



Cystic Fibrosis Trust Annual data report 2010

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UK CF Registry
Annual Data Report 2010**

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Preface

We are pleased to present the Annual Patient Registry Report 2010.

The UK CF Registry and its current software programme, Port CF, is now in its fifth year with the production of four annual reports. We are delighted to see continued progress, both in terms of the number of patients registered, which has increased to 9,385 in 2010 compared to 9,029 in 2009, and the total number of patients for whom a complete data set was recorded, again increasing to 85% in 2010 compared to 82% in 2009. It is important that we continue to improve these statistics and work towards 100% of patients registered having complete data, as this will help us to achieve our overall objective of driving up standards of clinical care throughout the UK.

In last year's report we incorporated an expansion of the service -specific analyses, making it possible to identify individual services and make comparisons between different models of care and we have repeated this again for 2010. We have also incorporated some trend data which we hope you will find useful in enabling comparison of, for example the rates of chronic lung infection and median FEV1 (% predicted) over the last 4 years, and we hope to incorporate further trend data in future reports.

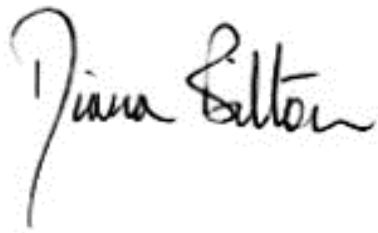
An important and notable feature in the summary table for 2010 is an increase in the median predicted survival from 34.4 in 2009 to 41.4 in 2010. In addition we have seen the median age of death increase from 27 in 2009 to 29 in 2010, and the number of reported deaths has fallen from 141 in 2009 to 103 in 2010 which is more in keeping with the overall trend since 2007.

We are pleased to see a high percentage of patients having been assessed for genotype, i.e. 95.2% particularly in the year in which mutation specific therapy has been associated with positive outcomes in a clinical trial. Knowledge of genotype will be critically important in deciding future targeted therapies and so we encourage further investigation where people with CF are unclear about their specific mutations.

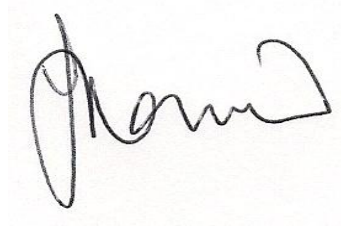
Through the combined efforts of many, namely the Cystic Fibrosis Trust, the UK CF Registry management team and the Registry Steering Committee, the biostatisticians at the National Heart and Lung Institute at Imperial College, London and, of course all of the CF patients and their families who contributed information via their care centre staff who work so hard to provide ongoing clinical care and submit data to the Registry year on year, we continue to be able to produce this annual report. We would therefore like to take this opportunity to thank everyone involved for their continued help, support and patience.

There has never been a more important time for us to monitor clinical outcomes for people with CF throughout the UK than now. We are facing increasing challenges, in terms of continuing to provide high quality care for the growing number of people with CF in the current challenging economic climate. Data from the registry allows us

to justify the level of resource required to deliver care in accordance with the UK CF Standards of Care for Adults and Children with CF, 2011 and to monitor the outcomes of that investment. We therefore hope that we can continue to rely upon all of you to continue to support this very valuable data set. Thank you.

A handwritten signature in black ink, appearing to read 'Diana Bilton'.

Dr Diana Bilton
Chair of CF Registry Steering Committee
The Cystic Fibrosis Trust

A handwritten signature in black ink, appearing to read 'Joanne Osmond'.

Joanne Osmond
Director of Clinical Care
The Cystic Fibrosis Trust

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Section 1: All UK Patients

1.1 Summary of the UK Cystic Fibrosis Registry

	<u>2004</u>	<u>2007</u>	<u>2008</u>	<u>2009</u>	<u>2010</u>
CF patients registered	7046	8080 ¹	8513 ¹	9029 ¹	9385 ¹
CF patients with “complete” data; n(%)	5561 (79%)	4408 ² (55%)	6082 ² (71%)	7377 ² (82%)	7937 ² (85%)
Age in years; median	16	18 ³	18 ³	17 ³	17 ³
All newly diagnosed patients (newborn screening and other)	164	239 ⁴	235 ⁴	261 ⁴	301 ⁴
Newly diagnosed patients identified through newborn screening					189
Age at diagnosis in months; median	5	5 ³	4 ³	3 ³	3 ³
Adults aged 16 yrs and over; %	51.4	56.7 ³	56.2 ³	55.1 ³	55.5 ³
Males; %	53.4	53.9 ³	53.3 ³	53.1 ³	53.1 ³
Genotyped; %	95	92.6 ³	93.7 ³	94.3 ³	95.2 ³
Median predicted survival in years (95% Confidence interval)		35.2 ⁵ (31.0, 42.6)	38.8 ⁵ (34.2, 47.3)	34.4 ⁵ (30.7, 37.0)	41.4 ⁵ (36.8, 46.7)
Total deaths reported	123	106	100	141	103
Age at death in years; median	26	24	27	27	29

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 2008/2009/2010/2011; and
- had no recorded date of death before 1 January 2007/2008/2009/2010

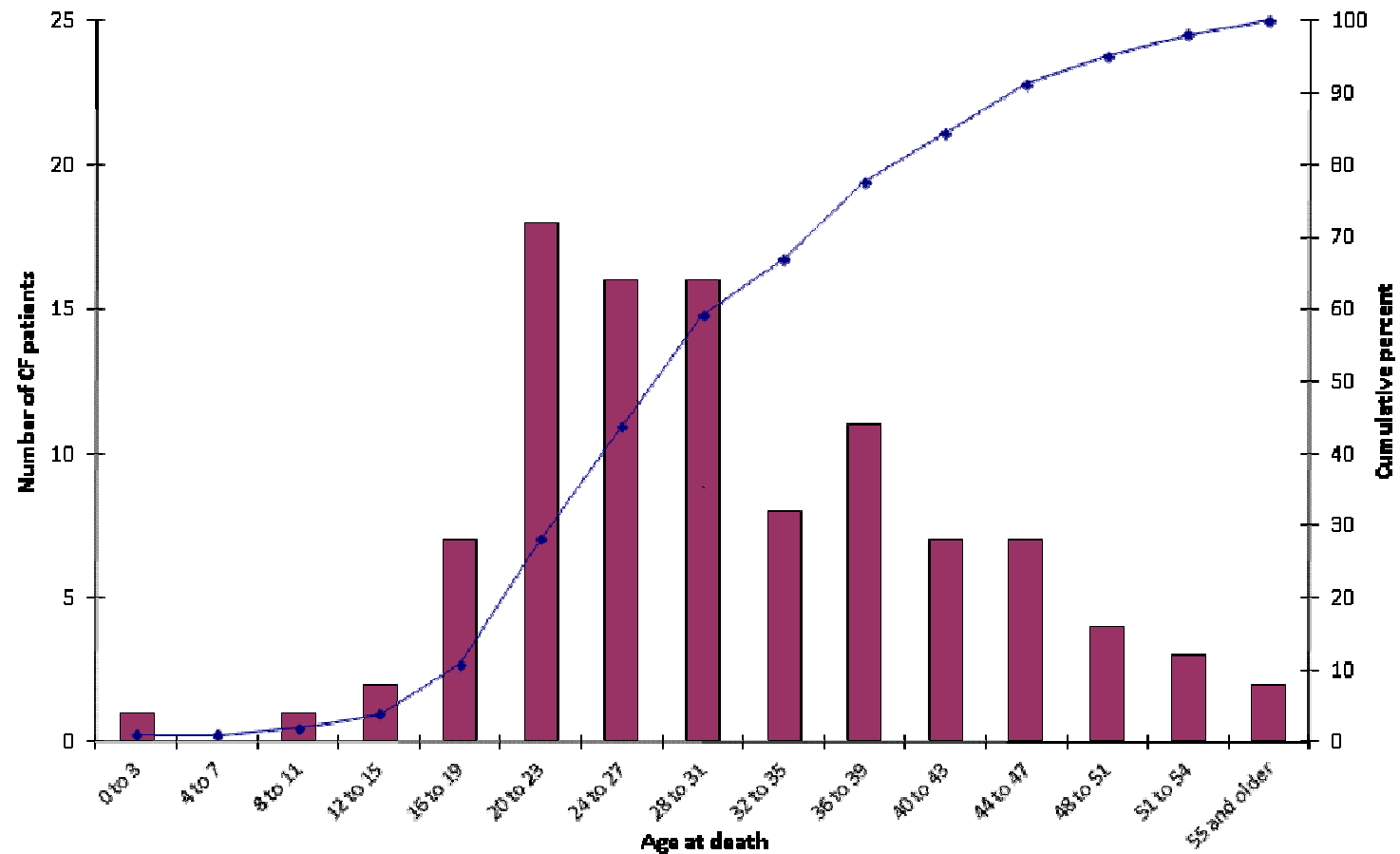
² From 2007, “complete data” is defined as having a clinical encounter when “well”.

³ Calculated for patients with “complete” data in that given year.

⁴ Calculated for all patients registered.

⁵ 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 2010

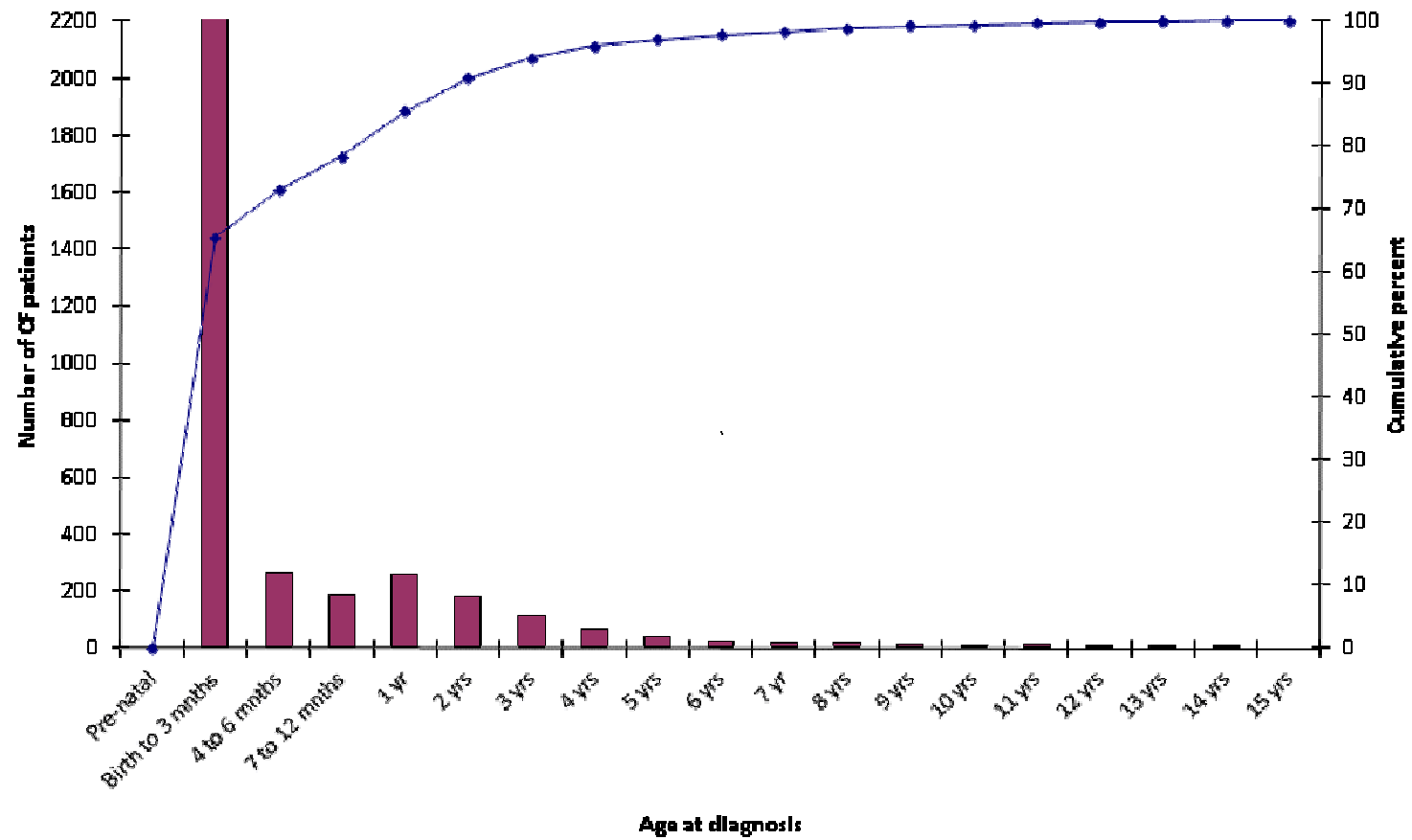


There were 103 recorded deaths in 2010. The median age at death was 29 years (min = 0 yrs; max = 61 years).

Analyses based on 7937 patients with complete* data at 2010 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 3499 of the 3531 children <16 years with annual review data.

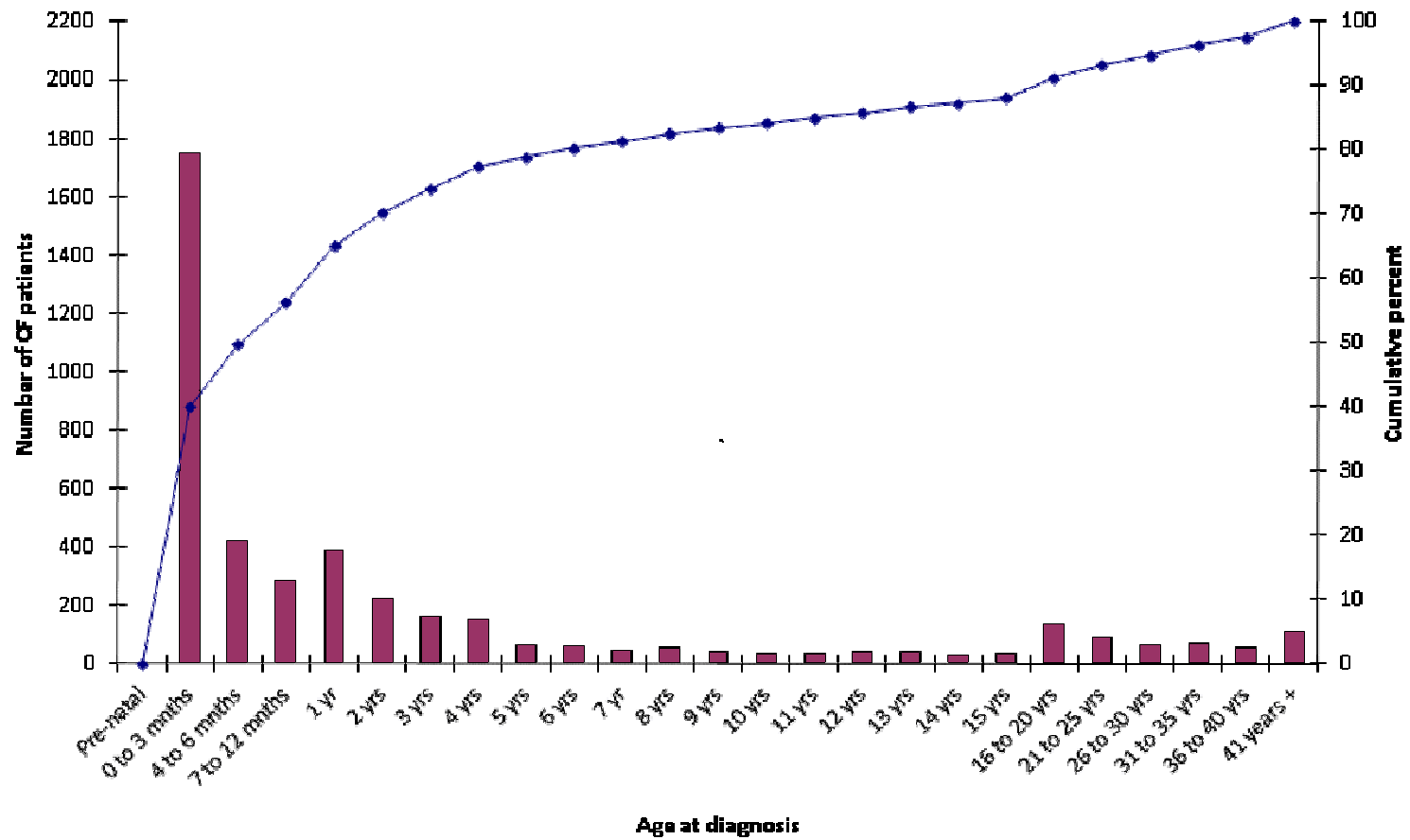
Age at diagnosis	n(%)
<i>Pre-natal</i>	0
<i>Birth – 3 months</i>	2292 (65.5)
<i>4-6 months</i>	263 (7.5)
<i>7-12 months</i>	187 (5.3)
<i>1 yr</i>	257 (7.3)
<i>2 yrs</i>	183 (5.2)
<i>3 yrs</i>	111 (3.2)
<i>4 yrs</i>	66 (1.9)
<i>5 yrs</i>	40 (1.1)
<i>6 yrs</i>	22 (0.6)
<i>7 yrs</i>	19 (0.5)
<i>8 yrs</i>	18 (0.5)
<i>9 yrs</i>	12 (0.3)
<i>10 yrs</i>	8 (0.2)
<i>11 yrs</i>	11 (0.3)
<i>12 yrs</i>	5 (0.1)
<i>13 yrs</i>	3 (0.1)
<i>14 yrs</i>	2 (0.1)
<i>15 yrs</i>	0

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

Of the 115 children with complete data born in 2010, 92 (80%) were identified by newborn screening.

In 2010, a total of 189 patients were identified by newborn screening (including patients with and without complete data). In 2008 this figure was 121 and 151 in 2009.

1.4 Age at diagnosis and screening statistics among adults



Date of diagnosis is available for 4361 of the 4406 adults aged 16 yrs + with annual review data. No patients were diagnosed prenatally.

