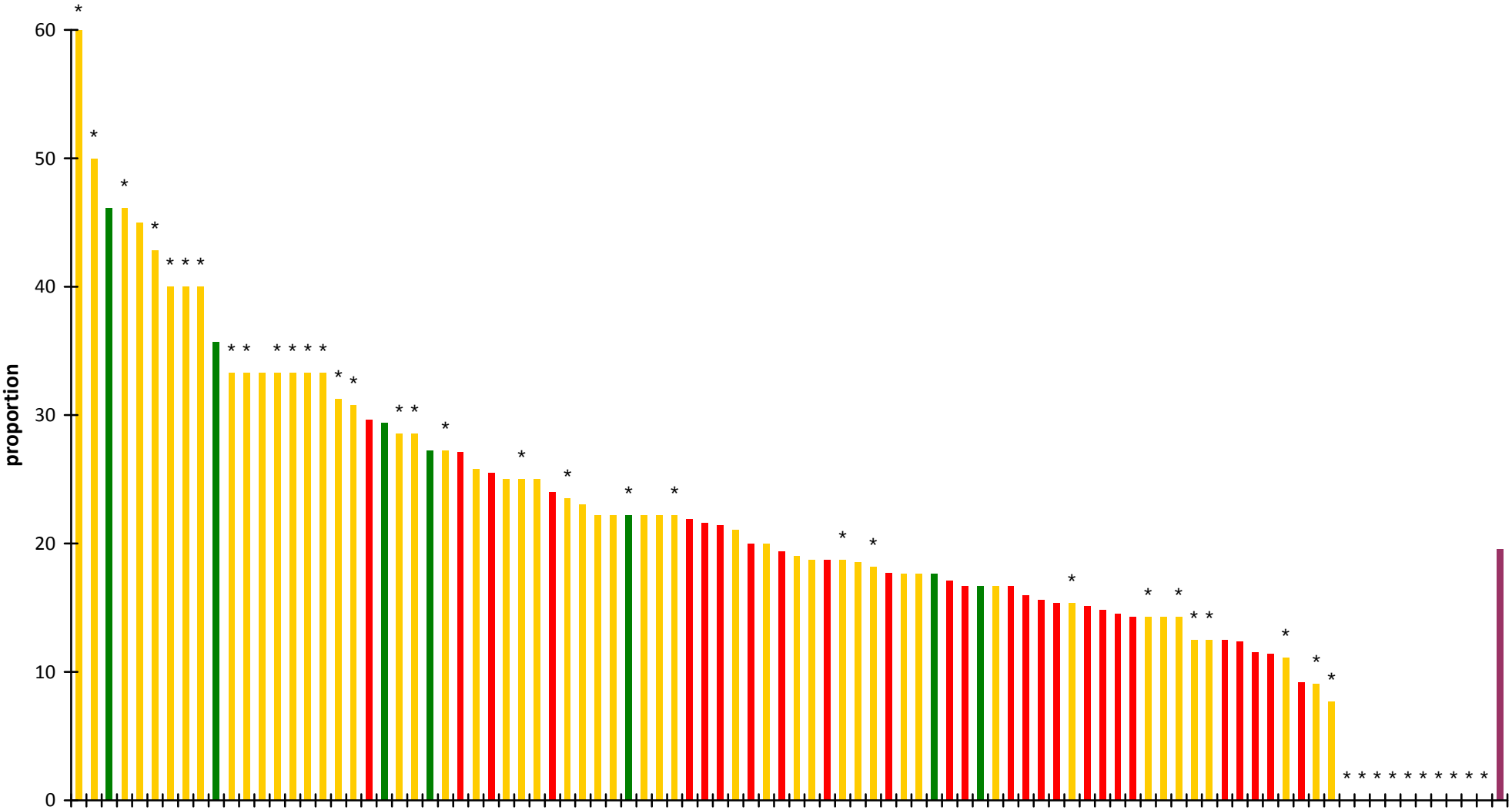
*Red: centres. Gold: network clinics. Plum: all. * Centre/clinic with a dataset submission of less than 20 patients*

Figure 2.4.4 Median weight percentile by paediatric stand-alone clinics



The median weight percentile for stand-alone paediatric clinics is 32.2 (min=0.2, max=99.9).
*Green: stand-alone clinics. Plum: all. * Clinic with a dataset submission of less than 20 patients*

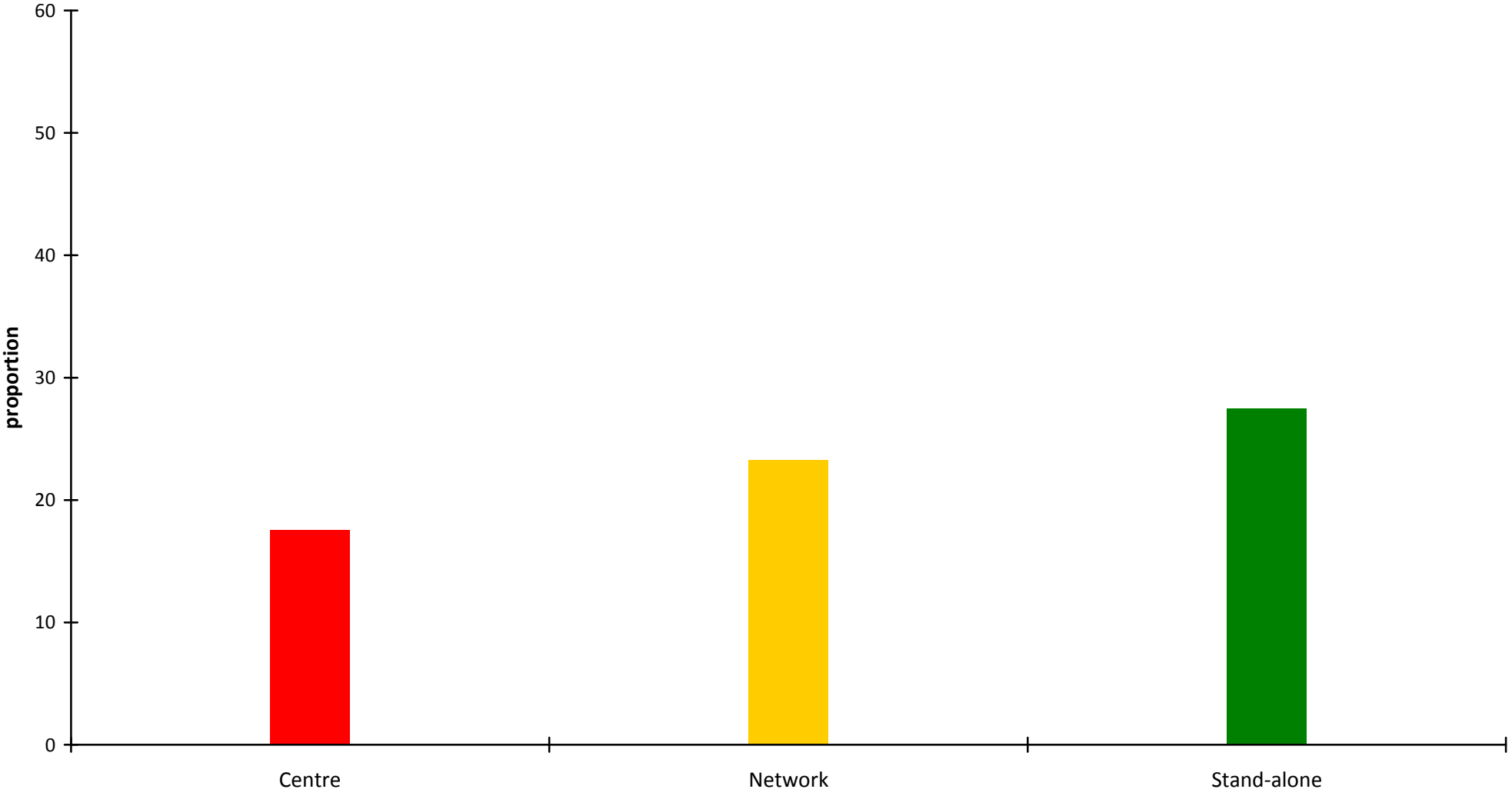
Figure 2.5.1 Proportion <10th percentile for height by paediatric centre/clinic – all centres, networks and stand-alone clinics



The proportion of patients at less than the 10th percentile for height for paediatric centres/clinics is 19.6%.

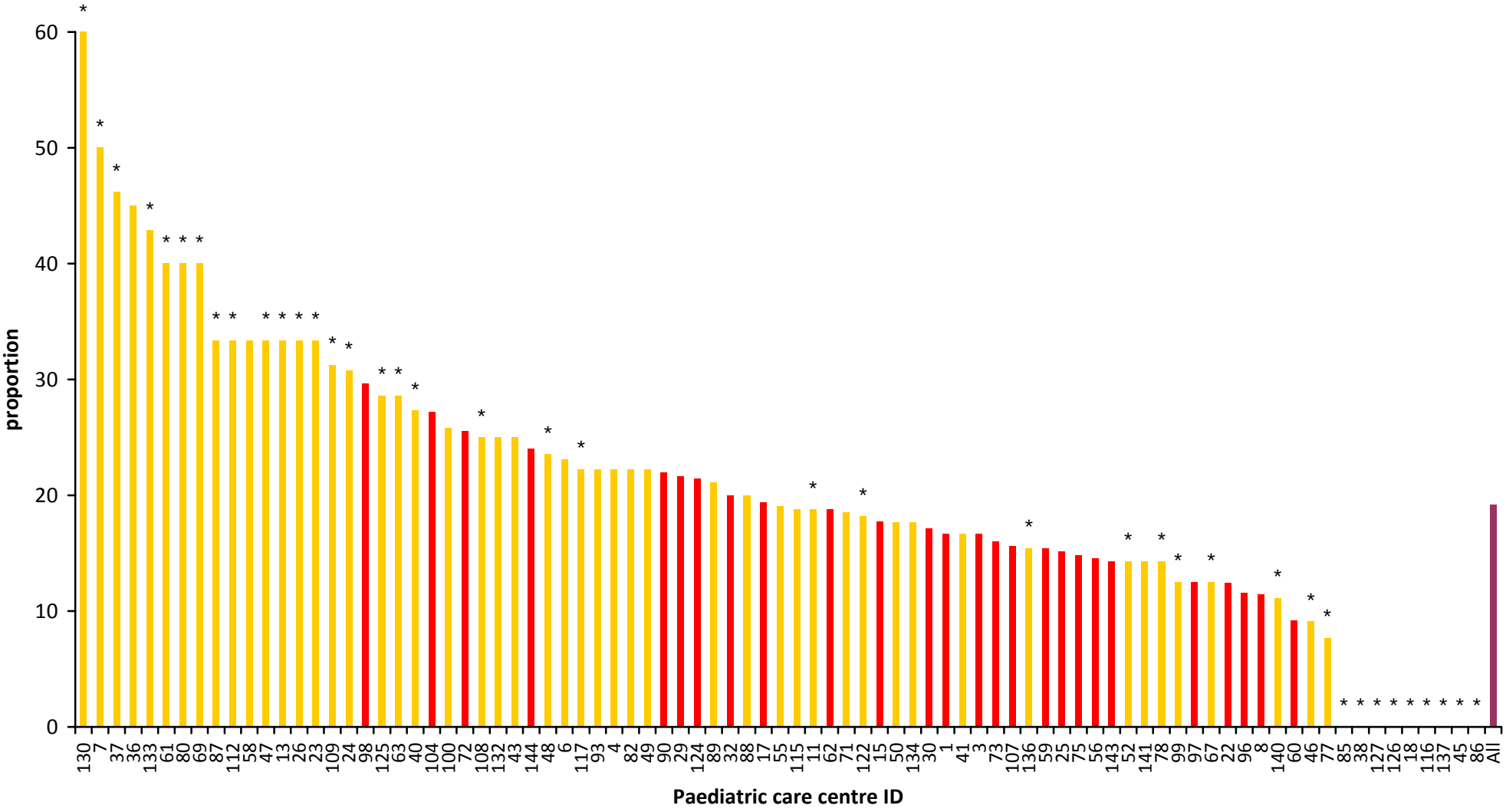
*Red: centres. Gold: network clinics. Green: stand-alone clinics. Plum: all. * Centre/clinic with a dataset submission of less than 20 patients*