Age at diagnosis	n(%)
<i>Pre-natal</i>	0
<i>Birth-3 months</i>	1746 (40.0)
<i>4-6 months</i>	424 (9.7)
<i>7-12 months</i>	282 (6.5)
<i>1 yr</i>	384 (8.8)
<i>2 yrs</i>	223 (5.1)
<i>3 yrs</i>	163 (3.7)
<i>4 yrs</i>	153 (3.5)
<i>5 yrs</i>	65 (1.5)
<i>6 yrs</i>	60 (1.4)
<i>7 yrs</i>	46 (1.1)
<i>8 yrs</i>	52 (1.2)
<i>9 yrs</i>	39 (0.9)
<i>10 yrs</i>	32 (0.7)
<i>11 yrs</i>	33 (0.8)
<i>12 yrs</i>	36 (0.8)
<i>13 yrs</i>	40 (0.9)
<i>14 yrs</i>	30 (0.7)
<i>15 yrs</i>	33 (0.8)
<i>16 – 20 yrs</i>	135 (3.1)
<i>21 – 25 yrs</i>	89 (2.0)
<i>26 – 30 yrs</i>	65 (1.5)
<i>31 – 35 yrs</i>	71 (1.6)
<i>36 – 40 yrs</i>	52 (1.2)
<i>41 yrs +</i>	108 (2.5)

The median (range) age at diagnosis is 7 months (0-79 years).

Of the 4406 adults with complete data in 2010, 329 were diagnosed by neonatal screening.

33 adults were diagnosed in 2010.

1.5 Genotyping

7555 (95.2%) patients have been genotyped with a recorded value

DF508 Mutations; n (%)

Homozygous DF508	3971 (52.6%)
Heterozygous DF508	2926 (38.7%)
No DF508 or both unidentified	658 (8.7%)

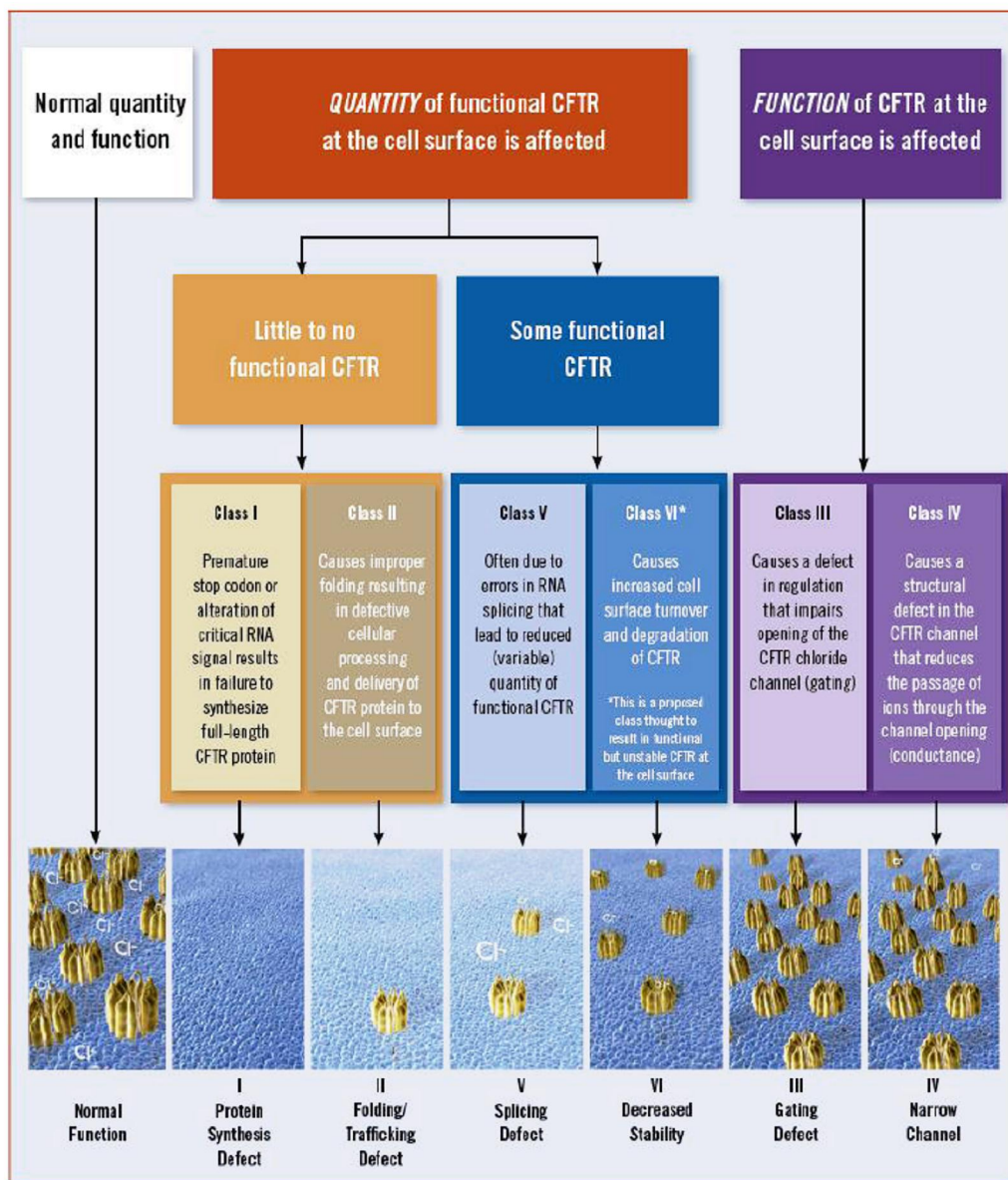
All mutations and their classes (*To be completed*)

All mutations

Current name	New name	Class	N	(%)
DF508	p.Phe508del	II	6897	91.3
G551D	p.Gly551Asp	III	432	5.7
R117H	p.Arg117His	IV	284	3.8
G542X	p.Gly542X	I	264	3.5
621+1G->T	c.489+1G>T	I	184	2.4
N1303K	p.Asn1303Lys	II	103	1.4
1898+1G->A	c.1766+1G>A	I	92	1.2
1717-1G->A	c.1585-1G>A	I	102	1.4
R560T	p.Arg560Thr	III	78	1.0
DI507	p.Ile507del	II	76	1.0
3659delC	c.3528delC	II	69	0.9
R553X	p.Arg553X	I	63	0.8
3849+10kbC->T	c.3717+10kbC>T	V	58	0.8
E60X	p.Glu60X	I	50	0.7
Q493X	p.Gln493X	I	47	0.6
G85E	p.Gly85Glu	IV	51	0.7
W1282X	p.Trp1282X	I	36	0.5
1078delT	c.948delT	II	32	0.4
2184delA	c.2052delA	II	25	0.3
D1152H	p.Asp1152His	IV	41	0.5
2789+5G->A	c.2657+5G>A	V	23	0.3
V520F	p.Val520Phe	III	24	0.3
R347P	p.Arg347Pro	IV	20	0.3
R1162X	p.Arg1162X	I	18	0.2
S549N	p.Ser549Asn	II	17	0.2
A455E	p.Ala455Glu	V	15	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	11	0.2
R347H	p.Arg347His	IV	10	0.1
R334W	p.Arg334Trp	IV	9	0.1

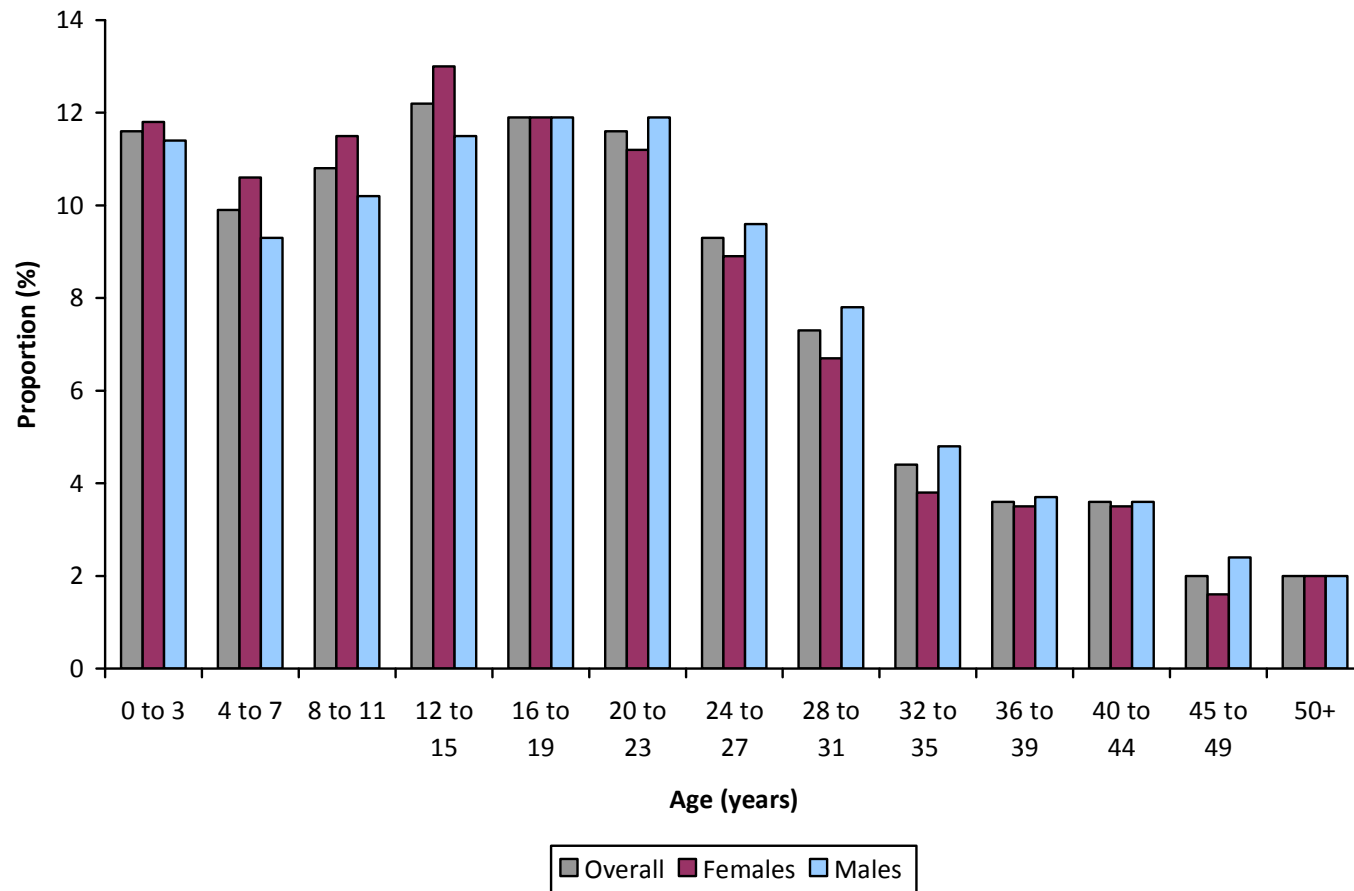
1161delC	c.1029delC	I	6	0.1
I148T	p.Ile148Thr	V	5	0.1
L206W	p.Leu206Trp	unknown	6	0.1
2183delAA->G	c.2051_2052delAAinsG	I	4	0.1
A559T	p.Ala559Thr	unknown	4	0.1
R352Q	p.Arg352Gln	unknown	6	0.1
K710X	p.Lys710X	I	3	0.04
3120G->A	c.2988G>A	V	1	0.01
P574H	p.Pro574His	IV	3	0.04
R1066C	p.Arg1066Cys	unknown	4	0.1
R117C	p.Arg117Cys	IV/V	2	0.03
R1283M	p.Arg1283Met	unknown	4	0.1
S549R	p.Ser549Arg	II/III	4	0.1
Y563D	p.Tyr563Asp	unknown	2	0.03
1677delTA	p.Tyr515x		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
2143delT	c.490-1G>A		3	0.04
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
2043delG	c.1911delG		2	0.03
G480C	p.Gly480Cys		1	0.01
S364P	p.Ser364Pro		1	0.01
W1089X	p.Trp1089X	I	1	0.01
Y1092X	p.Tyr1092X	I	4	0.1
<i>Other</i>			695	9.2
<i>Not identified</i>			974	12.9

Cystic Fibrosis mutations and their functional effects



Courtesy of Vertex Pharmaceuticals Incorporated

1.6 Age distribution

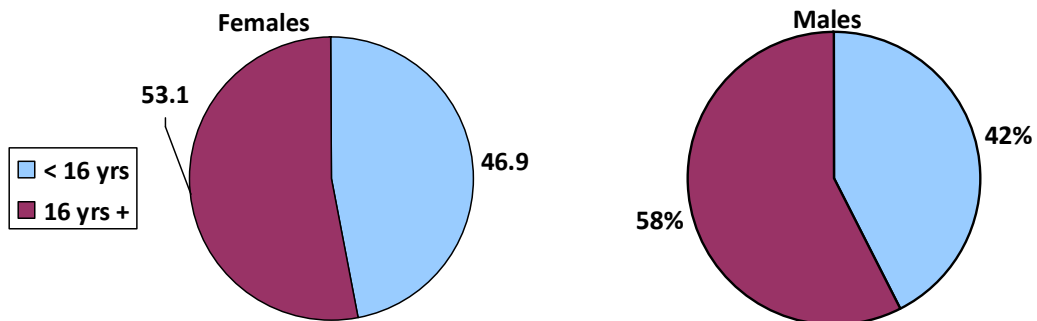


Age is calculated as the age at annual review encounter.

1.7 Age and sex distribution

Age	Overall N=7937	Female N=3720	Male N=4217
0-3 yrs	919 (11.6)	439 (11.8)	480 (11.4)
4-7	785 (9.9)	395 (10.6)	390 (9.3)
8-11	858 (10.8)	427 (11.5)	431 (10.2)
12-15	969 (12.2)	483 (13.0)	486 (11.5)
16-19	942 (11.9)	442 (11.9)	500 (11.9)
20-23	917 (11.6)	417 (11.2)	500 (11.9)
24-27	735 (9.3)	330 (8.9)	405 (9.6)
28-31	577 (7.3)	250 (6.7)	327 (7.8)
32-35	346 (4.4)	142 (3.8)	204 (4.8)
36-39	288 (3.6)	131 (3.5)	157 (3.7)
40-44	283 (3.6)	131 (3.5)	152 (3.6)
45-49	161 (2.0)	60 (1.6)	101 (2.4)
50+	157 (2.0)	73 (2.0)	84 (2.0)
Median (range)	17 yrs (0 - 79 yrs)	17 yrs (0 – 79 yrs)	18 yrs (0 – 77 yrs)

1.8 Age distribution by sex



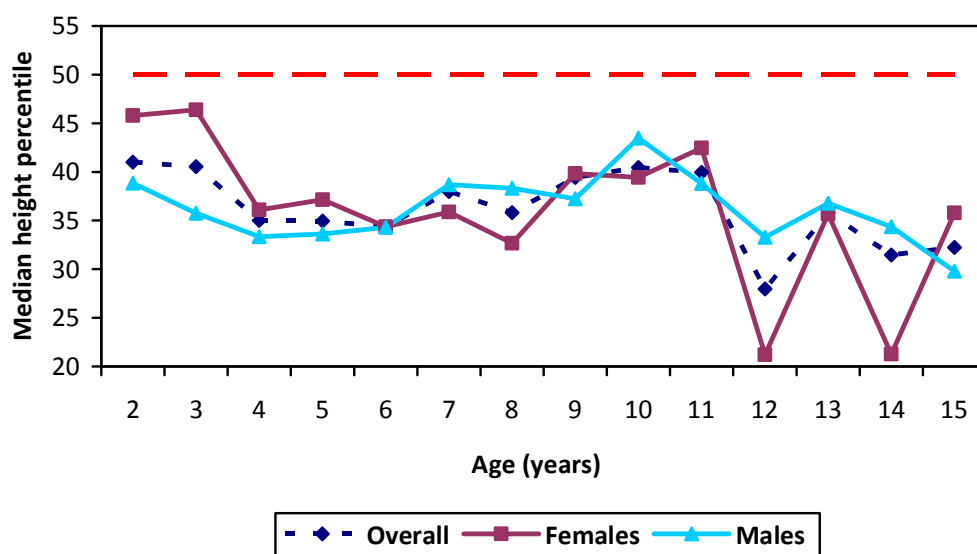
1.9 Employment and education status among adults aged 16 years and older

	<u>Number of patients</u>
Full-time working	1306
Part-time working	573
Student	855
Homemaker	227
Unemployed	712
“Disabled”	215
Retired	55
Unknown	440
<i>No data</i>	555

Note that these groups are not mutually exclusive.

Of the 3851 adults aged 16 years and older for whom an employment status questionnaire was completed (excluding “unknown”), 2684 (69.7%) reported being in work or study.