Figure 2.5.2 Proportion <10th percentile for height by model of care



The proportion of patients at less than the 10th percentile for height for paediatric centres/clinics is 19.6%.

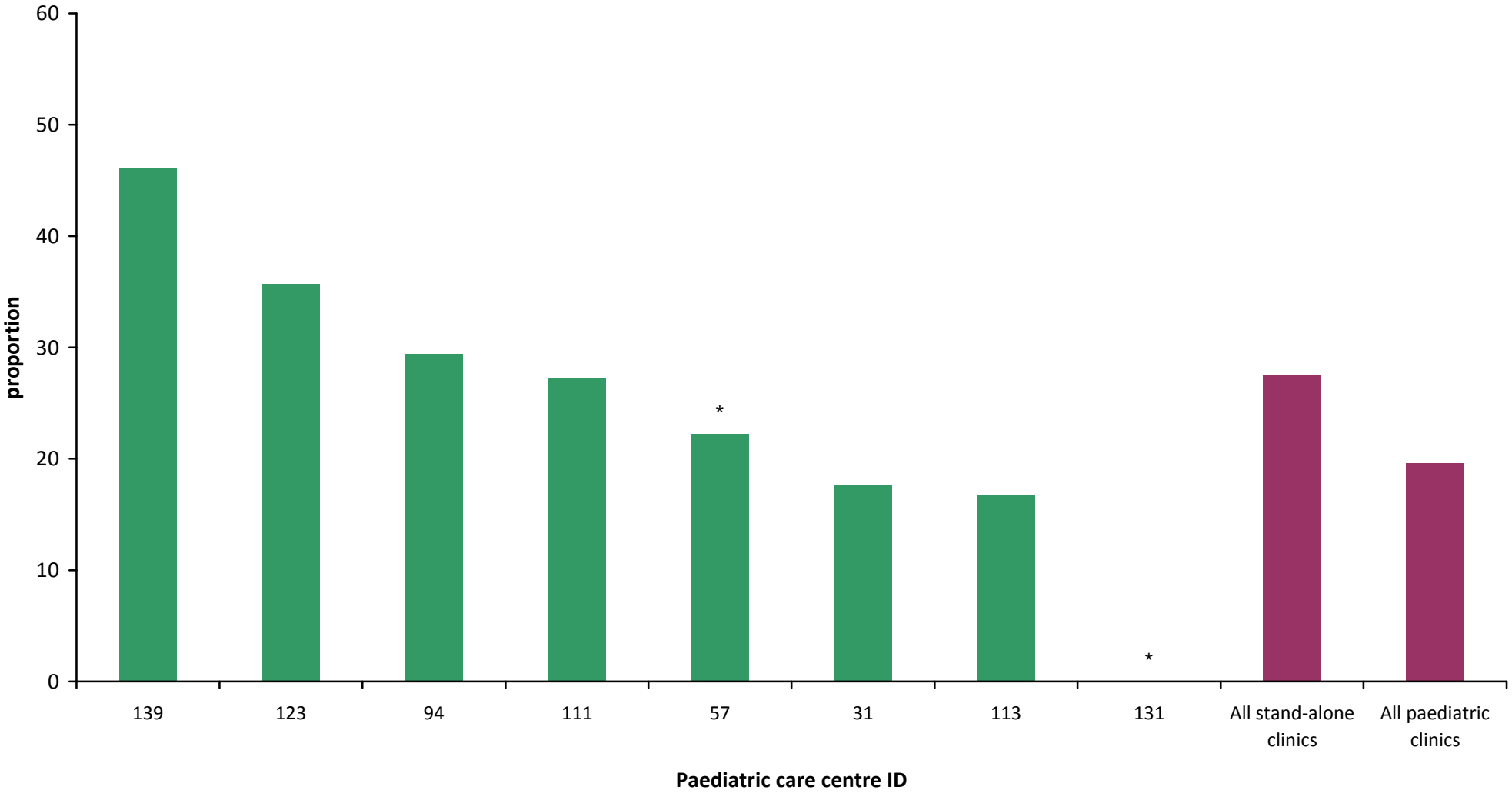
Figure 2.5.3 Proportion <10th percentile for height by paediatric centre/clinic – all centres and networks



The proportion of patients at less than the 10th percentile for height for paediatric centres and network clinics is 19.2%.

*Red: centres. Gold: network clinics. Plum: all. * Centre/clinic with a dataset submission of less than 20 patients*

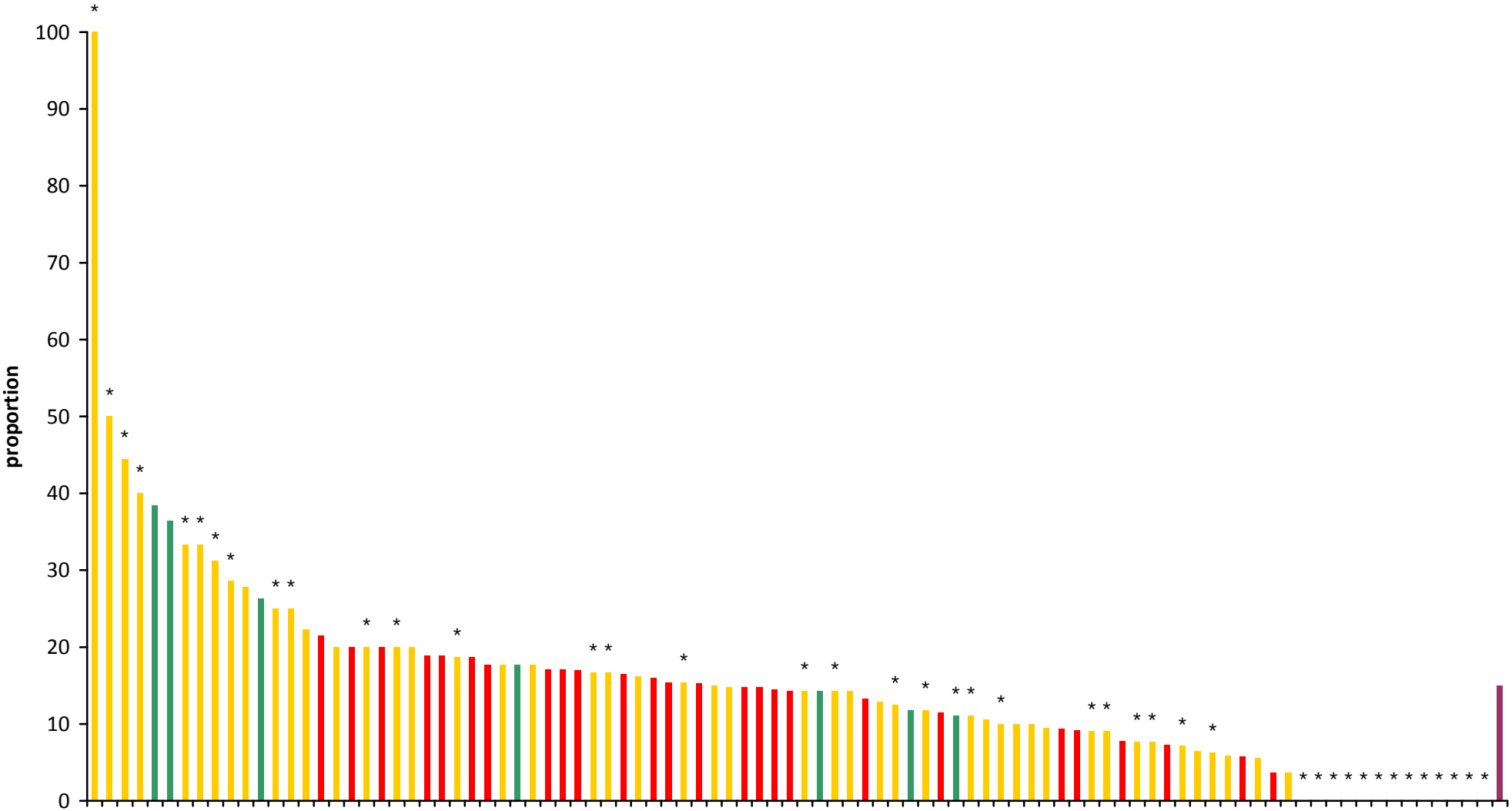
Figure 2.5.4 Proportion <10th percentile for height by paediatric stand-alone clinics



The proportion of patients at less than the 10th percentile for height for stand-alone paediatric clinics is 27.5%.

*Green: stand-alone clinics. Plum: all. * Clinic with a dataset submission of less than 20 patients*

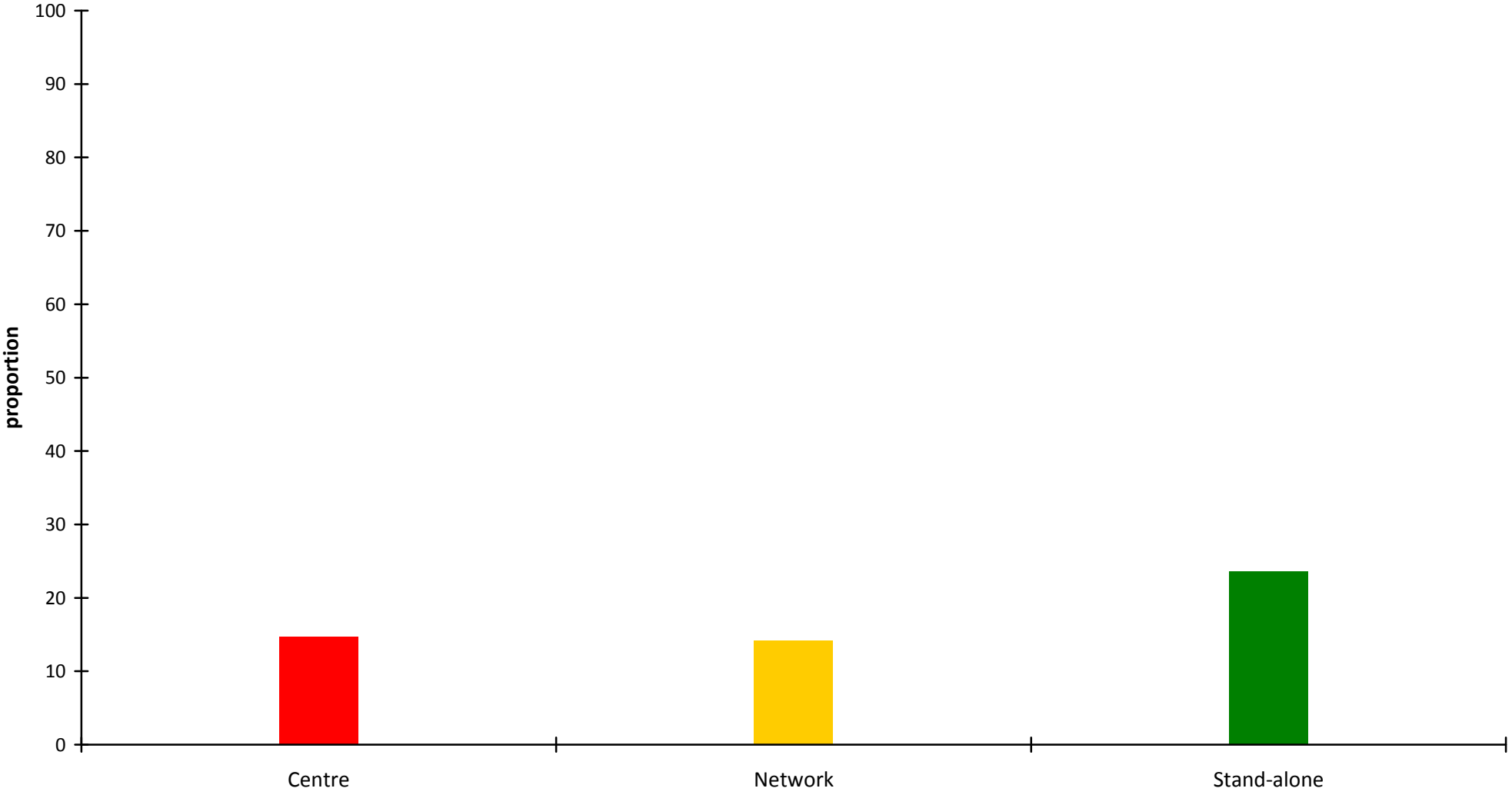
Figure 2.6.1 Proportion <10th percentile for weight by paediatric centre/clinic – all centres, networks and stand-alone clinics



The proportion of patients at less than the 10th percentile for weight for paediatric centres/clinics is 15.0%.

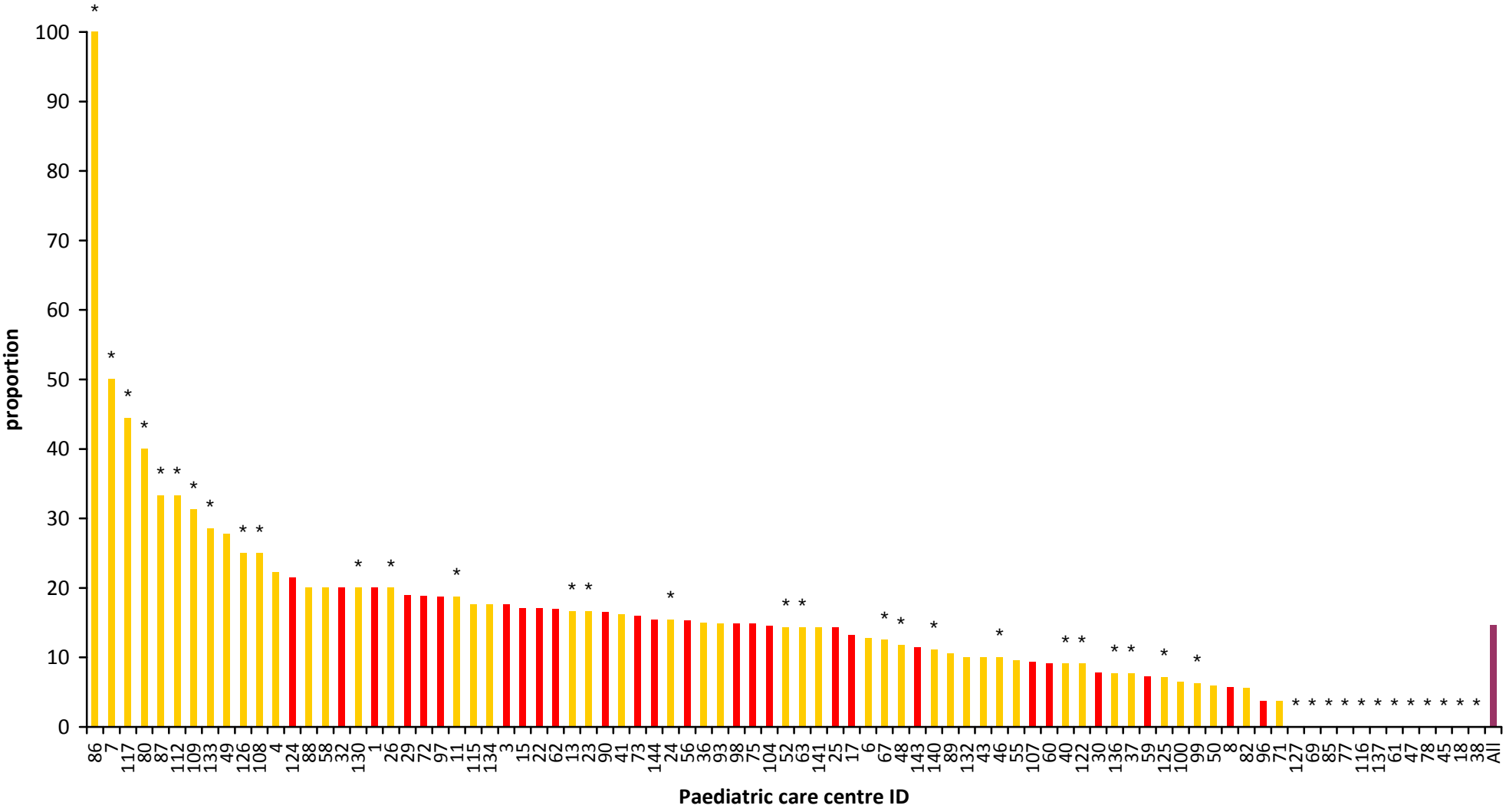
*Red: centres. Gold: network clinics. Green: stand-alone clinics. Plum: all. * Centre/clinic with a dataset submission of less than 20 patients*

Figure 2.6.2 Proportion <10th percentile for weight by model of care



The proportion of patients at less than the 10th percentile for weight for paediatric centres/clinics is 15.0%.

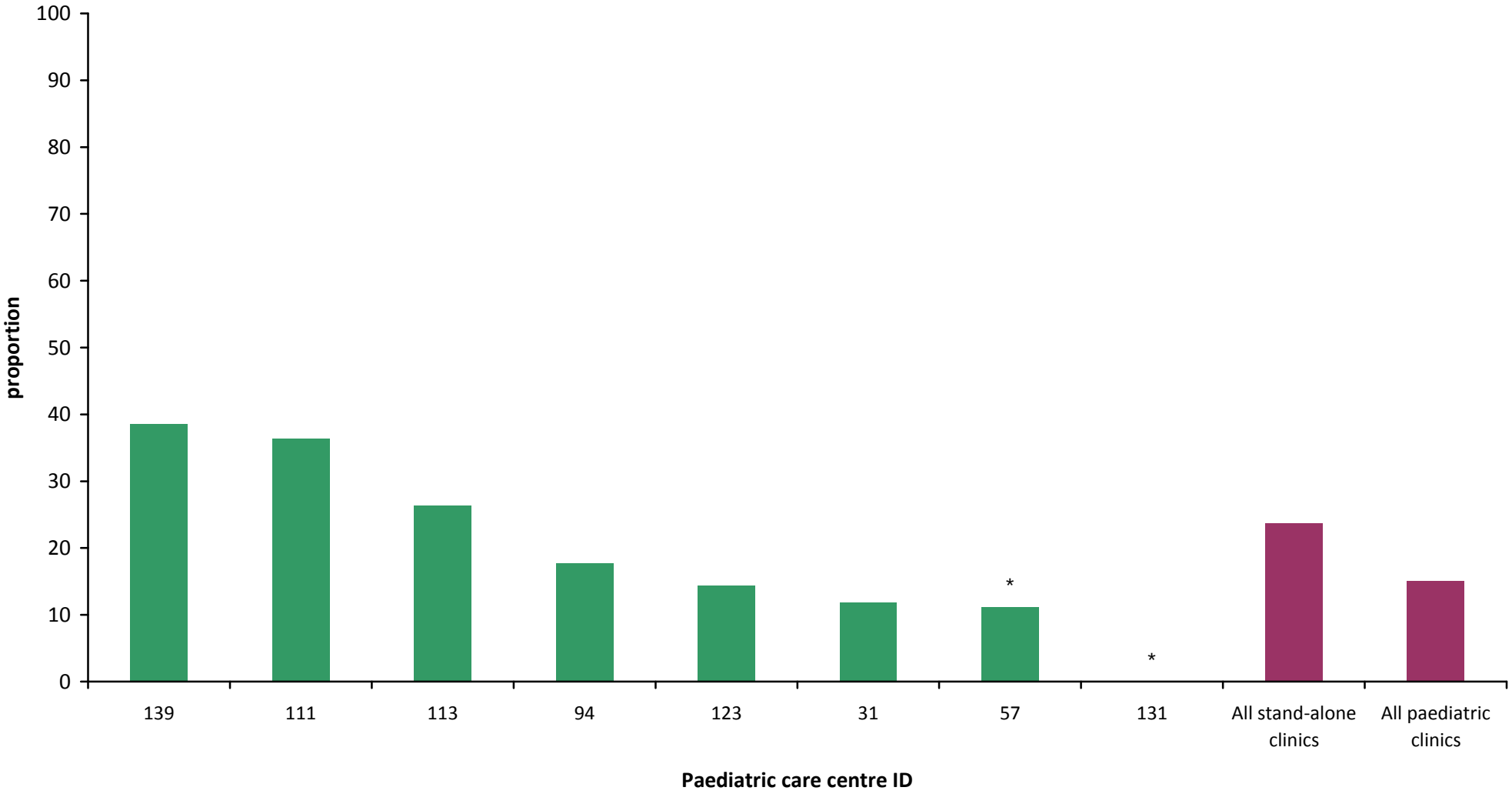
Figure 2.6.3 Proportion <10th percentile for weight by paediatric centre/clinic – all centres and networks