1.10 Median height percentiles among children (n=3043)

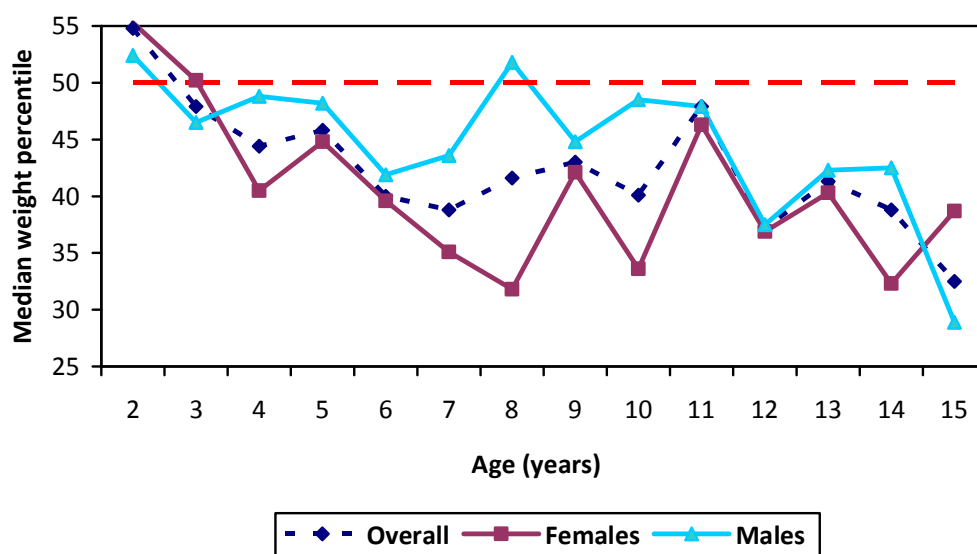


Age	Overall		Female		Male	
	N	Median (IQR)	N	Median (IQR)	N	Median (IQR)
2	248	41.0 (14.7-64.4)	121	45.8 (15.6-68.0)	127	38.8 (13.6-62.8)
3	241	40.5 (15.8-69.6)	115	46.4 (17.4-71.7)	126	35.7 (15.0-68.4)
4	186	35.0 (16.8-58.1)	92	36.1 (17.5-55.3)	94	33.3 (15.9-60.4)
5	207	34.9 (16.6-59.1)	97	37.1 (17.6-57.2)	110	33.6 (15.7-61.9)
6	198	34.4 (15.0-66.5)	100	34.4 (15.9-63.1)	98	34.3 (14.2-69.5)
7	177	38.0 (12.0-60.7)	100	35.9 (12.2-59.6)	77	38.7 (10.7-62.8)
8	192	35.8 (16.0-60.2)	102	32.7 (15.6-63.5)	90	38.3 (15.8-57.2)
9	199	39.4 (15.7-64.8)	99	39.8 (15.7-62.2)	100	37.2 (15.3-65.9)
10	198	40.5 (11.3-69.2)	101	39.4 (9.5-62.2)	97	43.5 (12.8-74.0)
11	252	40.0 (15.1-65.6)	118	42.5 (11.9-68.9)	134	38.8 (16.8-65.5)
12	221	28.0 (11.0-63.0)	101	21.2 (8.1-64.5)	120	33.3 (13.9-59.0)
13	247	35.8 (13.8-63.5)	111	35.7 (11.8-54.5)	136	36.8 (15.3-70.5)
14	253	31.5 (10.5-63.6)	130	21.3 (8.2-56.2)	123	34.3 (13.8-69.0)
15	224	32.2 (7.9-55.1)	121	35.8 (10.2-60.7)	103	29.8 (7.0-51.9)
Overall	3043	36.2 (13.8-63.4)	1508	35.8 (13.2-62.4)	1535	36.4 (14.4-64.5)
2-4 yrs	675	39.5 (15.8-64.6)	328	42.5 (17.1-66.5)	347	36.4 (15.0-62.8)
5-7 yrs	582	35.3 (14.8-61.4)	297	35.1 (15.3-60.3)	285	36.7 (14.6-65.3)
8-10 yrs	589	38.2 (13.9-65.0)	302	37.5 (12.8-62.3)	287	39.2 (14.6-68.7)
11-13 yrs	720	35.7 (13.2-63.6)	330	33.9 (10.6-62.5)	390	37.2 (15.4-65.5)
14-15 yrs	477	31.5 (9.0-59.1)	251	28.7 (8.9-59.0)	226	32.4 (9.0-60.5)

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=3065)

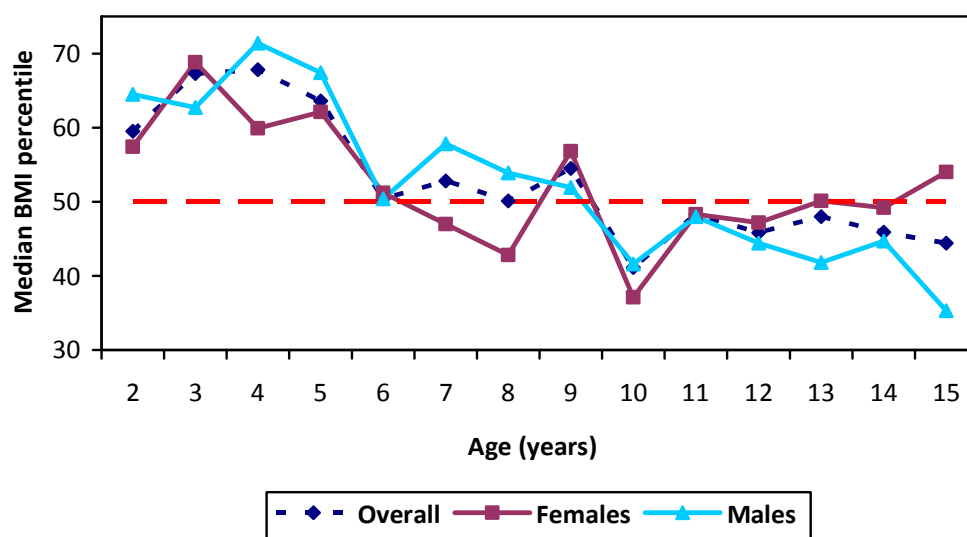


Age	Overall		Female		Male	
	N	Median (IQR)	N	Median (IQR)	N	Median (IQR)
2	253	54.8 (22.9-77.9)	125	55.3 (23.2-77.3)	128	52.4 (20.5-78.9)
3	249	47.9 (24.9-74.9)	116	50.2 (25.5-74.4)	133	46.5 (24.1-75.5)
4	188	44.4 (20.5-70.0)	92	40.5 (18.1-64.9)	96	49.8 (25.6-71.7)
5	208	45.8 (23.7-69.7)	98	44.8 (25.3-66.5)	110	48.2 (22.9-71.2)
6	199	40.0 (16.0-70.6)	101	39.6 (16.4-70.4)	98	41.9 (15.5-72.5)
7	179	38.8 (19.4-62.0)	100	35.1 (15.9-63.0)	79	43.6 (26.0-62.8)
8	191	41.6 (16.8-69.3)	101	31.8 (14.7-60.2)	90	51.8 (24.5-73.2)
9	199	43.0 (21.7-71.9)	99	42.1 (21.6-69.2)	100	44.8 (22.2-75.8)
10	199	40.1 (14.2-67.2)	102	33.6 (10.6-66.4)	97	48.5 (17.9-68.0)
11	250	47.9 (18.5-75.1)	116	46.3 (17.0-74.4)	134	47.9 (22.8-76.7)
12	220	37.2 (14.9-68.6)	100	36.9 (11.2-70.5)	120	37.5 (17.7-67.4)
13	250	41.3 (16.8-70.4)	113	40.3 (16.8-70.2)	137	42.3 (17.3-72.1)
14	255	38.8 (14.0-67.5)	131	32.3 (11.6-63.3)	124	42.5 (20.1-72.0)
15	225	32.5 (10.8-59.5)	122	38.7 (15.2-66.1)	103	28.9 (10.6-56.1)
Overall	3065	42.3 (18.0-69.7)	1516	40.6 (16.7-69.0)	1549	44.3 (20.5-70.3)
2-4 yrs	690	48.3 (23.0-75.0)	333	47.4 (23.0-74.6)	357	49.4 (22.9-76.5)
5-7 yrs	586	42.7 (18.9-67.9)	299	41.2 (17.7-66.4)	287	44.2 (20.0-69.4)
8-10 yrs	589	42.4 (18.3-69.3)	302	37.9 (15.6-64.3)	287	46.9 (21.8-71.5)
11-13 yrs	720	42.0 (17.4-70.8)	329	41.6 (15.1-70.8)	391	42.4 (19.5-70.8)
14-15 yrs	480	35.4 (13.7-63.5)	253	35.3 (12.8-63.9)	227	37.0 (14.3-63.5)

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=2906)

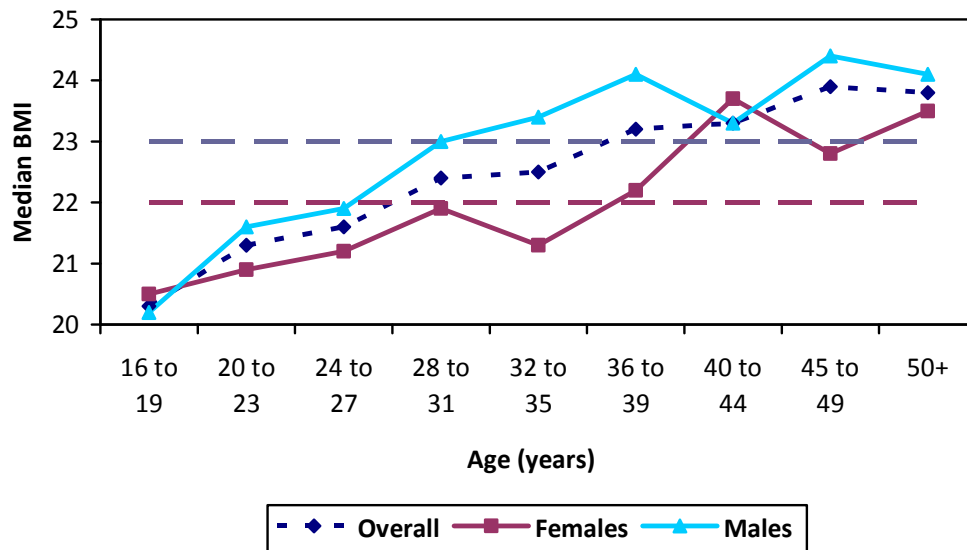


Age	Overall		Female		Male	
	N	Median (IQR)	N	Median (IQR)	N	Median (IQR)s
2	243	59.5 (32.0-85.9)	119	57.4 (32.8-83.3)	124	64.5 (29.8-88.2)
3	237	67.3 (37.4-85.9)	112	68.8 (36.7-84.2)	125	62.7 (37.5-86.6)
4	183	67.8 (34.7-86.5)	91	59.9 (33.4-78.2)	92	71.4 (37.3-87.7)
5	205	63.6 (40.6-81.3)	97	62.1 (42.3-78.3)	108	67.4 (36.7-82.9)
6	195	50.4 (28.2-76.2)	98	51.2 (27.4-81.6)	97	50.4 (29.7-72.1)
7	175	52.8 (31.4-70.4)	98	47.0 (27.4-71.5)	77	57.8 (33.3-70.3)
8	188	50.1 (24.9-73.5)	100	42.8 (22.2-65.9)	88	53.9 (28.7-78.6)
9	198	54.5 (25.9-74.3)	99	56.8 (28.3-72.3)	99	51.9 (23.3-75.0)
10	197	41.1 (21.6-67.3)	101	37.1 (21.6-67.3)	96	41.6 (21.6-67.7)
11	248	48.3 (24.8-69.6)	116	48.3 (25.0-67.6)	132	48.0 (23.9-70.2)
12	220	45.8 (19.8-70.8)	100	47.2 (25.1-71.7)	120	44.4 (17.1-66.7)
13	244	48.0 (22.1-71.6)	110	50.1 (31.3-73.8)	134	41.8 (18.2-67.8)
14	251	45.9 (26.2-66.3)	129	49.2 (27.6-69.8)	122	44.7 (24.7-62.5)
15	122	44.4 (15.0-66.1)	65	54.0 (23.1-67.7)	57	35.3 (8.7-62.0)
Overall	2906	52.2 (27.6-75.5)	1435	52.1 (28.5-74.8)	1471	52.3 (26.4-76.3)
2-4 yrs	663	65.5 (33.8-85.9)	322	64.1 (33.3-82.7)	341	67.4 (35.0-87.4)
5-7 yrs	575	57.5 (32.5-76.4)	293	54.9 (32.0-76.2)	282	58.5 (33.3-76.4)
8-10 yrs	583	48.5 (23.8-71.8)	300	45.5 (23.0-69.0)	283	50.3 (24.8-76.2)
11-13 yrs	712	47.3 (22.2-70.2)	326	48.7 (27.4-72.0)	386	44.9 (20.0-69.6)
14-15 yrs	373	45.6 (22.7-66.3)	194	49.4 (25.8-68.9)	179	43.3 (18.8-62.2)

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=4221)

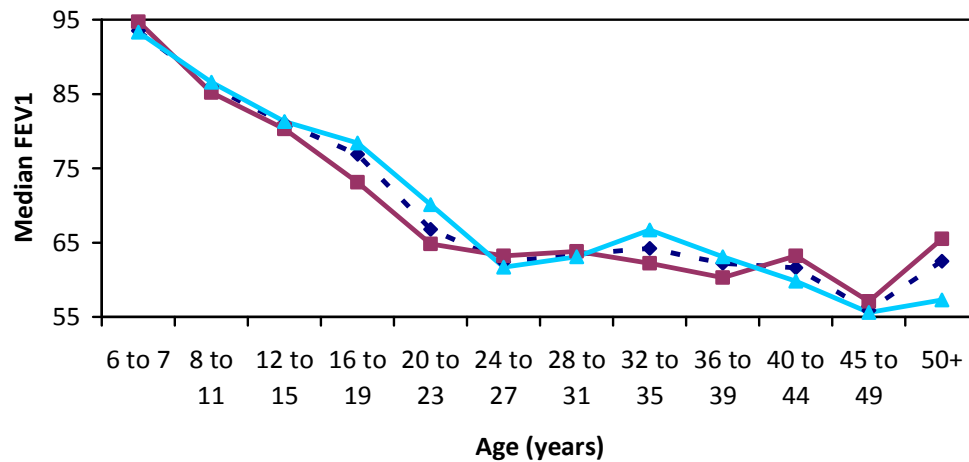


Age	Overall		Female		Male	
	N	Median (IQR)	N	Median (IQR)	N	Median (IQR)
16-19	903	20.3 (18.6-22.4)	421	20.5 (18.7-22.5)	482	20.2 (18.5-22.2)
20-23	881	21.3 (19.4-23.3)	402	20.9 (19.2-22.7)	479	21.6 (19.8-23.8)
24-27	701	21.6 (19.6-23.7)	315	21.2 (19.3-23.3)	386	21.9 (20.2-23.9)
28-31	549	22.4 (20.4-24.5)	238	21.9 (19.8-23.7)	311	23.0 (20.8-24.9)
32-35	334	22.5 (20.7-25.1)	134	21.3 (19.8-24.0)	200	23.4 (21.4-25.9)
36-39	273	23.2 (21.0-25.7)	124	22.2 (20.6-25.4)	149	24.1 (21.9-25.9)
40-44	273	23.3 (21.4-26.0)	126	23.7 (21.1-25.7)	147	23.3 (21.8-26.2)
45-49	155	23.9 (21.5-26.3)	57	22.8 (21.0-25.4)	98	24.4 (22.0-26.6)
50+	152	23.8 (21.6-26.6)	72	23.5 (20.6-26.5)	80	24.1 (22.3-26.6)
Overall	4221	21.8 (19.8-24.1)	1889	21.3 (19.4-23.5)	2332	22.2 (20.1-24.5)

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 FEV₁ (% predicted) among patients aged 6 years and older (n=6120)



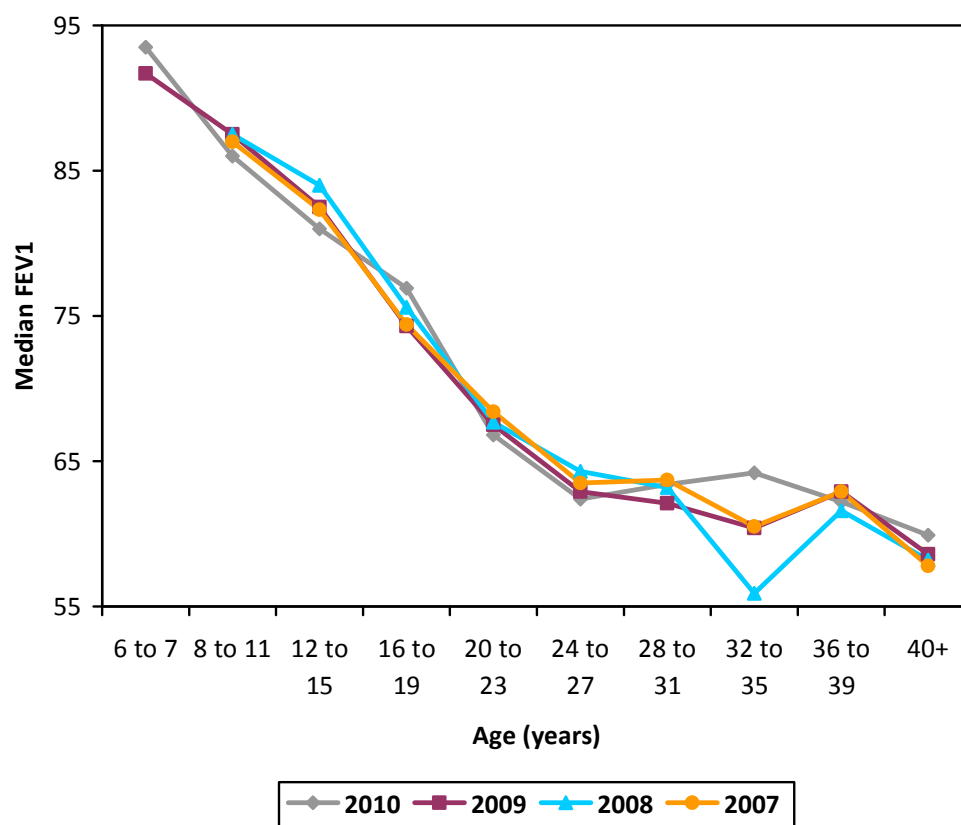
Age	Overall		Female		Male	
	N	Median (range)	N	Median (range)	N	Median (range)
6-7	319	93.5 (83.6-102.6)	174	94.7 (83.7-103.7)	145	93.3 (82.9-100.8)
8-11	771	86.0 (74.4-96.8)	387	85.2 (75.0-96.2)	384	86.6 (74.0-97.3)
12-15	879	81.0 (68.9-94.4)	435	80.3 (66.4-94.1)	444	81.3 (71.5-94.4)
16-19	874	76.9 (57.8-91.2)	407	73.1 (55.0-87.4)	467	78.4 (59.3-93.8)
20-23	867	66.8 (47.3-85.3)	398	64.8 (46.6-85.1)	469	70.1 (47.8-85.4)
24-27	696	62.4 (44.4-80.5)	312	63.2 (46.5-83.7)	384	61.7 (42.3-79.2)
28-31	543	63.4 (44.7-82.0)	240	63.8 (45.9-83.3)	303	63.1 (43.9-80.0)
32-35	332	64.2 (46.4-84.1)	135	62.2 (46.3-80.6)	197	66.7 (46.4-86.2)
36-39	265	62.2 (38.6-79.1)	119	60.3 (38.5-80.5)	146	63.1 (38.9-78.2)
40-44	271	61.6 (40.0-77.5)	124	63.2 (38.8-80.3)	147	59.8 (40.6-77.5)
45-49	154	55.9 (36.0-78.7)	57	57.1 (35.6-75.6)	97	55.6 (35.9-82.3)
50+	149	62.5 (40.5-82.4)	71	65.5 (46.2-82.4)	78	57.3 (38.2-82.7)
Overall	6120	74.2 (53.5-90.2)	2859	73.9 (53.3-90.0)	3261	74.4 (53.6-90.2)