The proportion of patients at less than the 10th percentile for weight for paediatric centres and networks is 14.6%.

*Red: centres. Gold: network clinics. Plum: all. * Centre/clinic with a dataset submission of less than 20 patients*

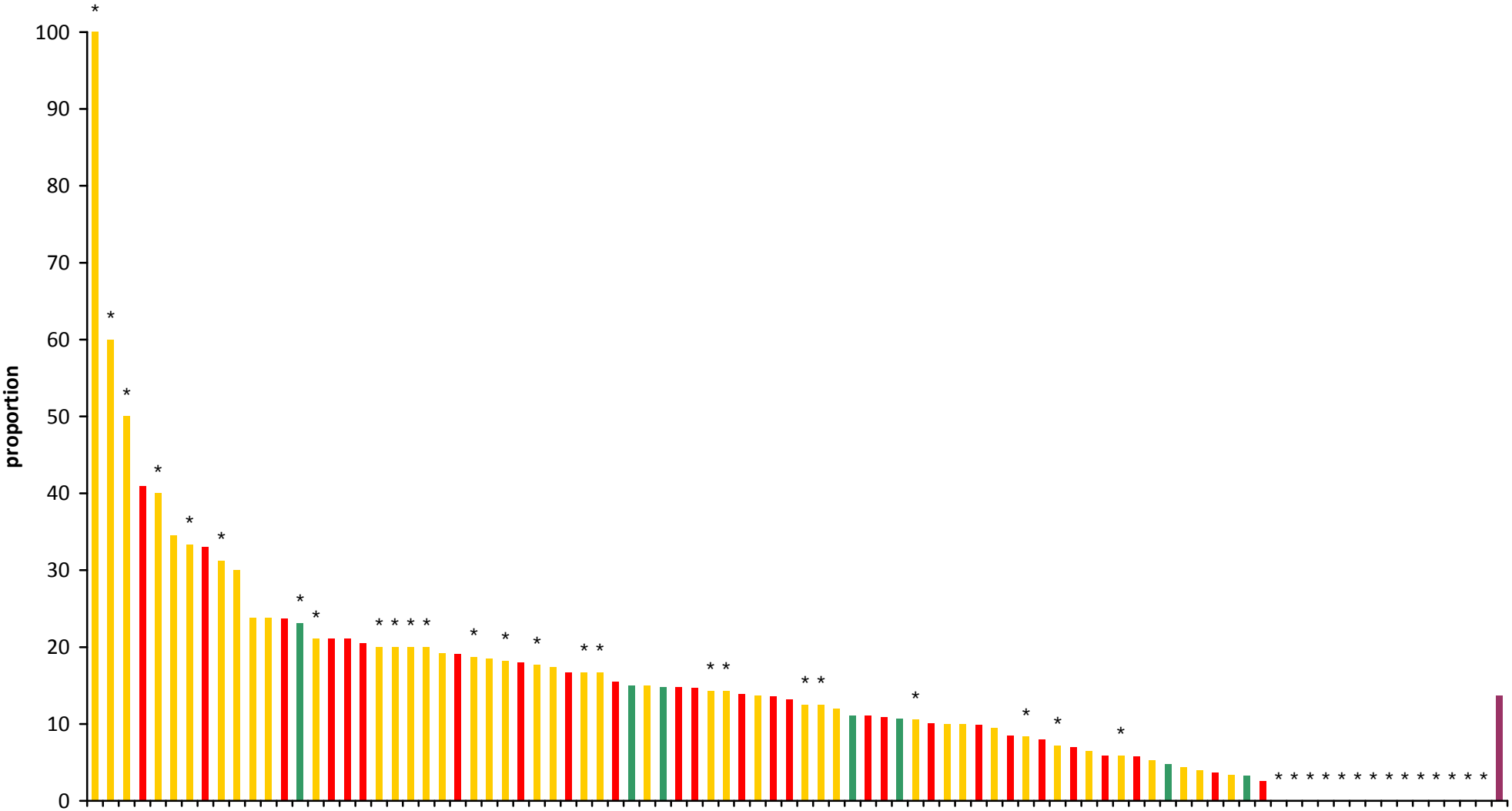
Figure 2.6.4 Proportion <10th percentile for weight by paediatric stand-alone clinics



The proportion of patients at less than the 10th percentile for weight for stand-alone paediatric clinics is 23.7%.

*Green: stand-alone clinics. Plum: all. * Clinic with a dataset submission of less than 20 patients*

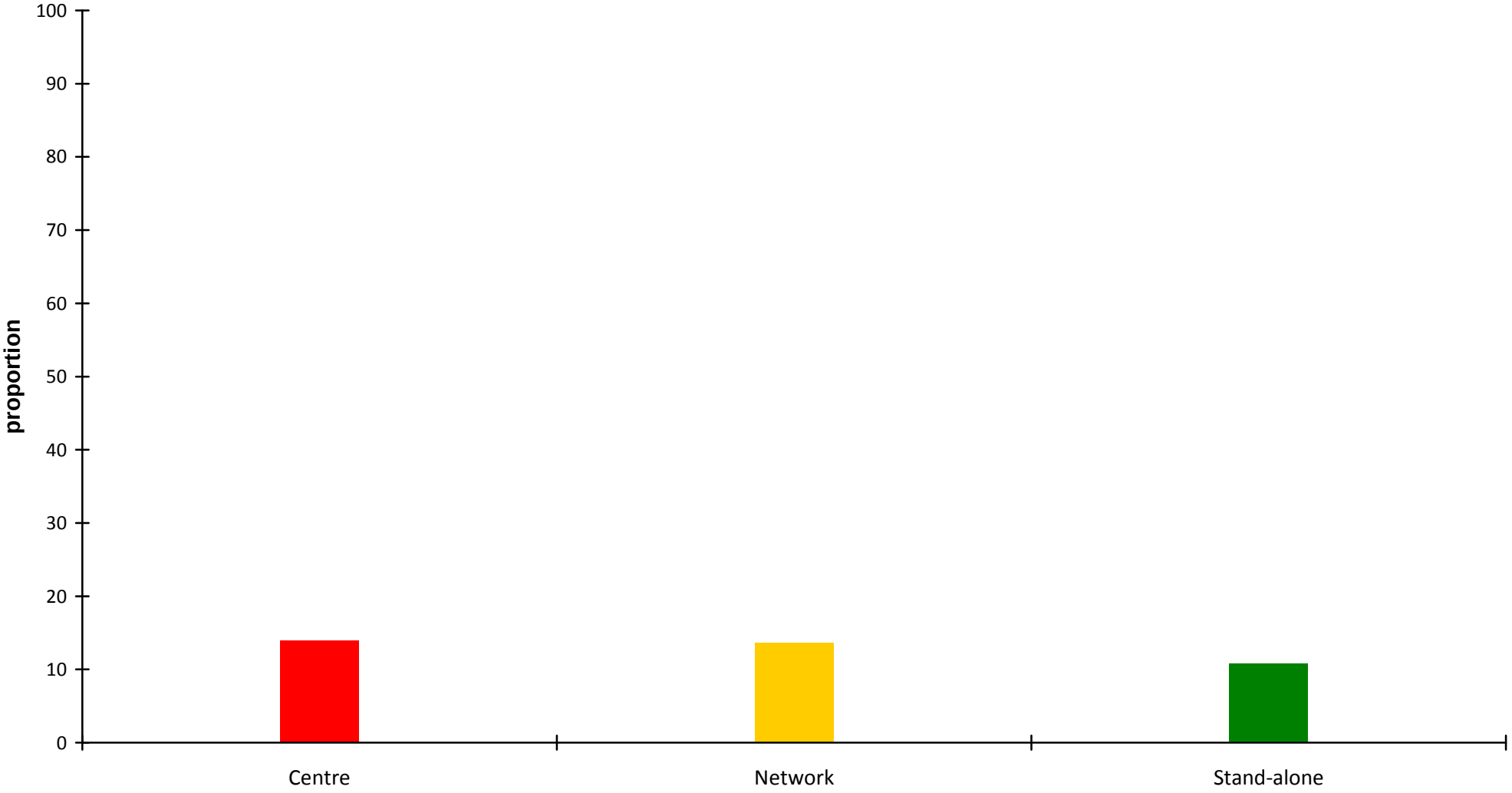
Figure 2.7.1 Proportion of patients with chronic *P.aeruginosa* by paediatric centre/clinic – all centres, networks and stand-alone clinics



The proportion of patients with chronic *P.aeruginosa* for paediatric centres/clinics is 13.7%.

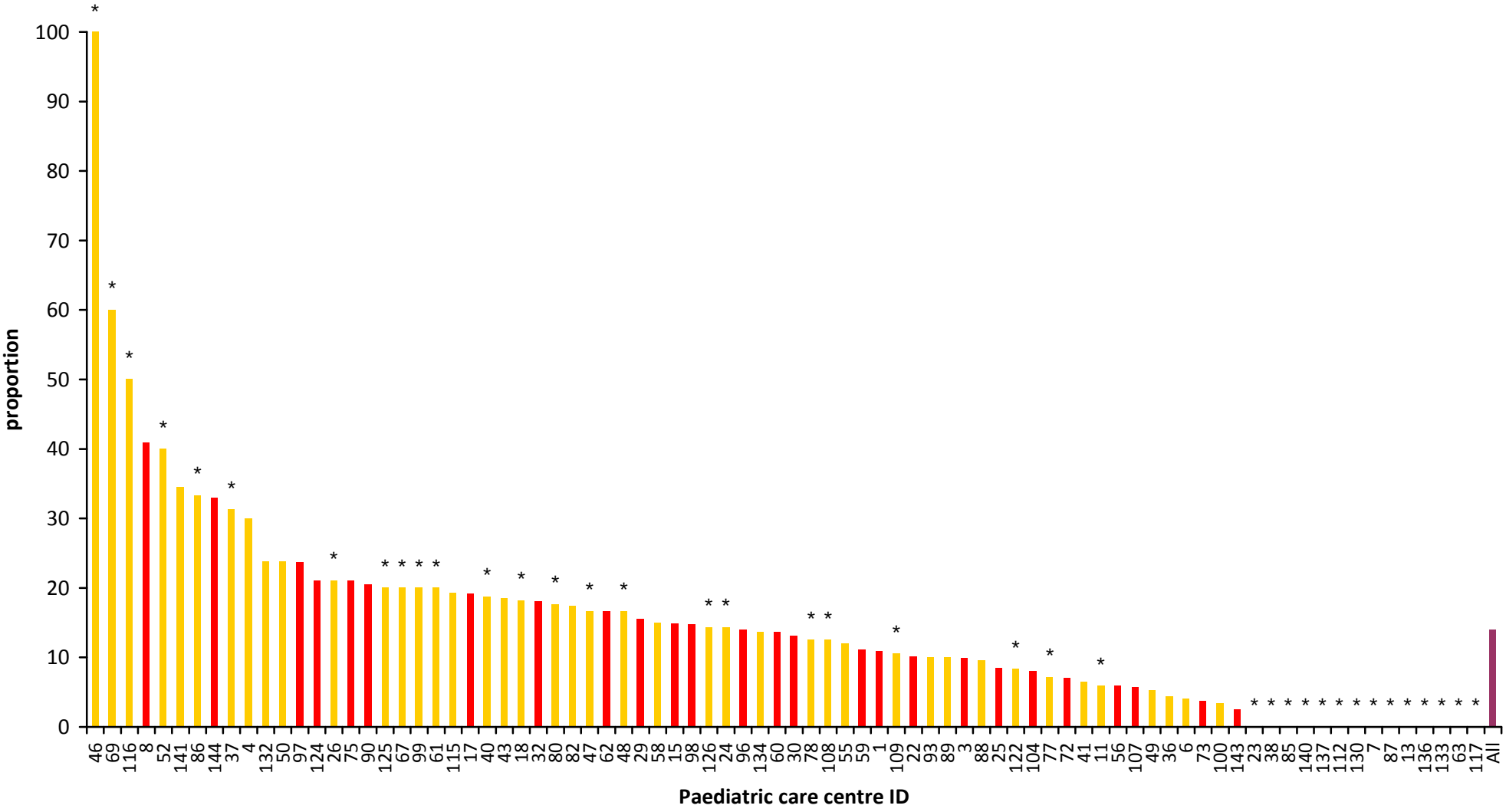
*Red: centres. Gold: network clinics. Green: stand-alone clinics. Plum: all. * Centre/clinic with a dataset submission of less than 20 patients*

Figure 2.7.2 Proportion of patients with chronic *P.aeruginosa* by model of care



The proportion of patients with chronic *P.aeruginosa* for paediatric centres/clinics is 13.7%.

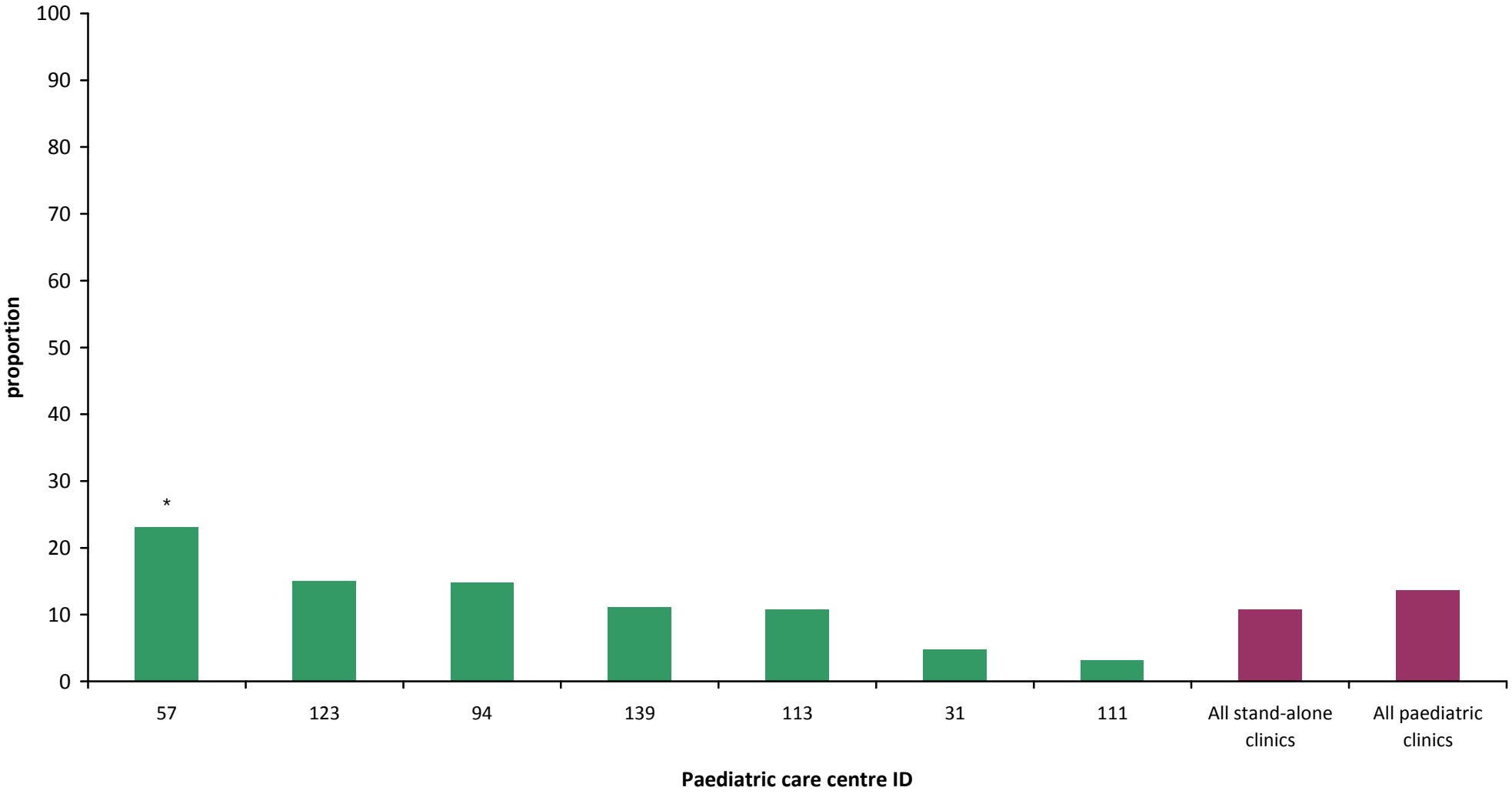
Figure 2.7.3 Proportion of patients with chronic *P. aeruginosa* by paediatric centre/clinic – all centres and networks



The proportion of patients with chronic *P. aeruginosa* for paediatric centres and networks is 13.9%.

*Red: centres. Gold: network clinics. Plum: all. * Centre/clinic with a dataset submission of less than 20 patients*

Figure 2.7.4 Proportion of patients with chronic *P.aeruginosa* by paediatric stand-alone clinics



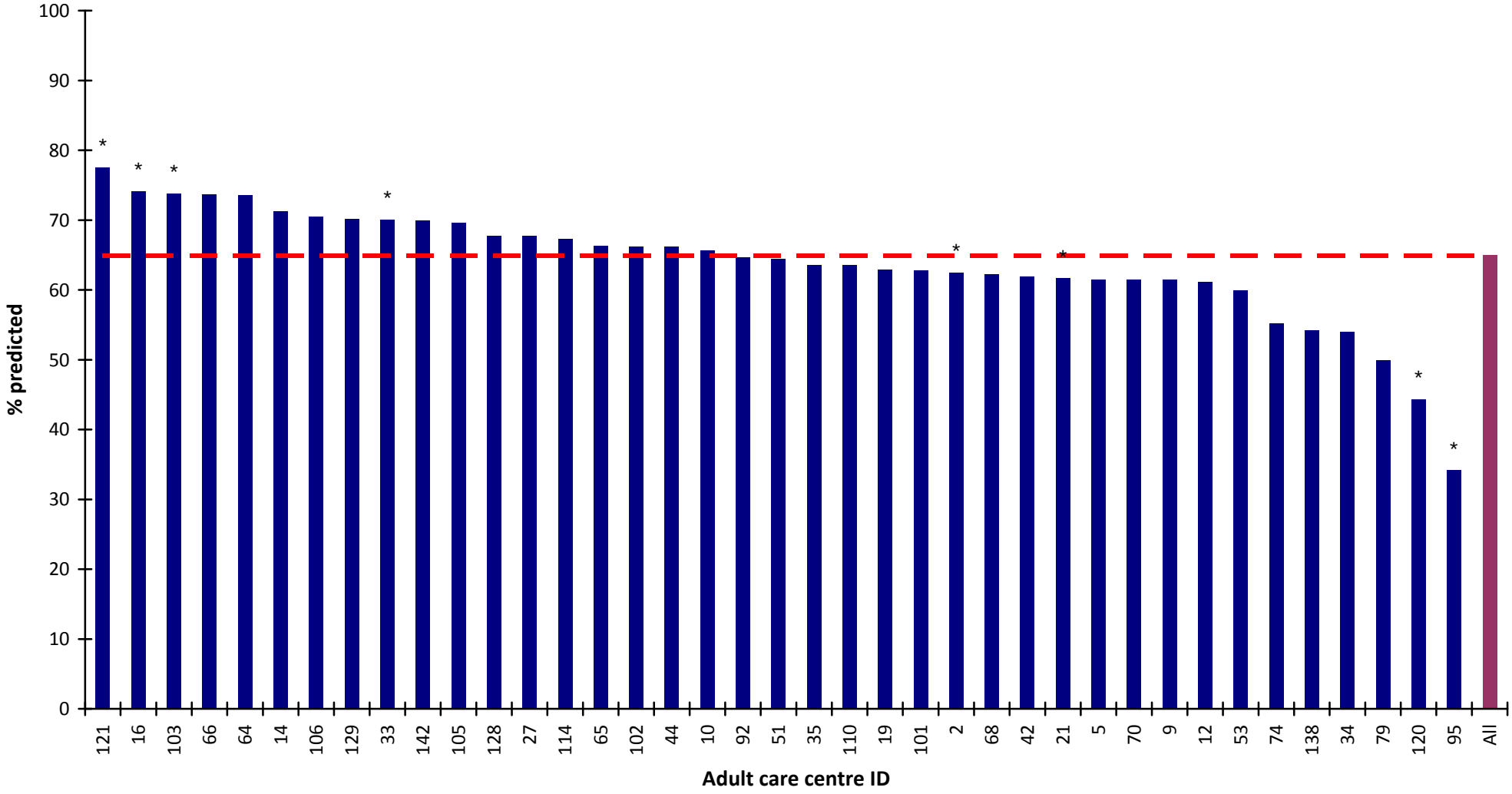
The proportion of patients with chronic *P.aeruginosa* for stand-alone paediatric clinics is 10.8%.
*Green: stand-alone clinics. Plum: all. * Clinic with a data set submission of less than 20 patients.*