N refers to the number of patients in each age/sex category among those with non-missing FEV₁ % predicted data

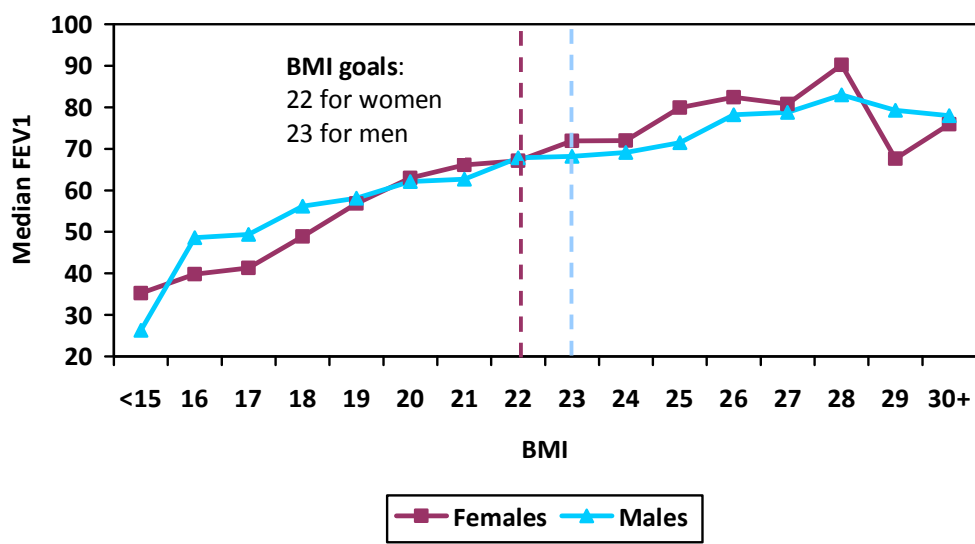
The dotted line in this figure illustrates a target FEV₁ % predicted of 85%, anything above this indicates normal or near-normal lung function values.

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 Median FEV₁ (% predicted) among patients aged 6 years and older by year since 2007

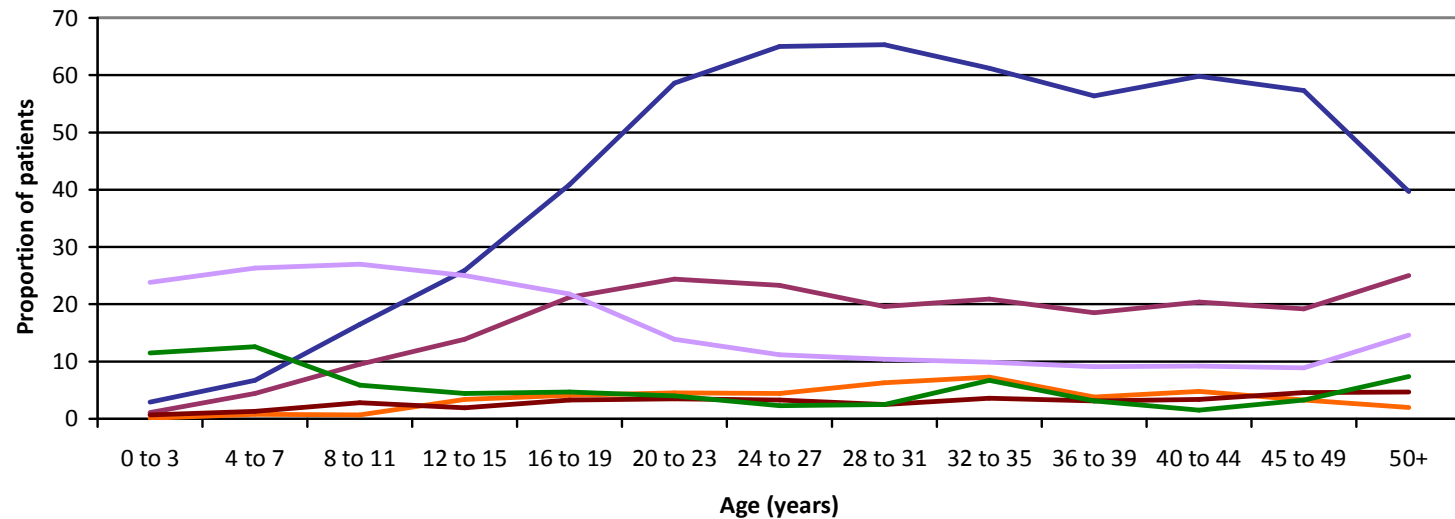


1.16 Median FEV₁ (% predicted) vs BMI among patients aged 16 years and older



Each point represents the median FEV₁ % predicted of patients for each given BMI value. Due to the wide range of BMIs in this population we grouped all BMI ≤ 15 into one group and BMI ≥ 30 into another.

1.17 Lung infections in 2010



N in age band	919	785	858	969	942	917	735	577	346	288	283	161	157
N cultures taken	871	756	826	929	903	886	698	553	331	262	269	153	148
Chronic <i>S.aureus</i> ; n=1150 (15.6%)				Chronic <i>P.aeruginosa</i> ; n=2806 (37.5%)			Intermittent <i>P.aeruginosa</i> ; n=1404 (18.8%)						
<i>B.cepacia</i> ; n=243 (3.2%)				MRSA; n=198 (2.6%)			<i>H.influenzae</i> ; n=442 (5.8%)						

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

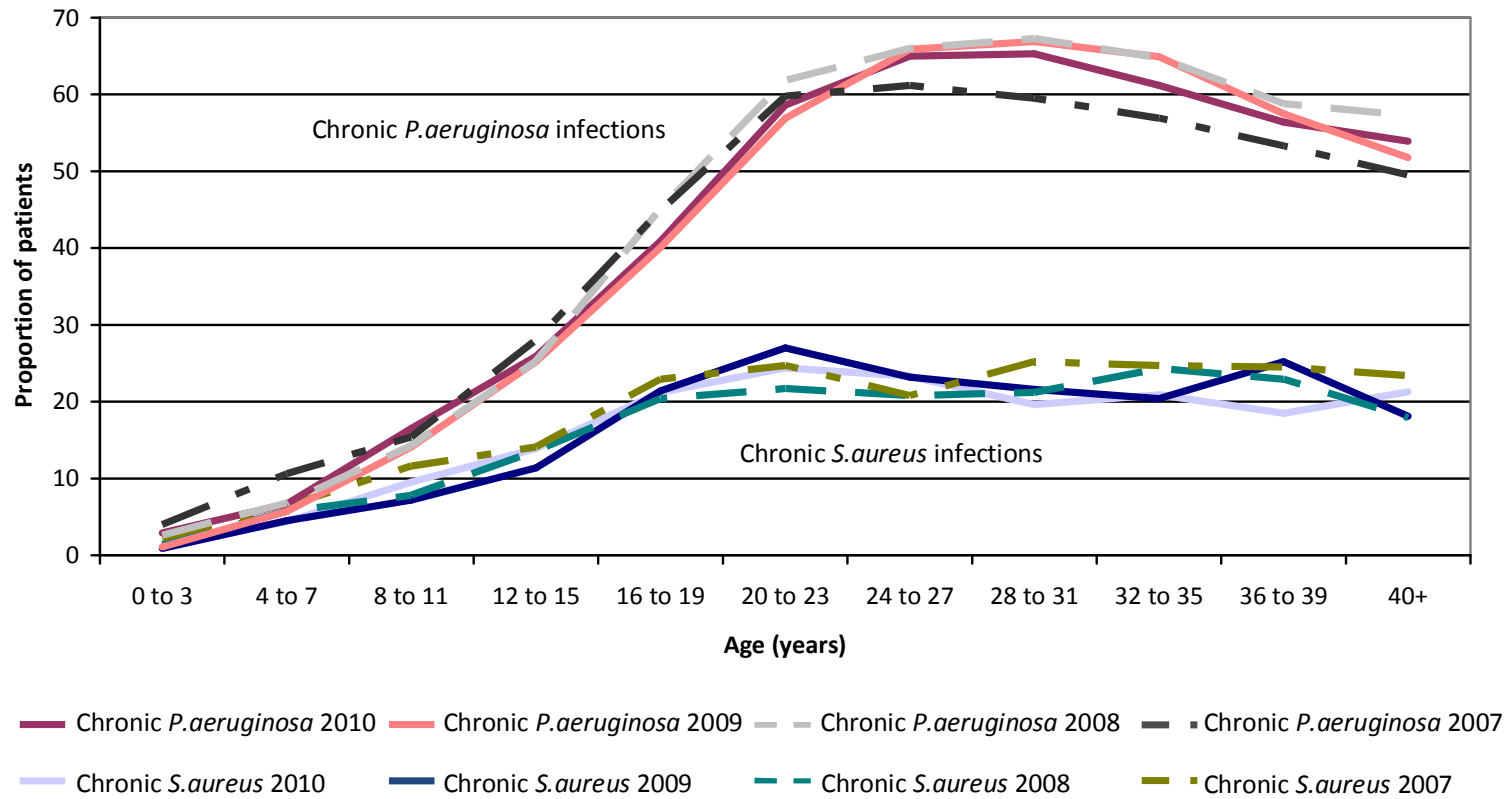
Current treatments and good cross-infection measures mean that we can aim to reduce the number of people with CF transferring from paediatric to adult care with chronic *Pseudomonas aeruginosa* infection, and currently the aim is for less than 30% of paediatric patients to be chronically infected at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

Lung infections in 2010

	Age (yrs)													Overall		
	0-3	4-7	8-11	12-15	16-19	20-23	24-27	28-31	32-35	36-39	40-44	45-49	50+	All	Children (<16 yrs)	Adults (≥16 yrs)
<i>N patients in age band</i>	919	785	858	969	942	917	735	577	346	288	283	161	157	7937	3531	4406
<i>N cultures taken at clinic</i>	871	756	828	929	903	886	698	553	331	262	269	153	148	7587	3384	4203
Chronic <i>S.aureus</i>; n(%)	9 (1.1)	32 (4.4)	76 (9.5)	124 (13.9)	186 (21.2)	215 (24.4)	158 (23.3)	107 (19.6)	70 (20.9)	50 (18.5)	55 (20.4)	30 (19.2)	38 (25.0)	1150 (15.6)	241 (7.5)	909 (21.8)
Chronic <i>P.aeruginosa</i>; n(%)	24 (2.9)	49 (6.7)	134 (16.5)	233 (25.9)	364 (40.9)	519 (58.6)	446 (65.0)	365 (65.3)	205 (61.2)	155 (56.4)	162 (59.8)	90 (57.3)	60 (39.7)	2806 (37.5)	440 (13.5)	2366 (56.2)
Intermittent <i>P.aeruginosa</i>; n(%)	196 (23.8)	193 (26.3)	219 (27.0)	225 (25.0)	194 (21.8)	123 (13.9)	77 (11.2)	58 (10.4)	33 (9.9)	25 (9.1)	25 (9.2)	14 (8.9)	22 (14.6)	1404 (18.8)	833 (25.5)	571 (13.6)
<i>B.cepacia</i>; n(%)	1 (0.1)	6 (0.8)	6 (0.7)	32 (3.4)	37 (4.1)	40 (4.5)	31 (4.4)	35 (6.3)	24 (7.3)	10 (3.8)	13 (4.8)	5 (3.3)	3 (2.0)	243 (3.2)	45 (1.3)	198 (4.7)
MRSA; n(%)	6 (0.7)	10 (1.3)	23 (2.8)	18 (1.9)	30 (3.3)	31 (3.5)	23 (3.3)	14 (2.5)	12 (3.6)	8 (3.1)	9 (3.4)	7 (4.6)	7 (4.7)	198 (2.6)	57 (1.7)	141 (3.4)
<i>H.influenza</i>; n(%)	100 (11.5)	95 (12.6)	49 (5.9)	41 (4.4)	42 (4.7)	35 (4.0)	16 (2.3)	14 (2.5)	22 (6.7)	8 (3.1)	4 (1.5)	5 (3.3)	11 (7.4)	442 (5.8)	285 (8.4)	157 (3.7)

Age is calculated as age at annual review

1.18 Trends in lung infections since 2007



1.19 Prevalence of complications

	Overall (n=7937)	<16 years (n=3531)	≥16 years (n=4406)
Nontuberculous mycobacteria or atypical mycobacteria; n(%) <i>Newly identified in 2010*</i>	269 (3.4) 91 (1.1)	68 (1.9) 34 (1.0)	201 (4.6) 57 (1.3)
Cirrhosis with no portal hypertension; n(%) <i>Newly identified in 2010*</i>	95 (1.2) 30 (0.4)	23 (0.7) 10 (0.3)	72 (1.6) 20 (0.5)
Cirrhosis with portal hypertension; n(%) <i>Newly identified in 2010*</i>	138 (1.7) 21 (0.3)	26 (0.7) 7 (0.2)	112 (2.5) 14 (0.3)
Gallbladder disease requiring surgery; n(%)	38 (0.5)	2 (0.1)	36 (0.8)
Nasal polyps requiring surgery; n(%)	274 (3.5)	55 (1.6)	219 (5.0)
Pneumothorax requiring chest tube; n(%)	50 (0.6)	3 (0.1)	47 (1.1)
Cancer confirmed by histology; n(%)	16 (0.2)	3 (0.1)	13 (0.3)
Fibrosing colonopathy/colonic stricture; n(%)	0	0	0
ABPA; n(%) <i>Newly identified in 2010*</i>	725 (9.1) 156 (2.0)	248 (7.0) 73 (2.1)	477 (10.8) 83 (1.9)
Port inserted or replaced; n(%)	468 (5.9)	177 (5.0)	291 (6.6)

** For patients who are reported to have had nontuberculous mycobacteria/atypical mycobacteria, cirrhosis (with/without portal hypertension) or ABPA in 2010 we explored their clinical history to determine if this was the first year in which such a complication was reported. This historical search was not limited to annual review encounters and where no clinical history was available it is assumed that 2010 was the year the complication first developed.*

1.20 CF-related diabetes

	Overall* (n=7653)	<16 years * (n=3337)	≥16 years * (n=4316)
Treatment for CF-related diabetes; n(%)	1314 (17.2)	120 (3.6)	1194 (27.7)

** Treatment for CF-related diabetes was enquired about in an annual review questionnaire which was completed by 7653 of the 7937 patients with “complete” annual review encounter data. For this reason the number of patients in each age group differs to section 1.19.*

1.21 Transplants

	2010	2009	2008
Number of patients that year with annual review data evaluated for transplants	169	143	126
Number accepted on the transplant list	82	79	55
Number receiving transplants	29	25*	24
Types of transplants received:			
Bilateral lung	26	19	16
Heart and lung	1	0	1
Liver	1	5	6
Kidney	1	2	1

* One patient received two transplants

1.22 Other therapy

	Overall (n=7937)	<16 years (n=3531)	≥16 years (n=4406)
NIV; n(%)	192 (2.6)	39 (1.2)	153 (3.6)
Long-term oxygen; n(%)	503 (6.7)	97 (3.0)	406 (9.5)
Among those who had long-term oxygen therapy:			
Continuously	97 (19.3)	7 (7.2)	90 (22.2)
Nocturnal+exertion	140 (27.8)	29 (29.9)	111 (27.3)
PRN	71 (14.1)	6 (6.2)	65 (16.0)
With exacerbation	195 (38.8)	55 (56.7)	140 (34.5)

1.23 Feeding

	All patients (n=7937)	<16 years (n=3531)	≥16 years (n=4406)
Any supplemental feeding; n(%)	2353 (30.7)	921 (26.9)	1431 (33.8)
Nasogastric Tube	108 (4.6)	17 (1.9)	91 (6.4)
Gastrostomy Tube / Button	488 (20.8)	194 (21.1)	294 (20.6)
Jejunal	2 (0.1)	0	2 (0.1)
TPN	4 (0.2)	4 (0.4)	0