Section 3: Analyses by Adult Service

(based on 3773 patients from adult services with complete* data at 2009 annual review)

** "Complete" data refers to the minimum data required to produce the range of clinical outcomes presented in this report.*

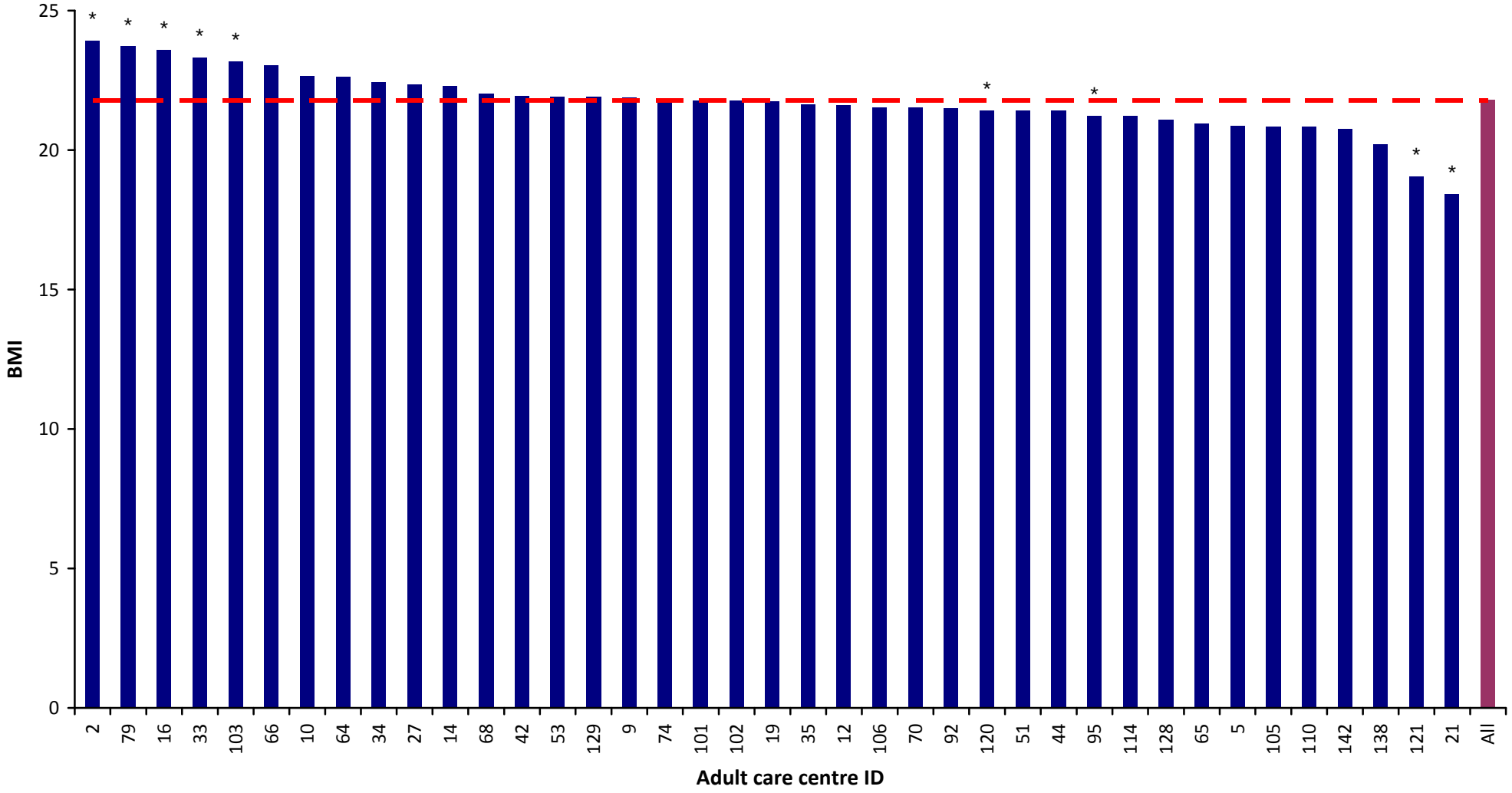
3.1 Median FEV_1 (% predicted) by adult service



The median FEV_1 (% predicted) for adult services is 64.9% (min=10.4%, max=147.0%).

*Blue: individual clinics. Plum: all. Red line: median for adult services. * Centre/clinic with a dataset submission of less than 20 patients*

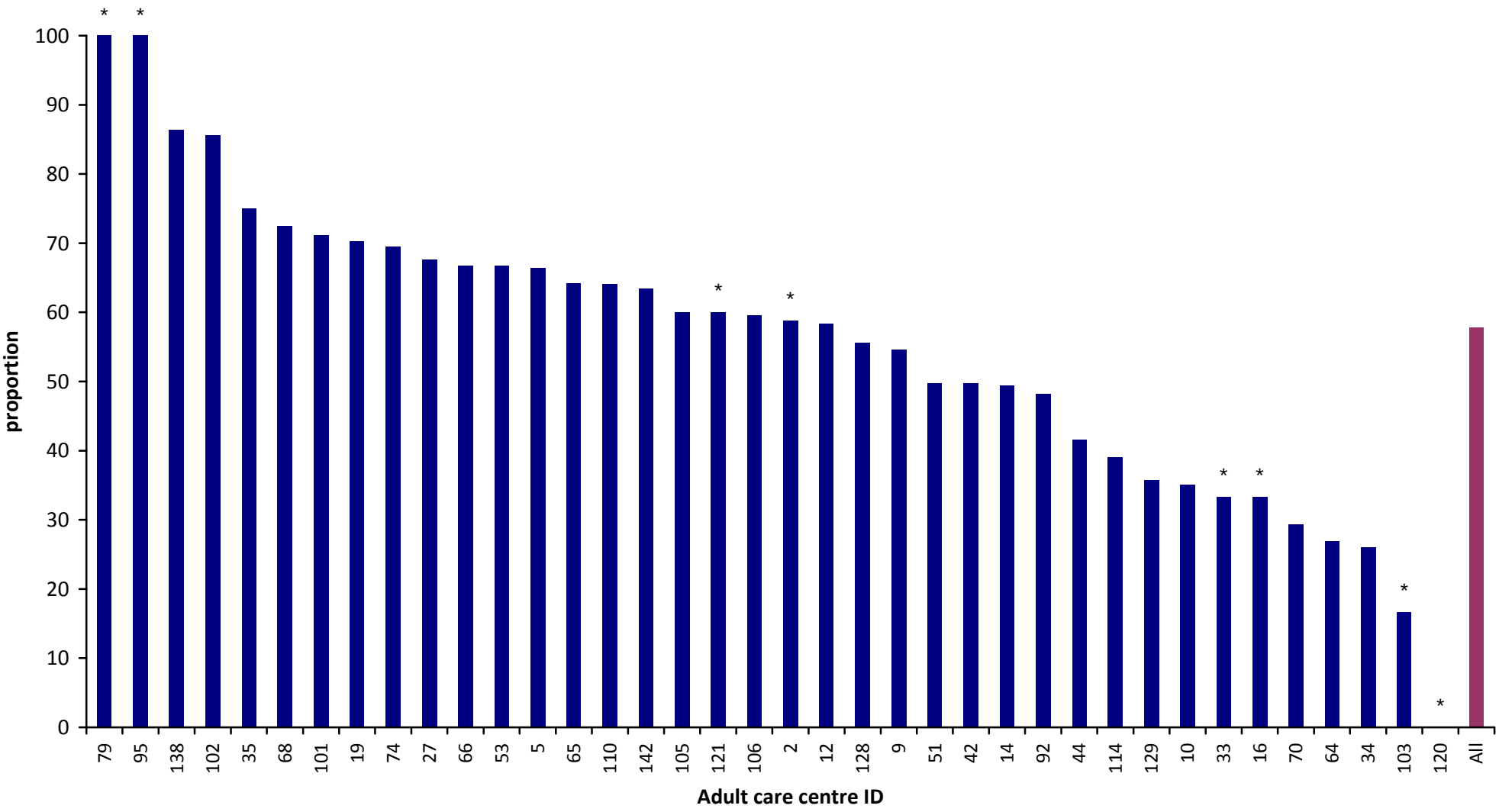
3.2 Median BMI by adult services



The median BMI for adult services is 21.8 (min=12.7, max=46.6).

*Blue: individual clinics. Plum: all. Red line: median for adult services. * Centre/clinic with a dataset submission of less than 20 patients*

Figure 3.3 Proportion of patients with chronic *P.aeruginosa* by adult services



The proportion of patients with chronic *P.aeruginosa* for adult services is 57.8%.