1.24 Days on IV antibiotics

Age	Home		Hospital		Total	
	N (%)	Median (IQR)	N (%)	Median (IQR)	N (%)	Median (IQR)
0-3	42 (5.1)	10 (7-19)	236 (28.4)	14 (10-20)	241 (29.0)	14 (13-25)
4-7	101 (13.6)	15 (11-30)	218 (29.4)	14 (7-23)	246 (33.2)	14 (14-33)
8-11	192 (23.7)	26 (14-42)	312 (38.6)	14 (7-28)	364 (45.0)	28 (14-56)
12-15	278 (30.5)	24 (14-42)	417 (45.7)	15 (10-42)	498 (54.6)	28 (14-56)
16-19	327 (36.1)	22 (14-42)	431 (47.5)	16 (9-37)	523 (57.7)	29 (14-56)
20-23	355 (39.6)	26 (14-45)	460 (51.3)	19 (10-42)	566 (63.1)	35 (14-59)
24-27	310 (43.8)	24 (14-42)	336 (47.5)	17 (10-38)	455 (64.3)	29 (14-56)
28-31	247 (43.7)	28 (14-42)	248 (43.9)	18 (10-35)	350 (62.0)	35 (15-60)
32-35	134 (39.4)	27 (14-42)	117 (34.4)	14 (7-28)	187 (55.0)	28 (14-42)
36-39	106 (37.6)	22 (14-44)	99 (35.1)	14 (7-31)	153 (54.3)	28 (14-43)
40-44	90 (32.3)	28 (14-38)	100 (35.8)	14 (7-34)	134 (48.0)	28 (14-52)
45-49	56 (35.4)	21 (14-40)	53 (33.5)	14 (8-38)	82 (51.9)	28 (14-42)
50+	36 (23.5)	14 (10-36)	45 (29.4)	15 (10-35)	58 (37.9)	24 (14-50)
Overall	2274 (30.0)	24 (14-42)	3072 (40.5)	14 (9-33)	3857 (50.9)	28 (14-56)

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

1.25 Nebulised drug treatment

Age	DNase treatment; n(%)
0-3 yrs	87 (9.5)
4-7	172 (21.9)
8-11	367 (42.8)
12-15	528 (54.5)
16-19	509 (54.0)
20-23	491 (53.5)
24-27	389 (52.9)
28-31	304 (52.7)
32-35	155 (44.8)
36-39	127 (44.1)
40-44	123 (43.5)
45-49	73 (45.3)
50+	66 (42.0)
Overall	3391 (42.7)

Antibiotic use among patients with chronic *Pseudomonas aeruginosa*

	Overall	<16 years	≥16 years
Patients with chronic pseudomonas	2806	440	2366
<i>Tobramycin solution; n(%)</i>	691 (24.6)	97 (22.0)	594 (25.1)
<i>Other aminoglycoside; n(%)</i>	66 (2.4)	15 (3.4)	51 (2.2)
<i>Colistin; n(%)</i>	1237 (44.1)	238 (54.1)	999 (42.2)
<i>Promixin; n(%)</i>	726 (25.9)	119 (27.0)	607 (25.7)
<i>At least one of the above; n(%)</i>	2212 (78.8)	383 (87.1)	1829 (77.3)

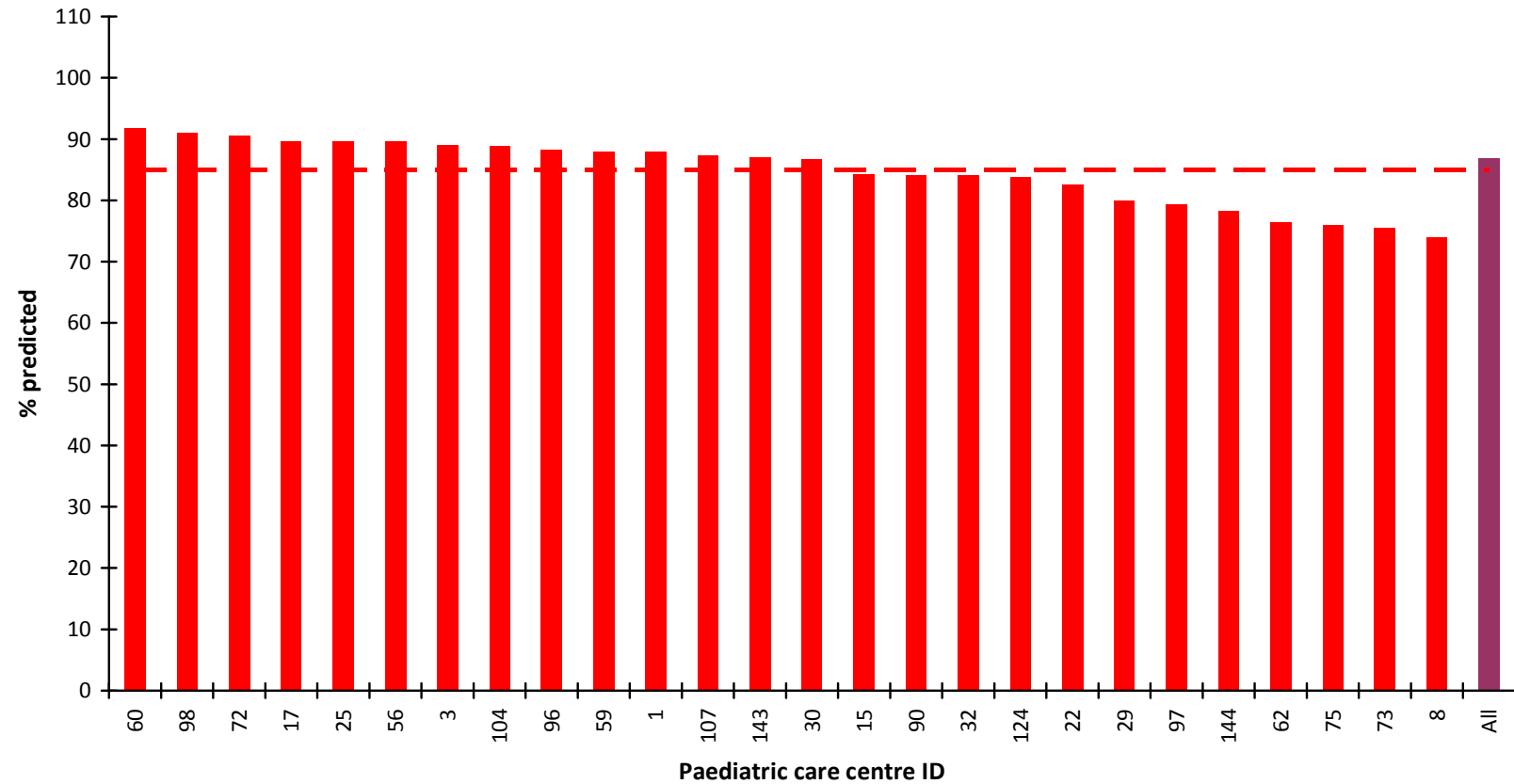
The consensus view in the UK is that 90% of patients chronically infected with *Pseudomonas aeruginosa* should be prescribed at least one of the above nebulised antibiotics.

Section 2: Analyses by paediatric care centre/clinic

(based on 3824 patients from paediatric care centres with complete* data at 2010 annual review)

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

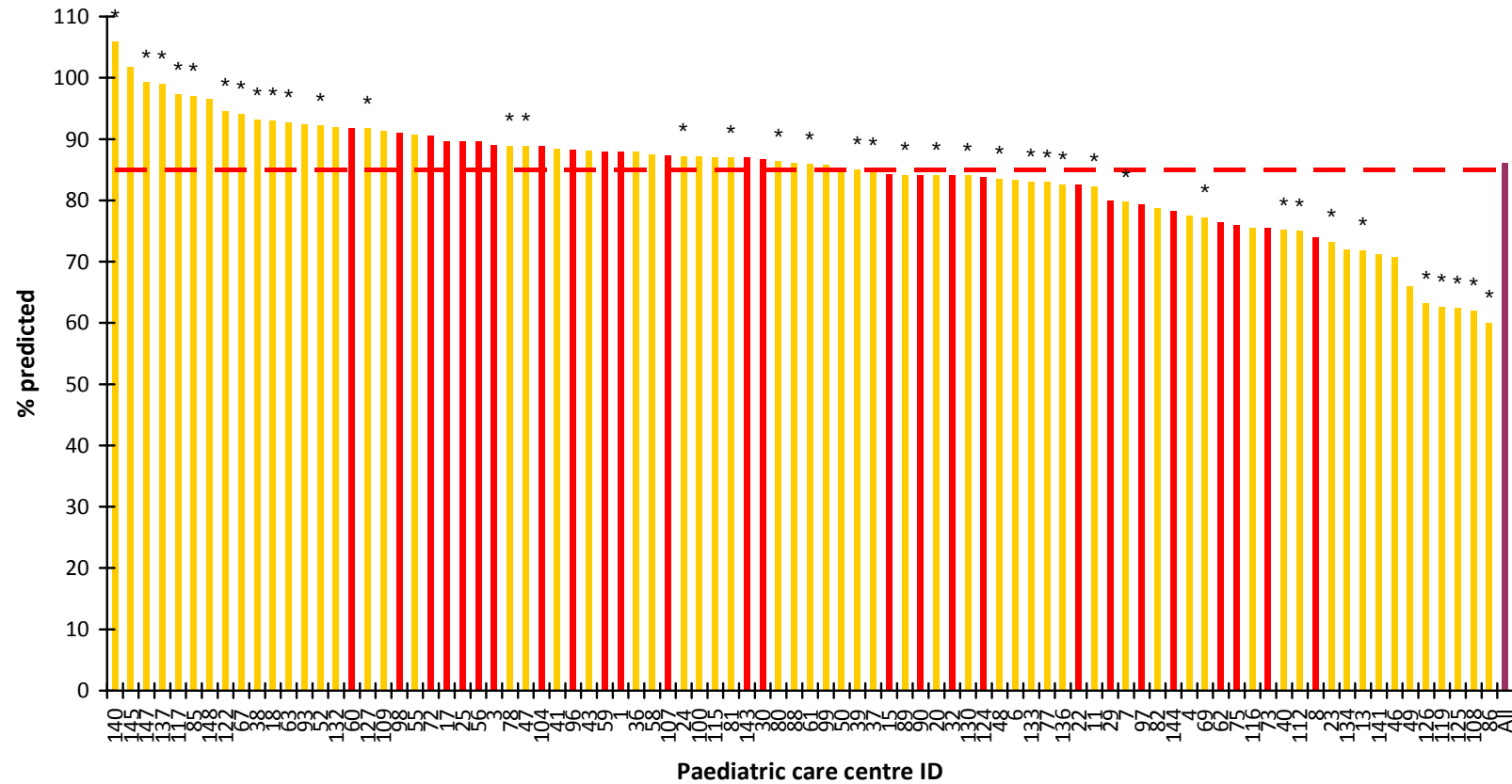
Figure 2.1.1 Median FEV₁ % predicted by paediatric centre/clinic – all centres



The median FEV₁ % predicted for paediatric centres is 85.2% predicted (IQR: 73.3-96.6).

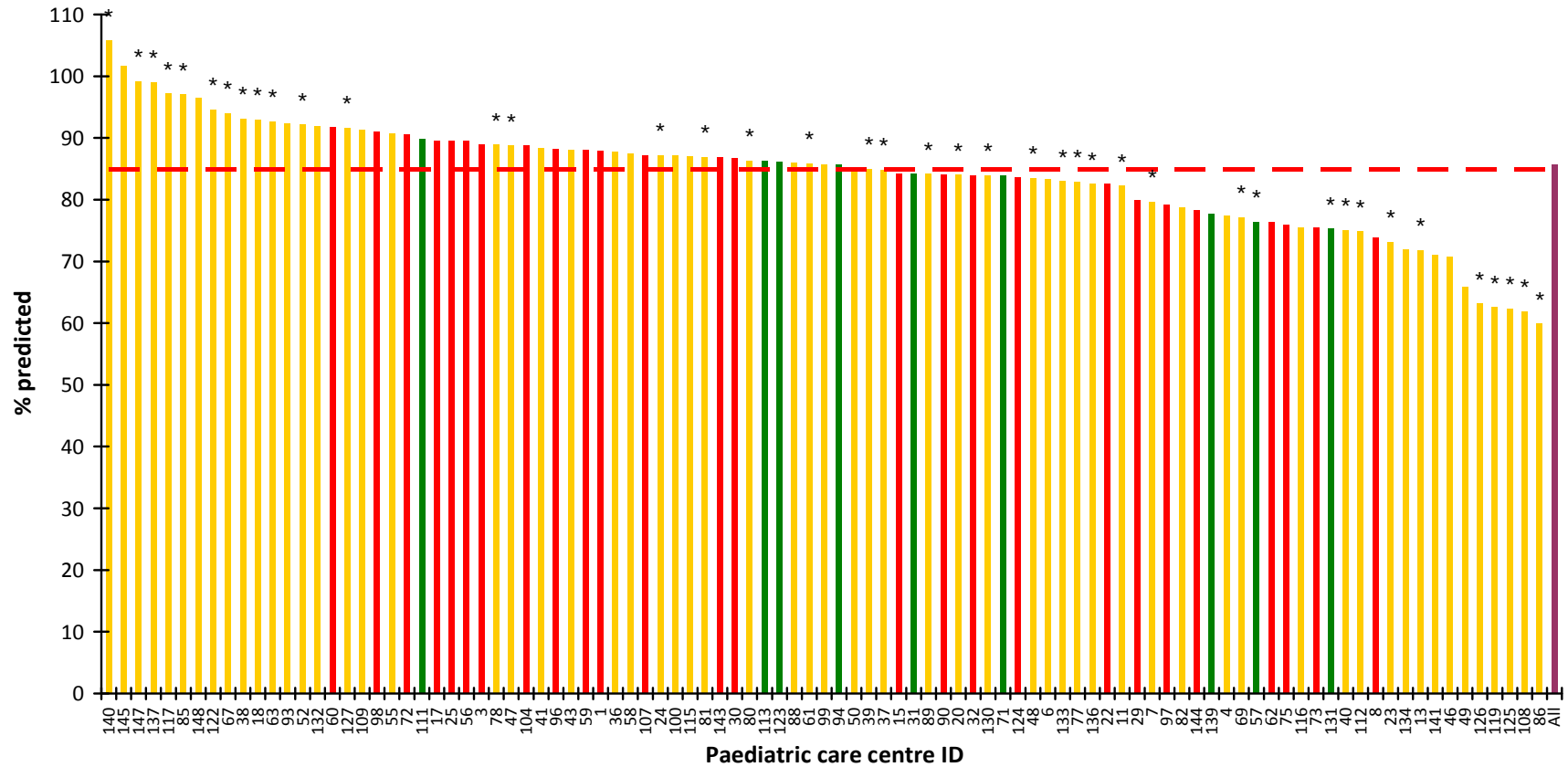
*Red: centres. Plum: all. * Centre with a dataset submission of less than 20 patients.*

Figure 2.1.2 Median FEV₁ % predicted by paediatric centre/clinic – all centres and networks



The median FEV₁ % predicted for paediatric centres and networks is 85.3% predicted (IQR: 72.5-96.7).
 Red: centres. Gold: network clinics. Plum: all. * Centre/clinic with a dataset submission of less than 20 patients.

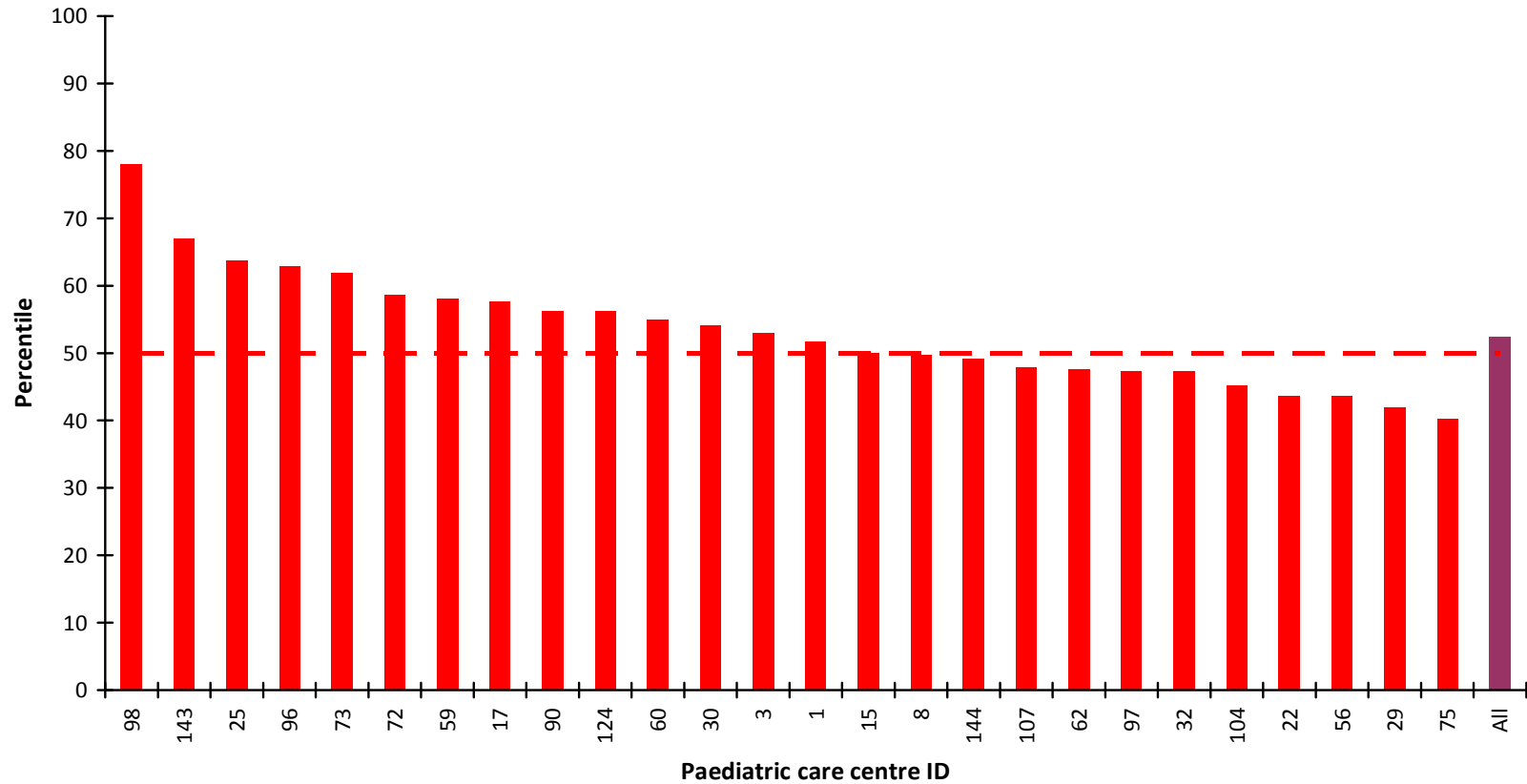
Figure 2.1.3 Median FEV₁ % predicted by paediatric centre/clinic – all centres, networks and stand-alone clinics



The median FEV₁ % predicted for paediatric centres/clinics is 85.2% predicted (IQR: 72.1-96.7).