*Blue: individual clinics. Plum: all. * Centre/clinic with a dataset submission of less than 20 patients*

Section 4: Care centres/clinics providing data in 2009

4.1 Paediatric centres/clinics providing data in 2009 – ordered by clinic ID

Country	Location	Centre/clinic	Clinic ID	Network ID	Number of patients registered	Number of patients providing data in 2009
England	Leicester	Leicester Royal Infirmary	1	1	69	58
England	Sheffield	Sheffield Children's Hospital	3	3	147	123
England	Preston	Preston Royal Infirmary	4	144	21	20
England	Wolverhampton	New Cross Hospital	6	104	50	50
England	Barnsley	Barnsley Hospital	7	25	4	4
England	Stoke	University Hospital of North Staffordshire	8	8	74	44
England	Kings Lynn	Queen Elizabeth Hospital	11	98	18	17
Wales	Hereford	Hereford County Hospital	13	72	8	8
England	London - South West	Royal Brompton Hospital	15	15	338	219
England	London	King's College Hospital	17	17	107	92
England	Huntingdon	Hinchingbrooke Hospital	18	107	11	11
England	Oxford	John Radcliffe Hospital	22	22	172	142
Wales	Llantrisant	Royal Glamorgan Hospital	23	72	7	7

England	Kings Mill	Kings Mill Hospital	24	62	14	14
England	Leeds	St James's University Hospital	25	25	198	154
England	Torbay	Torbay Hospital	26	96	19	19
England	Southampton	Southampton General hospital	29	29	181	135
England	London - East	Royal London Hospital	30	30	114	99
Scotland	Inverness	Raigmore Hospital	31	31	25	23
England	Bristol	Bristol Royal Hospital for Children	32	32	81	61
England	Bath	Royal United Hospital	36	32	25	24
England	Taunton	Musgrove Park Hospital	37	32	18	16
Wales	Haverfordwest	Withybush General Hospital	38	72	6	6
England	Chester	Countess of Chester Hospital	40	97	17	17
England	Birmingham	Birmingham Heartlands Hospital	41	104	33	32
England	Brighton	Royal Alexandra Children's Hospital	43	17	32	31
England	Middlesborough-split	James Cook University Hospital	45	59	2	2
England	Blackburn	Royal Blackburn Hospital	46	144	15	14
Wales	Carmarthen	West Wales General Hospital	47	72	7	7

England	Canterbury & Thanet	Kent & Canterbury Hospital	48	17	19	19
England	Derby	Derby Hospital	49	62	27	22
England	Shrewsbury & Telford	Princess Royal Hospital and Royal Shrewsbury Hospital.	50	8	25	22
England	Lancaster	Royal Lancaster Hospital	52	144	14	11
England	Ipswich	Ipswich General Hospital	55	107	29	25
Scotland	Glasgow	Royal Hospital for Sick Children	56	56	241	141
England	Barnstaple	North Devon District Hospital	57	57	13	13
England	Boston	Pilgrim Hospital	58	62	23	23
England	Newcastle	Royal Victoria Infirmary	59	59	124	111
Northern Ireland	Belfast	Royal Belfast Hospital for Sick Children	60	60	229	164
Wales	Aberystwyth	Bronglais Hospital	61	72	5	5
England	Nottingham	Nottingham City Hospital	62	62	91	74
Wales	Bridgend	Princess of Wales Hospital	63	72	9	7
England	Bangor	Ysbyty Gwynedd	67	97	10	10
England	Burton	Queen's Hospital	69	8	5	5
England	Middlesborough – stand-alone	James Cook University Hospital	71	71		35

Wales	Cardiff	Children's Hospital for Wales	72	72	102	66
Scotland	Dundee	Ninewells Hospital	73	73	31	27
Scotland	Aberdeen	Royal Aberdeen Children's Hospital	75	75	40	35
Wales	Newport	Royal Gwent Hospital	77	72	30	17
Wales	Abergavenny	Nevill Hall Hospital	78	72	10	9
England	Luton	Luton & Dunstable Hospital	80	90	17	17
England	Warrington	Warrington District General Hospital	82	97	26	24
England	Scarborough	Scarborough District General Hospital	85	25	3	1
England	Cheltenham and Gloucester	Cheltenham General Hospital and Gloucester Royal Hospital	86	32	6	3
England	Macclesfield	Macclesfield District General Hospital	87	97	5	4
England	Ashford & Dover	William Harvey Hospital	88	17	22	22
England	Glan Clwyd (Rhyl)	Glan Clwyd General Hospital	89	97	20	20
England	London – Central	Great Ormond Street Hospital for Sick Children	90	90	169	127
England	Coventry	Walsgrave Hospital	93	104	37	30
England	Truro	Royal Cornwall Hospital	94	94	29	27
England	Exeter	Royal Devon & Exeter Hospital	96	96	48	39

England	Liverpool	Alder Hey Children's Hospital	97	97	92	76
England	Norwich	Norfolk & Norwich University Hospital	98	98	40	35
England	Sunderland	Sunderland Royal Hospital	99	59	19	19
Wales	Swansea	Singleton Hospital	100	72	33	33
England	Birmingham	Birmingham Children's Hospital	104	104	212	183
England	Cambridge	Addenbrookes Hospital	107	107	40	36
England	Huddersfield & Halifax	Huddersfield Royal Infirmary and Calderdale Royal Hospital	108	25	9	9
England	Lincoln	Lincoln Hospital	109	62	20	19
England	Hull	Hull Royal Infirmary	111	111	41	32
England	Burnley	Burnley General Hospital	112	144	18	17
England	Carshalton	Queen Mary's Hospital for Children	113	113	34	31
England	Wigan	Royal Albert Edward Infirmary	115	97	31	30
England	Wythenshawe	Wythenshawe Hospital	116	144	8	4
England	West Suffolk	West Suffolk General Hospital	117	107	11	9
England	Bishop Auckland & Darlington	Bishop Auckland General Hospital	122	59	12	12
Scotland	Ayr/Kilmarnock	Crosshouse Hospital	123	123	40	24

England	London - South East	University Hospital Lewisham	124	124	43	39
England	Crewe	Leighton Hospital	125	97	17	15
England	Chesterfield	Chesterfield Hospital	126	62	9	9
Scotland	Dumfries and Galloway	Dumfries and Galloway Royal Infirmary	127	56	5	2
England	Great Yarmouth	James Paget Hospital	130	98	14	14
England	Bradford	St Luke's Hospital	131	131	17	10
England	Wirral	Arrowe Park Hospital	132	97	24	22
England	Ormskirk/Southport	Ormskirk & District General Hospital	133	97	16	11
England	Peterborough	Peterbrough District General Hospital	134	107	25	23
England	Whiston	Whiston Hospital	136	97	14	14
England	Barnsley	Barnsley Hospital	137	3	6	6
England	Plymouth	Derriford Hospital	139	139	33	31
England	Whitehaven	West Cumberland Hospital	140	59	11	11
England	Blackpool	Victoria Hospital	141	144	29	29
Scotland	Edinburgh	Royal Hospital for Sick Children	143	143	118	85
England	Manchester	Royal Manchester Children's Hospital (previously: University of Central Manchester Hospital)	144	144	247	110

4.2 Adult centres/clinics providing data in 2009 – ordered by clinic ID

Country	Location	Centre/clinic	Clinic ID	Network ID	Number of patients registered	Number of patients providing data in 2009
England	Wolverhampton	New Cross Hospital, Wolverhampton	2	27	17	17
England	London - South East	King's College Hospital, London	5	5	117	103
England	Newcastle	Royal Victoria Infirmary, Newcastle	9	9	216	198
England	Bath	Bath Royal United Hospital	10	106	20	20
England	London - South West	Royal Brompton Hospital, London	12	12	685	563
Northern Ireland	Belfast	Belfast City Hospital	14	14	206	181
England	Taunton	Musgrove Park Hospital, Taunton	16	34	12	12
England	Frimley	Frimley Park Hospital, Camberley	19	19	111	97
Scotland	Dundee	Ninewells Hospital, Dundee	21	44	41	1
England	Birmingham	Birmingham Heartlands Hospital	27	27	299	263
England	Barnstaple	North Devon District Hospital, Barnstaple	33	34	6	6
England	Exeter	Royal Devon & Exeter Hospital, Exeter	34	34	32	30
England	Poole	Poole Hospital	35	110	22	22
England	Leeds	St James's University Hospital, Leeds	42	42	374	348

Scotland	Edinburgh	Western General Hospital, Edinburgh	44	44	139	112
England	Cambridge	Papworth Hospital	51	51	246	195
Scotland	Inverness-split	Raigmore Hospital, Inverness	53	44	21	20
England	Plymouth	Derriford Hospital, Plymouth	64	64	42	42
England	Sheffield	Northern General Hospital, Sheffield	65	65	122	119
England	Liverpool	Liverpool Heart and Chest Hospital	66	66	237	229
Wales	Llandough	Llandough Hospital	68	68	144	137
Scotland	Aberdeen	Aberdeen Royal Infirmary	70	70	52	47
England	Stoke	University Hospital of North Staffordshire, Stoke-on-Trent	74	74	40	39
Scotland	Glasgow	Gartnavvel General Hospital, Glasgow	79	79	99	2
England	London - East	London Chest Hospital	92	92	141	122
England	Portsmouth	Queen Alexandra Hospital, Portsmouth	95	95	18	1
England	Nottingham	Nottingham City hospital	101	101	117	105
England	Manchester	Wythenshawe Hospital, Manchester	102	102	305	273
England	Torbay	Torbay Hospital	103	34	13	12
England	London - South East	University Hospital Lewisham, London	105	105	43	41
England	Bristol	Bristol Royal Infirmary	106	106	106	91

England	Southampton	Southampton General hospital	110	110	144	123
England	Norwich	Norfollk & Norwich University Hospital, Norwich	114	114	50	45
England	York	York Hospital	120	42	5	2
Scotland	Dumfries and Galloway	Dumfries and Galloway Royal Infirmary	121	44	5	5
England	Oxford	Churchill Hospital, Oxford	128	128	61	44
England	Truro	Royal Cornwall Hospital, Truro	129	129	29	28
England	Hull	Castle Hill Hospital, Hull	138	138	26	26
England	Leicester	Glenfield Hospital, Leicester	142	142	52	52

4.3 Paediatric centres/clinics providing data in 2009 – alphabetical order

England

Location		Centre/clinic	Clinic ID	Network ID	Number of patients registered	Number of patients providing data in 2009
Barnstaple		North Devon District Hospital	57	57	13	13
Birmingham	*Birmingham*	Birmingham Children's Hospital	104	104	212	183
	Birmingham	Birmingham Heartlands Hospital	41	104	33	32
	Coventry	Walsgrave Hospital	93	104	37	30
	Wolverhampton	New Cross Hospital	6	104	50	50
Bradford		St Luke's Hospital	131	131	17	10
Bristol	*Bristol*	Bristol Royal Hospital for Children	32	32	81	61
	Bath	Royal United Hospital	36	32	25	24
	Cheltenham and Gloucester	Cheltenham General Hospital and Gloucester Royal Hospital	86	32	6	3
	Taunton	Musgrove Park Hospital	37	32	18	16
Cambridge	*Cambridge*	Addenbrookes Hospital	107	107	40	36
	Huntingdon	Hinchingbrooke Hospital	18	107	11	11
	Ipswich	Ipswich General Hospital	55	107	29	25
	Peterborough	Peterbrough District General Hospital	134	107	25	23
	West Suffolk	West Suffolk General Hospital	117	107	11	9
Carshalton		Queen Mary's Hospital for Children	113	113	34	31
Exeter	*Exeter*	Royal Devon & Exeter Hospital	96	96	48	39
	Torbay	Torbay Hospital	26	96	19	19

Hull		Hull Royal Infirmary	111	111	41	32
Leeds	Leeds	St James's University Hospital	25	25	198	154
	Barnsley	Barnsley Hospital	7	25	4	4
	Huddersfield & Halifax	Huddersfield Royal Infirmary and Calderdale Royal Hospital	108	25	9	9
	Scarborough	Scarborough District General Hospital	85	25	3	1
Leicester	*Leicester*	Leicester Royal Infirmary	1	1	69	58
Liverpool	*Liverpool*	Alder Hey Children's Hospital	97	97	92	76
	Bangor	Ysbyty Gwynedd	67	97	10	10
	Chester	Countess of Chester Hospital	40	97	17	17
	Crewe	Leighton Hospital	125	97	17	15
	Glan Clwyd (Rhyl)	Glan Clwyd General Hospital	89	97	20	20
	Macclesfield	Macclesfield District General Hospital	87	97	5	4
	Ormskirk/Southport	Ormskirk & District General Hospital	133	97	16	11
	Warrington	Warrington District General Hospital	82	97	26	24
	Whiston	Whiston Hospital	136	97	14	14
	Wigan	Royal Albert Edward Infirmary	115	97	31	30
	Wirral	Arrowe Park Hospital	132	97	24	22
London - Central	*London - Central*	Great Ormond Street Hospital for Sick Children	90	90	169	127
	Luton	Luton & Dunstable Hospital	80	90	17	17
London - East		Royal London Hospital	30	30	114	99
London - South East	*London*	King's College Hospital	17	17	107	92
	Ashford & Dover	William Harvey Hospital	88	17	22	22
	Brighton	Royal Alexandra Children's Hospital	43	17	32	31
	Canterbury & Thanet	Kent & Canterbury Hospital	48	17	19	19
London - South East		University Hospital Lewisham	124	124	43	39

London - South West		Royal Brompton Hospital	15	15	338	219
Manchester	*Manchester*	Royal Manchester Children's Hospital (previously: University of Central Manchester Hospital)	144	144	247	110
	Blackburn	Royal Blackburn Hospital	46	144	15	14
	Blackpool	Victoria Hospital	141	144	29	29
	Burnley	Burnley General Hospital	112	144	18	17
	Lancaster	Royal Lancaster Hospital	52	144	14	11
	Preston	Preston Royal Infirmary	4	144	21	20
	Wythenshawe	Wythenshawe Hospital	116	144	8	4
Newcastle	*Newcastle*	Royal Victoria Infirmary	59	59	124	111
	Bishop Auckland & Darlington	Bishop Auckland General Hospital	122	59	12	12
	Middlesborough-split	James Cook University Hospital	45	59	2	2
	Sunderland	Sunderland Royal Hospital	99	59	19	19
	Whitehaven	West Cumberland Hospital	140	59	11	11
Newcastle	*Middlesborough – standalone*	James Cook University Hospital	71	71	41	35
Norwich	*Norwich*	Norfolk & Norwich University Hospital	98	98	40	35
	Great Yarmouth	James Paget Hospital	130	98	14	14
	Kings Lynn	Queen Elizabeth Hospital	11	98	18	17
Nottingham	*Nottingham*	Nottingham City Hospital	62	62	91	74
	Boston	Pilgrim Hospital	58	62	23	23
	Chesterfield	Chesterfield Hospital	126	62	9	9
	Derby	Derby Hospital	49	62	27	22
	Kings Mill	Kings Mill Hospital	24	62	14	14
	Lincoln	Lincoln Hospital	109	62	20	19

Oxford		John Radcliffe Hospital	22	22	172	142
Plymouth		Derriford Hospital	139	139	33	31
Sheffield	*Sheffield*	Sheffield Children's Hospital	3	3	147	123
	Barnsley	Barnsley Hospital	137	3	6	6
Southampton		Southampton General hospital	29	29	181	135
Stoke	*Stoke*	University Hospital of North Staffordshire	8	8	74	44
	Burton	Queen's Hospital	69	8	5	5
	Shrewsbury & Telford	Princess Royal Hospital and Royal Shrewsbury Hospital.	50	8	25	22
Truro	*Truro*	Royal Cornwall Hospital	94	94	29	27

Northern Ireland

Location	Centre/clinic	Clinic ID	Network ID	Number of patients registered	Number of patients providing data in 2009
Belfast	Royal Belfast Hospital for Sick Children	60	60	229	164

Scotland

Location		Centre/clinic	Clinic ID	Network ID	Number of patients registered	Number of patients providing data in 2009
Aberdeen		Royal Aberdeen Children's Hospital	75	75	40	35
Ayr/Kilmarnock		Crosshouse Hospital	123	123	40	24
Dundee		Ninewells Hospital	73	73	31	27
Edinburgh		Royal Hospital for Sick Children	143	143	118	85
Glasgow	*Glasgow*	Royal Hospital for Sick Children	56	56	241	141
	Dumfries and Galloway	Dumfries and Galloway Royal Infirmary	127	56	5	2
Inverness		Raigmore Hospital	31	31	25	23

Wales

Location		Centre/clinic	Clinic ID	Network ID	Number of patients registered	Number of patients providing data in 2009
Cardiff	*Cardiff*	Children's Hospital for Wales	72	72	102	66
	Abergavenny	Nevill Hall Hospital	78	72	10	9
	Aberystwyth	Bronglais Hospital	61	72	5	5
	Bridgend	Princess of Wales Hospital	63	72	9	7
	Carmarthen	West Wales General Hospital	47	72	7	7
	Haverfordwest	Withybush General Hospital	38	72	6	6
	Hereford	Hereford County Hospital	13	72	8	8
	Llantrisant	Royal Glamorgan Hospital	23	72	7	7
	Newport	Royal Gwent Hospital	77	72	30	17
	Swansea	Singleton Hospital	100	72	33	33

4.4 Adult centres/clinics providing data in 2009 – alphabetical order

England

Location		Centre/clinic	Clinic ID	Network ID	Number of patients registered	Number of patients providing data in 2009
Birmingham	*Birmingham*	Birmingham Heartlands Hospital	27	27	299	263
	Wolverhampton	New Cross Hospital, Wolverhampton	2	27	17	17
Bristol	*Bristol*	Bristol Royal Infirmary	106	106	106	91
	Bath	Bath Royal United Hospital	10	106	20	20
Cambridge		Papworth Hospital	51	51	246	195
Exeter	*Exeter*	Royal Devon & Exeter Hospital, Exeter	34	34	32	30
	Taunton	Musgrove Park Hospital, Taunton	16	34	12	12
	Torbay	Torbay Hospital	103	34	13	12
	Barnstaple	North Devon District Hospital, Barnstaple	33	34	6	6
Frimley		Frimley Park Hospital, Camberley	19	19	111	97
Hull		Castle Hill Hospital, Hull	138	138	26	26
Leeds	*Leeds*	St James's University Hospital, Leeds	42	42	374	348
	York	York Hospital	120	42	5	2
Leicester		Glenfield Hospital, Leicester	142	142	52	52
Liverpool		Liverpool Heart and Chest Hospital	66	66	237	229
London - East		London Chest Hospital	92	92	141	122

London - South East		King's College Hospital, London	5	5	117	103
London - South East		University Hospital Lewisham, London	105	105	43	41
London - South West		Royal Brompton Hospital, London	12	12	685	563
Manchester		Wythenshawe Hospital, Manchester	102	102	305	273
Newcastle		Royal Victoria Infirmary, Newcastle	9	9	216	198
Norwich		Norfollk & Norwich University Hospital, Norwich	114	114	50	45
Nottingham		Nottingham City hospital	101	101	117	105
Oxford		Churchill Hospital, Oxford	128	128	61	44
Papworth		Papworth Hospital	51	51	246	195
Plymouth		Derriford Hospital, Plymouth	64	64	42	42
Portsmouth		Queen Alexandra Hospital, Portsmouth	95	95	18	1
Sheffield		Northern General Hospital, Sheffield	65	65	122	119
Southampton	*Southampton*	Southampton General hospital	110	110	144	123
	Poole	Poole Hospital	35	110	22	22
Stoke		University Hospital of North Staffordshire, Stoke-on-Trent	74	74	40	39

Truro		Royal Cornwall Hospital, Truro	129	129	29	28

Northern Ireland

Location	Centre/clinic	Clinic ID	Network ID	Number of patients registered	Number of patients providing data in 2009
Belfast	Belfast City Hospital	14	14	206	181

Scotland

Location		Centre/clinic	Clinic ID	Network ID	Number of patients registered	Number of patients providing data in 2009
Aberdeen		Aberdeen Royal Infirmary	70	70	52	47
Edinburgh	*Edinburgh*	Western General Hospital, Edinburgh	44	44	139	112
	Inverness-split	Raigmore Hospital, Inverness	53	44	21	20
	Dundee	Ninewells Hospital, Dundee	21	44	41	1
	Dumfries and Galloway	Dumfries and Galloway Royal Infirmary	121	44	5	5
Glasgow		Gartnavvel General Hospital, Glasgow	79	79	99	2

Wales

Location	Centre/clinic	Clinic ID	Network ID	Number of patients registered	Number of patients providing data in 2009
Llandough	Llandough Hospital	68	68	144	137