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

Figure 2.2.1 Median BMI percentile by paediatric centre/clinic – all centres



The median BMI percentile for paediatric centres is 51.6 (IQR: 26.6 – 75.4).
 Red: centres. Plum: all. * Centre with a dataset submission of less than 20 patients.

Figure 2.2.2 Median BMI percentile by paediatric centre/clinic – all centres and networks

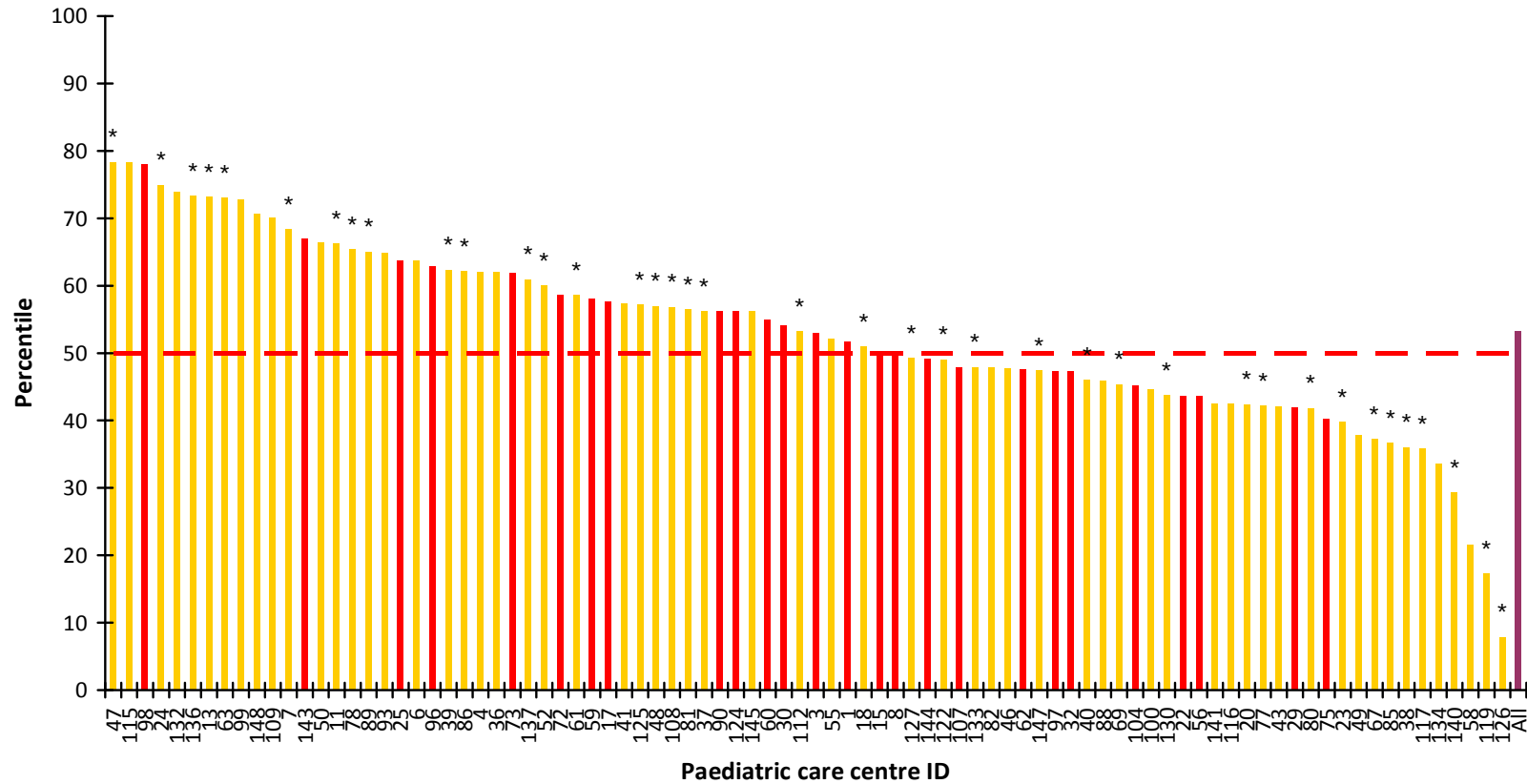
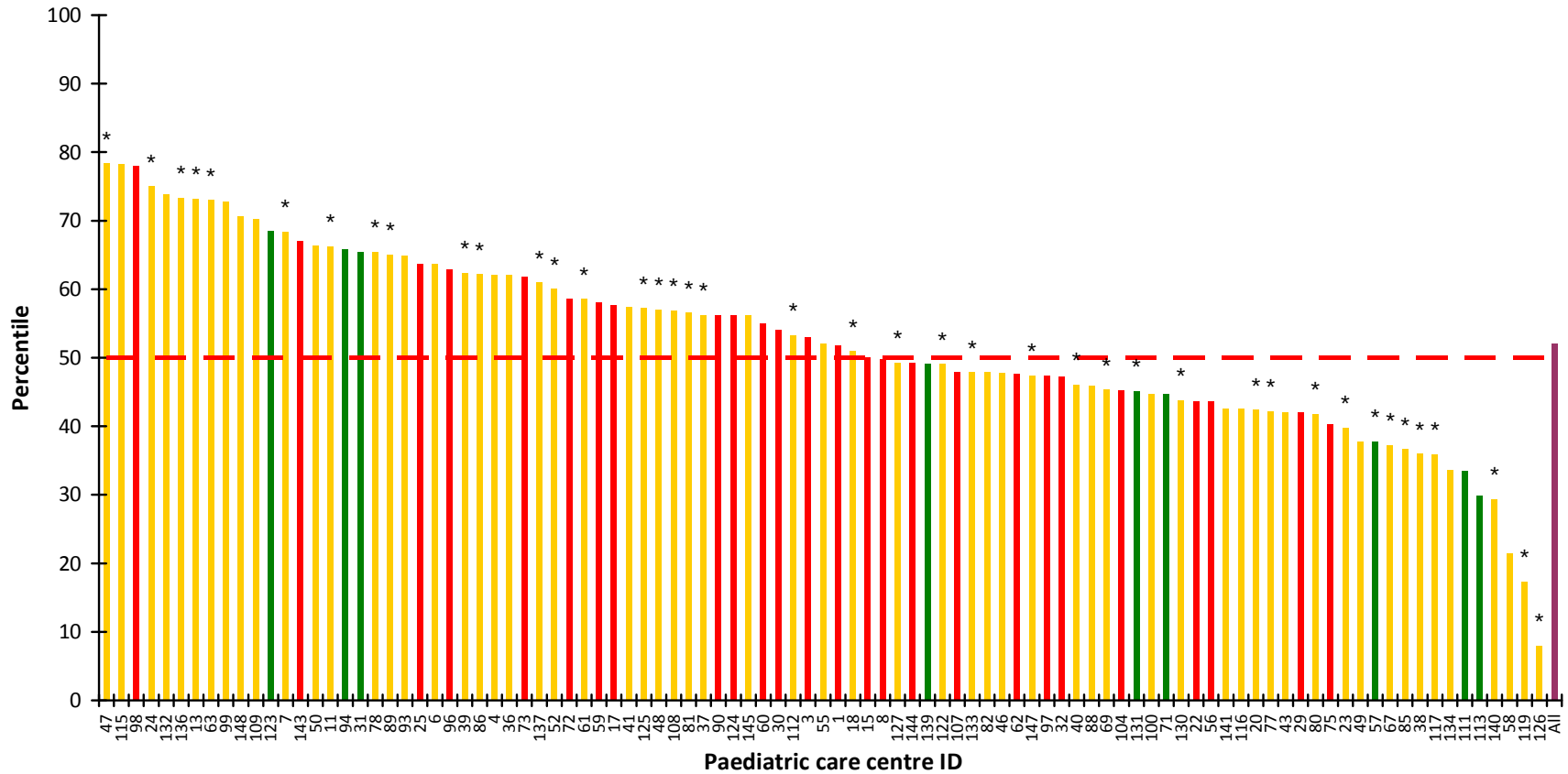


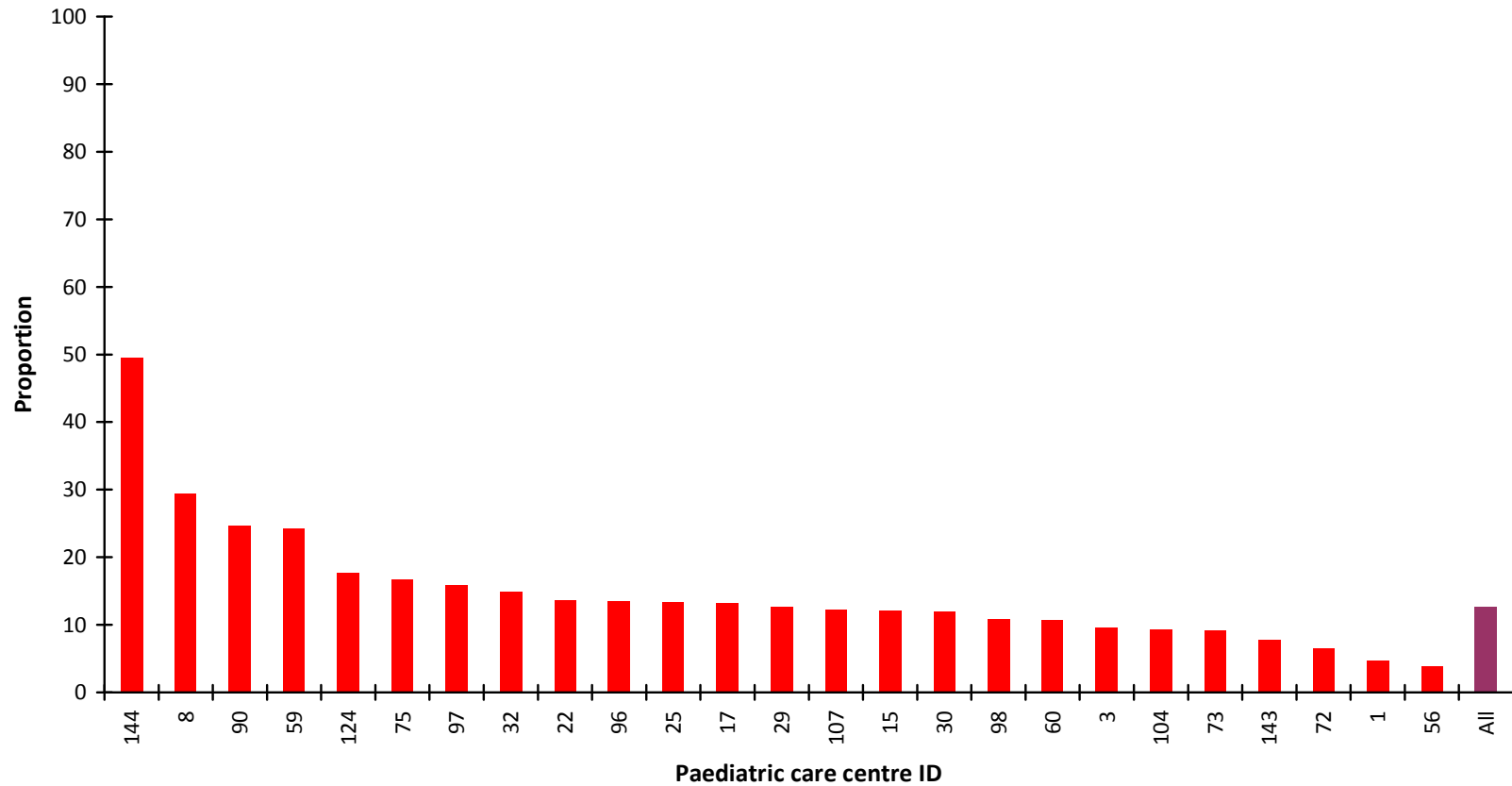
Figure 2.2.3 Median BMI percentile by paediatric centre/clinic – all centres, networks and stand-alone clinics



The median BMI percentile for paediatric centres/clinics is 52.2 (IQR: 27.6-75.5).

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

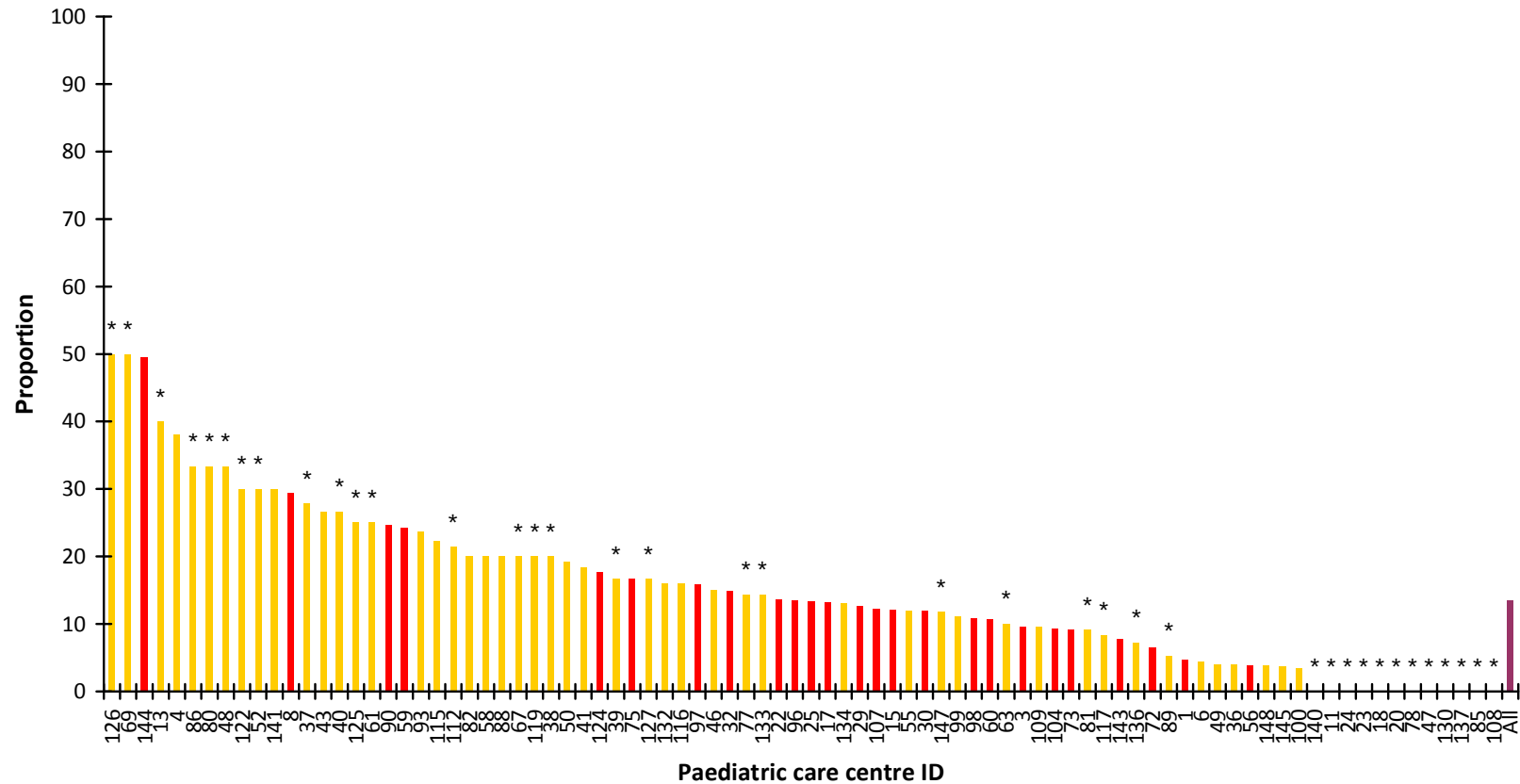
Figure 2.3.1 Proportion of patients with chronic *P.aeruginosa* by paediatric centre/clinic – all centres



The proportion of patients with chronic *P.aeruginosa* for paediatric centres is 14.7%.

Red: centres. Plum: all. * Centre with a dataset submission of less than 20 patients.

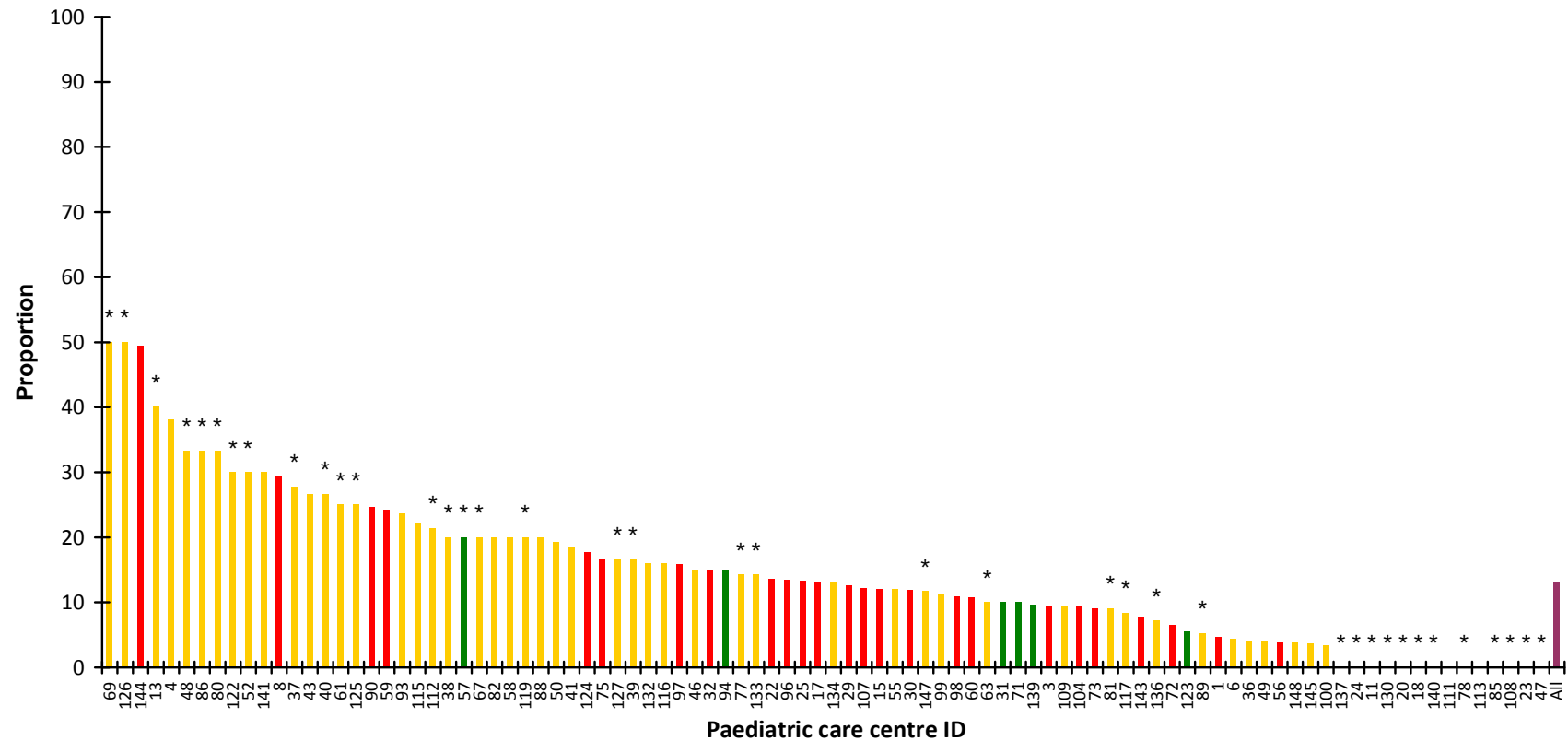
Figure 2.3.2 Proportion of patients with chronic *P.aeruginosa* by paediatric centre/clinic – all centres and networks



The proportion of patients with chronic *P. aeruginosa* for paediatric centres and networks is 14.9%.

Red: centres. Gold: network clinics. Plum: all. * Centre/clinic with a dataset submission of less than 20 patients. Clinic 7 had no available data.

Figure 2.3.3 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 14.5%.

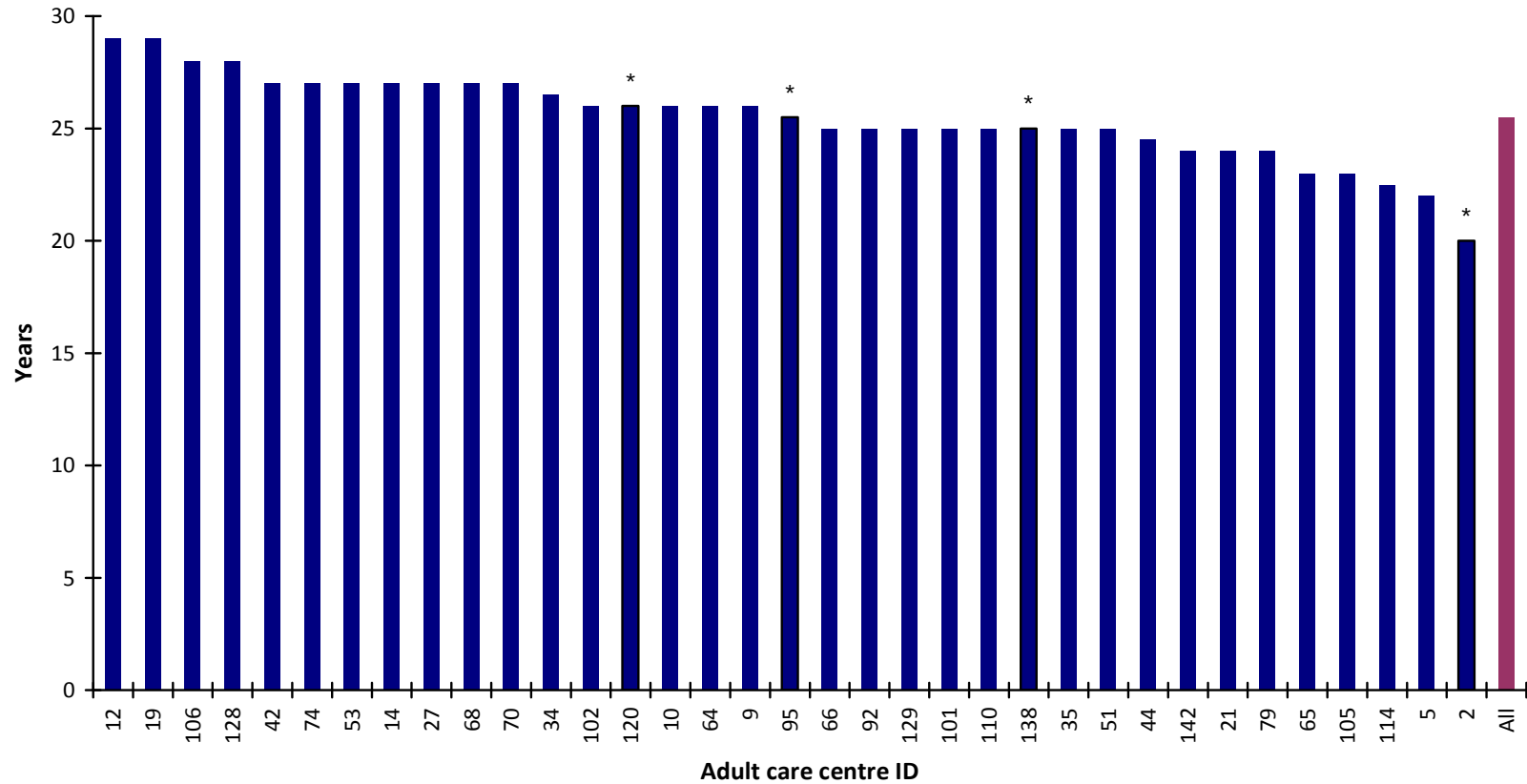
Red: centres. Gold: network clinics. Green: stand-alone clinics. Plum: all. * Centre/clinic with a dataset submission of less than 20 patients. Clinics 131 and 7 had no available data.

Section 3: Analyses by Adult Service

(based on 4113 patients from adult services with complete* data at 2010 annual review)

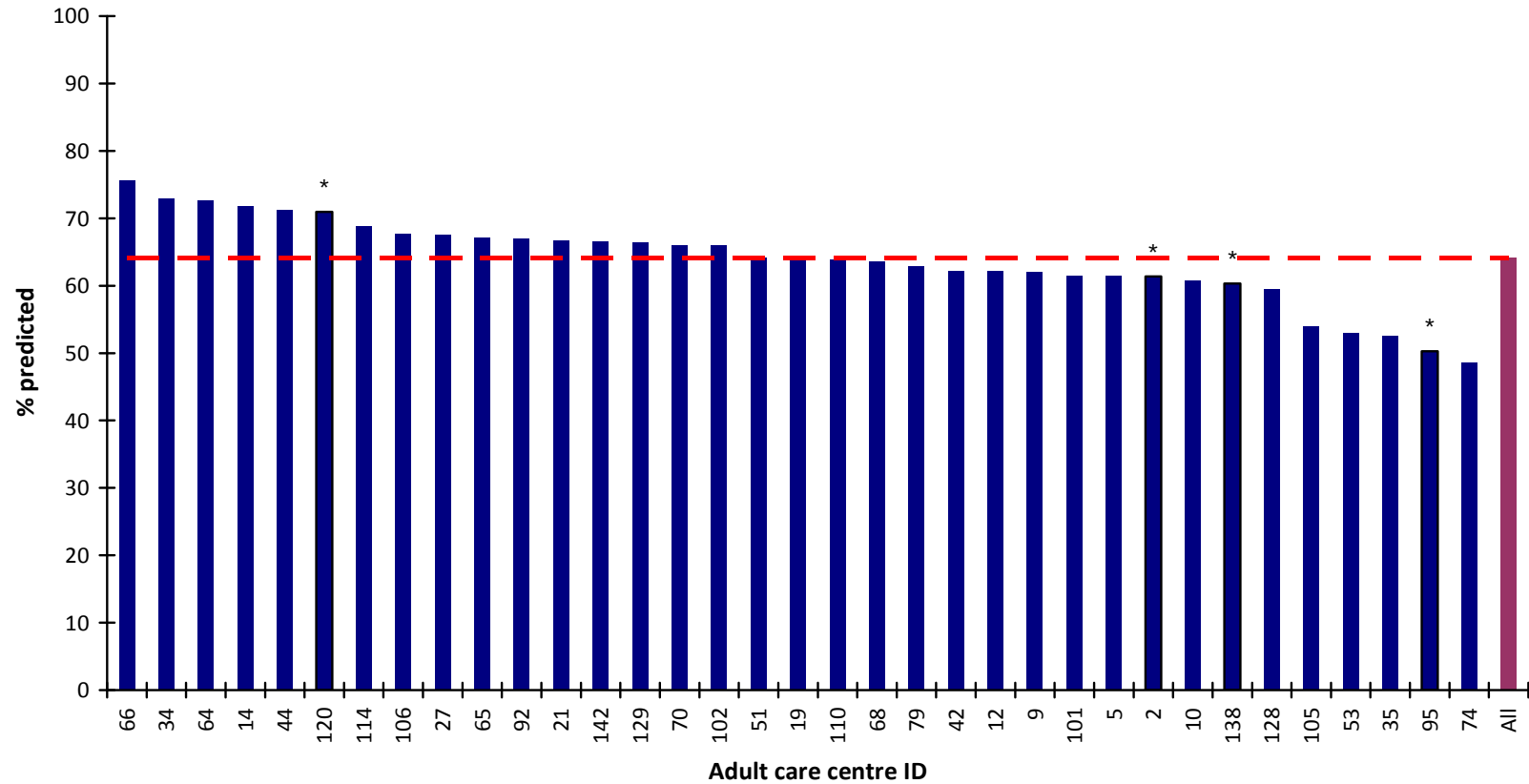
** "Complete" data refers to the minimum data required to produce the range of clinical outcomes presented in this report.*

Figure 3.1 Median age (years) by adult services



The median age in adult services is 26 years (IQR: 21-34).
*Blue: individual clinics. Plum: all. * Clinic with a dataset submission of less than 20 patients.*

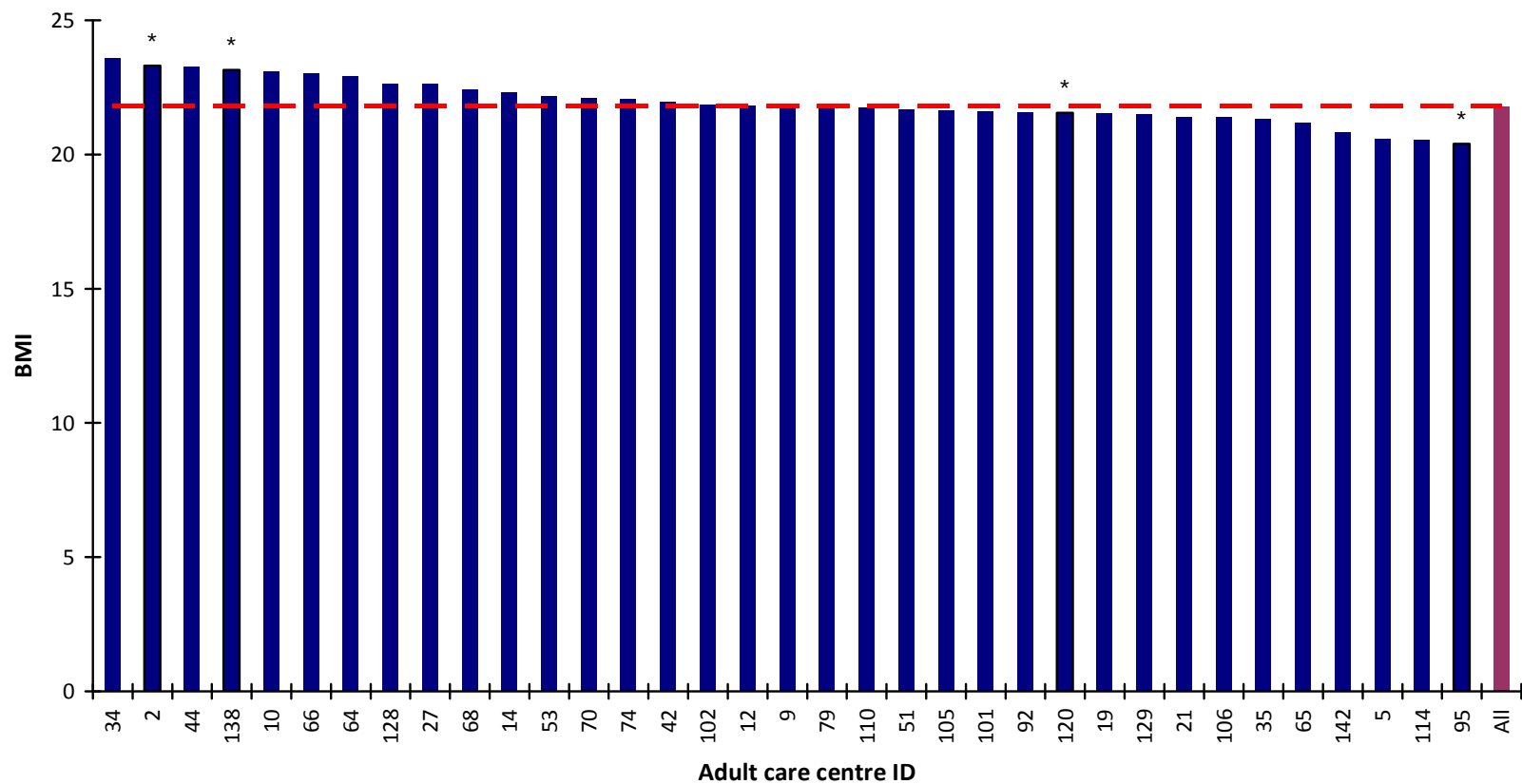
Figure 3.2 Median FEV₁ (% predicted) by adult services



The median FEV₁ (% predicted) in adult services is 65.1% (IQR: 45.6 – 83.8).

*Blue: individual clinics. Plum: all. Red line: median across all adult services * Clinic with a dataset submission of less than 20 patients.*

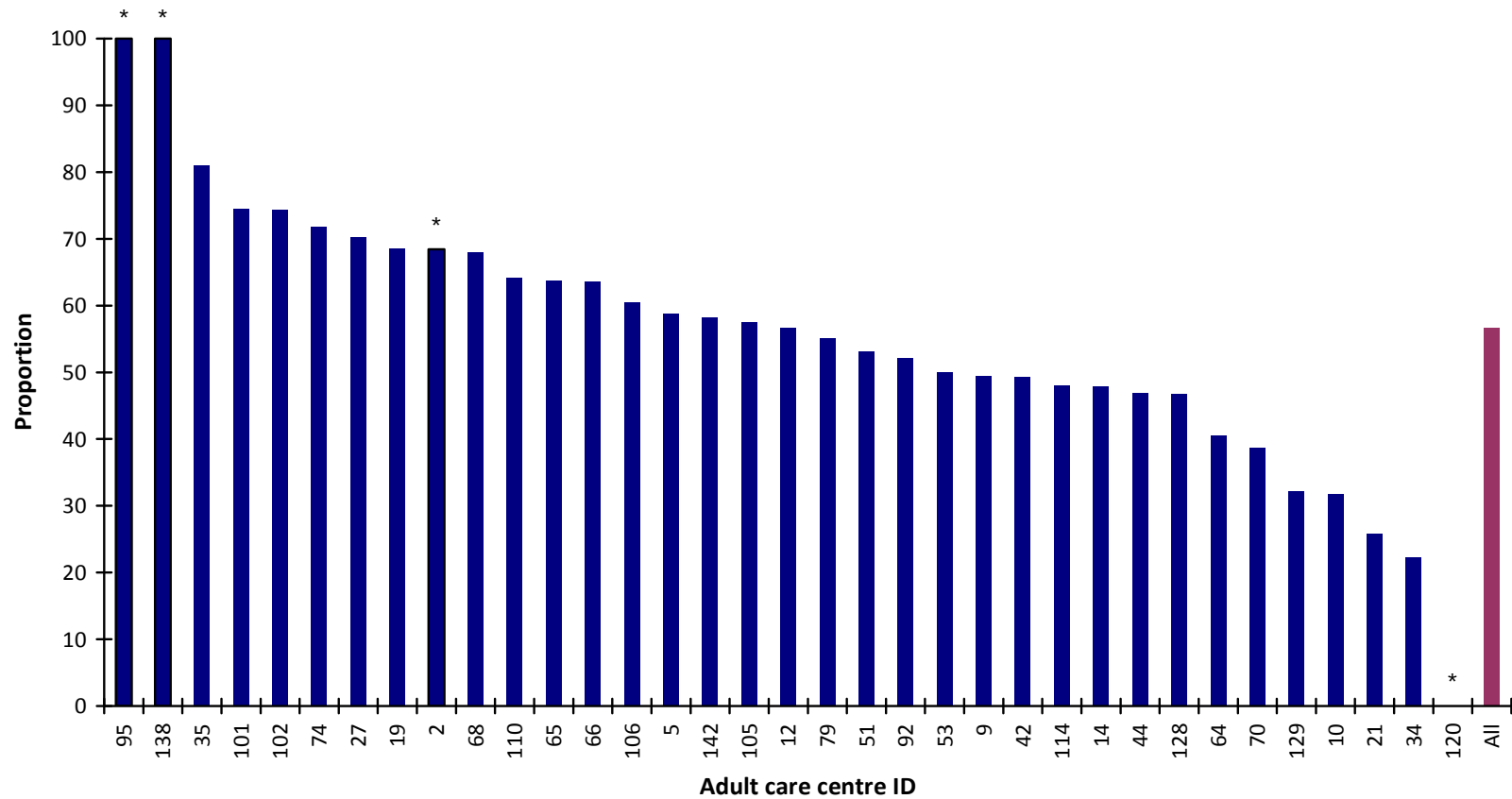
Figure 3.3 Median BMI by adult services



The median BMI in adult services is 21.9 (IQR: 19.9 – 24.2).

*Blue: individual clinics. Plum: all. Red line: median across all adult services * Clinic with a dataset submission of less than 20 patients.*

Figure 3.4 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. * Clinic with a dataset submission of less than 20 patients.

Section 4: Care centres/clinics providing data in 2010

4.1 Paediatric centres/clinics providing data in 2010 – ordered by clinic ID

The number of patients registered at any given centre will fluctuate throughout the year based on new diagnoses, deaths, and transfers. The figures quoted for each centre (in this and all subsequent sections) are therefore estimates based on where patients had their annual review encounter in 2010 and, for those patients alive in 2010 who did not have an annual review encounter, where they had their last encounter.

Country	Location	Centre/clinic	Clinic ID	Number of patients registered	Number of patients providing data in 2010
England	Leicester	Leicester Royal Infirmary	1	55	46
England	Sheffield	Sheffield Children's Hospital	3	131	118
England	Preston	Preston Royal Infirmary	4	22	21
England	Wolverhampton	New Cross Hospital	6	48	45
England	Barnsley	Barnsley Hospital	7	4	4
England	Stoke	University Hospital of North Staffordshire	8	61	55
England	Kings Lynn	Queen Elizabeth Hospital	11	16	16
Wales	Hereford	Hereford County Hospital	13	9	7
England	London - South West	Royal Brompton Hospital	15	343	269
England	London	King's College Hospital	17	90	78

England	Huntingdon	Hinchingbrooke Hospital	18	10	9
England	Birmingham	Birmingham City Hospital	20	20	18
England	Oxford	John Radcliffe Hospital	22	141	125
Wales	Llantrisant	Royal Glamorgan Hospital	23	10	8
England	Kings Mill	Kings Mill Hospital	24	14	12
England	Leeds	St James's University Hospital	25	173	105
England	Southampton	Southampton General hospital	29	186	163
England	London - East	Royal London Hospital	30	113	104
Scotland	Inverness	Raigmore Hospital	31	23	21
England	Bristol	Bristol Royal Hospital for Children	32	82	67
England	Bath	Royal United Hospital	36	26	25
England	Taunton	Musgrove Park Hospital	37	19	18
Wales	Haverfordwest	Withybush General Hospital	38	7	5
England	Kettering	Kettering General Hospital	39	14	12
England	Chester	Countess of Chester Hospital	40	15	15
England	Birmingham	Birmingham Heartlands Hospital	41	51	50

England	Brighton	Royal Alexandra Children's Hospital	43	32	31
England	Blackburn	Royal Blackburn Hospital	46	23	20
Wales	Carmarthen	West Wales General Hospital	47	12	6
England	Canterbury & Thanet	Kent & Canterbury Hospital	48	18	17
England	Derby	Derby Hospital	49	27	25
England	Shrewsbury & Telford	Princess Royal Hospital and Royal Shrewsbury Hospital.	50	30	27
England	Lancaster	Royal Lancaster Hospital	52	12	10
England	Ipswich	Ipswich General Hospital	55	29	28
Scotland	Glasgow	Royal Hospital for Sick Children	56	148	130
England	Barnstaple	North Devon District Hospital	57	12	10
England	Boston	Pilgrim Hospital	58	21	20
England	Newcastle	Royal Victoria Infirmary	59	126	119
Northern Ireland	Belfast	Royal Belfast Hospital for Sick Children	60	224	184
Wales	Aberystwyth	Bronglais Hospital	61	4	4
England	Nottingham	Nottingham City Hospital	62	92	85

Wales	Bridgend	Princess of Wales Hospital	63	11	10
England	Bangor	Ysbyty Gwynedd	67	10	10
England	Burton	Queen's Hospital	69	6	6
England	Middlesbrough	James Cook University Hospital	71	52	47
Wales	Cardiff	Children's Hospital for Wales	72	85	64
Scotland	Dundee	Ninewells Hospital	73	33	24
Scotland	Aberdeen	Royal Aberdeen Children's Hospital	75	37	36
Wales	Newport	Royal Gwent Hospital	77	28	17
Wales	Abergavenny	Nevill Hall Hospital	78	12	8
England	Luton	Luton & Dunstable Hospital	80	18	16
England	York	York Hospital	81	11	11
England	Warrington	Warrington District General Hospital	82	27	26
England	Scarborough	Scarborough District General Hospital	85	9	9
England	Cheltenham and Gloucester	Cheltenham General Hospital and Gloucester Royal Hospital	86	11	3
England	Ashford & Dover	William Harvey Hospital	88	21	21
England	Glan Clwyd (Rhyl)	Glan Clwyd General Hospital	89	21	19

England	London – Central	Great Ormond Street Hospital for Sick Children	90	178	136
England	Coventry	Walsgrave Hospital	93	44	38
England	Truro	Royal Cornwall Hospital	94	28	27
England	Exeter	Royal Devon & Exeter Hospital	96	60	57
England	Liverpool	Alder Hey Children's Hospital	97	85	82
England	Norwich	Norfolk & Norwich University Hospital	98	39	37
England	Sunderland	Sunderland Royal Hospital	99	20	20
Wales	Swansea	Singleton Hospital	100	39	29
England	Birmingham	Birmingham Children's Hospital	104	141	118
England	Cambridge	Addenbrookes Hospital	107	46	41
England	Huddersfield & Halifax	Huddersfield Royal Infirmary and Calderdale Royal Hospital	108	14	7
England	Lincoln	Lincoln Hospital	109	21	21
England	Hull	Hull Royal Infirmary	111	40	30
England	Burnley	Burnley General Hospital	112	15	15
England	Carshalton	Queen Mary's Hospital for Children	113	29	27
England	Wigan	Royal Albert Edward Infirmary	115	27	27

England	Wythenshawe	Wythenshawe Hospital	116	26	25
England	Bury St Edmonds	West Suffolk General Hospital	117	12	12
England	Stockport	Stepping Hill Hospital	119	18	6
England	Bishop Auckland & Darlington	Bishop Auckland General Hospital	122	11	11
Scotland	Ayr/Kilmarnock	Crosshouse Hospital	123	28	20
England	London - South East	University Hospital Lewisham	124	38	35
England	Crewe	Leighton Hospital	125	17	16
England	Chesterfield	Chesterfield Hospital	126	8	7
Scotland	Dumfries and Galloway	Dumfries and Galloway Royal Infirmary	127	6	6
England	Great Yarmouth	James Paget Hospital	130	12	12
England	Bradford	St Luke's Hospital	131	22	17
England	Wirral	Arrowe Park Hospital	132	25	25
England	Ormskirk/Southport	Ormskirk & District General Hospital	133	15	14
England	Peterborough	Peterbrough District General Hospital	134	25	23
England	Whiston	Whiston Hospital	136	14	14
England	Barnsley	Barnsley Hospital	137	7	7

England	Plymouth	Derriford Hospital	139	36	34
England	Whitehaven	West Cumberland Hospital	140	11	10
England	Blackpool	Victoria Hospital	141	30	30
Scotland	Edinburgh	Royal Hospital for Sick Children	143	132	102
England	Manchester	Royal Manchester Children's Hospital (previously: University of Central Manchester Hospital)	144	195	155
England	Northampton	Northampton General Hospital	145	27	27
England	Eastbourne	Eastbourne District General Hospital	147	19	19
England	Worcester	Worcester and Redditch Hospitals	148	30	26

4.2 Adult centres/clinics providing data in 2010 – ordered by clinic ID

Country	Location	Centre/clinic	Clinic ID	Number of patients registered	Number of patients providing data in 2010
England	Wolverhampton	New Cross Hospital	2	19	19
England	London - South East	King's College Hospital	5	137	119
England	Newcastle	Royal Victoria Infirmary	9	226	206
England	Bath	Bath Royal United Hospital	10	23	22
England	London - South West	Royal Brompton Hospital	12	703	584
Northern Ireland	Belfast	Belfast City Hospital	14	223	187
England	Frimley	Frimley Park Hospital	19	116	103
Scotland	Dundee	Ninewells Hospital	21	45	33
England	Birmingham	Birmingham Heartlands Hospital	27	306	247
England	Exeter	Royal Devon & Exeter Hospital	34	77	70
England	Poole	Poole Hospital	35	23	21
England	Leeds	St James's University Hospital	42	386	362
Scotland	Edinburgh	Western General Hospital	44	141	34

England	Cambridge	Papworth Hospital	51	261	193
Scotland	Inverness	Raigmore Hospital	53	22	20
England	Plymouth	Derriford Hospital	64	41	40
England	Sheffield	Northern General Hospital	65	135	131
England	Liverpool	Liverpool Heart and Chest Hospital	66	268	247
Wales	Llandough	Llandough Hospital	68	149	130
Scotland	Aberdeen	Aberdeen Royal Infirmary	70	50	47
England	Stoke-on-Trent	University Hospital of North Staffordshire	74	52	50
Scotland	Glasgow	Gartnavel General Hospital	79	218	188
England	London - East	London Chest Hospital	92	141	118
England	Portsmouth	Queen Alexandra Hospital	95	20	8
England	Nottingham	Nottingham City hospital	101	122	111
England	Manchester	Wythenshawe Hospital	102	372	336
England	London - South East	University Hospital Lewisham	105	43	41
England	Bristol	Bristol Royal Infirmary	106	116	81
England	Southampton	Southampton General hospital	110	142	133
England	Norwich	Norfolk & Norwich University Hospital	114	59	54

England	York	York Hospital	120	13	11
England	Oxford	Churchill Hospital	128	81	66
England	Truro	Royal Cornwall Hospital	129	33	31
England	Hull	Castle Hill Hospital	138	30	3
England	Leicester	Glenfield Hospital	142	68	67

4.3 Paediatric centres/clinics providing data in 2010 – alphabetical order

England Location		Centre/clinic	Clinic ID	Number of patients registered	Number of patients providing data in 2010
Barnstaple		North Devon District Hospital	57	12	10
Birmingham	<i>Birmingham</i>	Birmingham Children's Hospital	104	141	118
	<i>Birmingham</i>	Birmingham City Hospital	20	20	18
	<i>Birmingham</i>	Birmingham Heartlands Hospital	41	51	50
	<i>Coventry</i>	Walsgrave Hospital	93	44	38
	<i>Wolverhampton</i>	New Cross Hospital	6	48	45
	<i>Worcester</i>	Worcester and Redditch Hospital	148	30	26
Bradford		St Luke's Hospital	131	22	17
Bristol	<i>Bristol</i>	Bristol Royal Hospital for Children	32	82	67
	<i>Bath</i>	Royal United Hospital	36	26	25
	<i>Cheltenham and Gloucester</i>	Cheltenham General Hospital and Gloucester Royal Hospital	86	11	3
	<i>Taunton</i>	Musgrove Park Hospital	37	19	18
Cambridge	<i>Cambridge</i>	Addenbrookes Hospital	107	46	41
	<i>Huntingdon</i>	Hinchingbrooke Hospital	18	10	9
	<i>Ipswich</i>	Ipswich General Hospital	55	29	28
	<i>Peterborough</i>	Peterborough District General Hospital	134	25	23
	<i>West Suffolk</i>	West Suffolk General Hospital	117	12	12
Carshalton		Queen Mary's Hospital for Children	113	29	27
Exeter	<i>Exeter</i>	Royal Devon & Exeter Hospital	96	60	57

Hull		Hull Royal Infirmary	111	40	30
Leeds	Leeds	St James's University Hospital	25	173	105
	Barnsley	Barnsley Hospital	7	4	4
	Huddersfield & Halifax	Huddersfield Royal Infirmary and Calderdale Royal Hospital	108	14	7
	Scarborough	Scarborough District General Hospital	85	9	9
	York	York Hospital	81	11	11
Leicester	Leicester	Leicester Royal Infirmary	1	55	46
	Kettering	Kettering General Hospital	39	14	12
Liverpool	Liverpool	Alder Hey Children's Hospital	97	85	82
	Bangor	Ysbyty Gwynedd	67	10	10
	Chester	Countess of Chester Hospital	40	15	15
	Crewe	Leighton Hospital	125	17	16
	Glan Clwyd (Rhyl)	Glan Clwyd General Hospital	89	21	19
	Ormskirk/Southport	Ormskirk & District General Hospital	133	15	14
	Warrington	Warrington District General Hospital	82	27	26
	Whiston	Whiston Hospital	136	14	14
	Wigan	Royal Albert Edward Infirmary	115	27	27
	Wirral	Arrowe Park Hospital	132	25	25
London - Central	London - Central	Great Ormond Street Hospital for Sick Children	90	178	136
	Luton	Luton & Dunstable Hospital	80	18	16
London - East		Royal London Hospital	30	113	104
London - South East	London	King's College Hospital	17	90	78
	Ashford & Dover	William Harvey Hospital	88	21	21
	Brighton	Royal Alexandra Children's Hospital	43	32	31
	Canterbury & Thanet	Kent & Canterbury Hospital	48	18	17
	Eastbourne	Eastbourne General Hospital	147	19	19

London - South East		University Hospital Lewisham	124	38	35
London - South West		Royal Brompton Hospital	15	343	269
Manchester	<i>Manchester</i>	Royal Manchester Children's Hospital (previously: University of Central Manchester Hospital)	144	195	155
	<i>Blackburn</i>	Royal Blackburn Hospital	46	23	20
	<i>Blackpool</i>	Victoria Hospital	141	30	30
	<i>Burnley</i>	Burnley General Hospital	112	15	15
	<i>Lancaster</i>	Royal Lancaster Hospital	52	12	10
	<i>Preston</i>	Preston Royal Infirmary	4	22	21
	<i>Stockport</i>	Stepping Hill Hospital	119	18	6
	<i>Wythenshawe</i>	Wythenshawe Hospital	116	26	25
Newcastle	<i>Newcastle</i>	Royal Victoria Infirmary	59	126	119
	<i>Bishop Auckland & Darlington</i>	Bishop Auckland General Hospital	122	11	11
	<i>Sunderland</i>	Sunderland Royal Hospital	99	20	20
	<i>Whitehaven</i>	West Cumberland Hospital	140	11	10
Newcastle	<i>Middlesborough</i>	James Cook University Hospital	71	52	47
Norwich	<i>Norwich</i>	Norfolk & Norwich University Hospital	98	39	37
	<i>Great Yarmouth</i>	James Paget Hospital	130	12	12
	<i>Kings Lynn</i>	Queen Elizabeth Hospital	11	16	16
Nottingham	<i>Nottingham</i>	Nottingham City Hospital	62	92	85
	<i>Boston</i>	Pilgrim Hospital	58	21	20
	<i>Chesterfield</i>	Chesterfield Hospital	126	8	7
	<i>Derby</i>	Derby Hospital	49	27	25
	<i>Kings Mill</i>	Kings Mill Hospital	24	14	12

	<i>Lincoln</i>	Lincoln Hospital	109	21	21
Oxford	<i>Oxford</i>	John Radcliffe Hospital	22	141	125
	<i>Northampton</i>	Northampton General Hospital	145	27	27
Plymouth		Derriford Hospital	139	36	34
Sheffield	<i>Sheffield</i>	Sheffield Children's Hospital	3	131	118
	<i>Barnsley</i>	Barnsley Hospital	137	7	7
Southampton		Southampton General hospital	29	186	163
Stoke	<i>Stoke-on-Trent</i>	University Hospital of North Staffordshire	8	61	55
	<i>Burton</i>	Queen's Hospital	69	6	6
	<i>Shrewsbury & Telford</i>	Princess Royal Hospital and Royal Shrewsbury Hospital	50	30	27
Truro	<i>Truro</i>	Royal Cornwall Hospital	94	28	27

Northern Ireland

Location	Centre/clinic	Clinic ID	Number of patients registered	Number of patients providing data in 2010
Belfast	Royal Belfast Hospital for Sick Children	60	224	184

Scotland

Location		Centre/clinic	Clinic ID	Number of patients registered	Number of patients providing data in 2010
Aberdeen		Royal Aberdeen Children's Hospital	75	37	36
Ayr/Kilmarnock		Crosshouse Hospital	123	28	20
Dundee		Ninewells Hospital	73	33	24
Edinburgh		Royal Hospital for Sick Children	143	132	102
Glasgow	<i>Glasgow</i>	Royal Hospital for Sick Children	56	148	130
	<i>Dumfries and Galloway</i>	Dumfries and Galloway Royal Infirmary	127	6	6
Inverness		Raigmore Hospital	31	23	21

Wales

Location		Centre/clinic	Clinic ID	Number of patients registered	Number of patients providing data in 2010
Cardiff	<i>Cardiff</i>	Children's Hospital for Wales	72	85	64
	<i>Abergavenny</i>	Nevill Hall Hospital	78	12	8
	<i>Aberystwyth</i>	Bronglais Hospital	61	4	4
	<i>Bridgend</i>	Princess of Wales Hospital	63	11	10
	<i>Carmarthen</i>	West Wales General Hospital	47	12	6
	<i>Haverfordwest</i>	Withybush General Hospital	38	7	5
	<i>Hereford</i>	Hereford County Hospital	13	9	7
	<i>Llantrisant</i>	Royal Glamorgan Hospital	23	10	8
	<i>Newport</i>	Royal Gwent Hospital	77	28	17
	<i>Swansea</i>	Singleton Hospital	100	39	29

4.4 Adult centres/clinics providing data in 2010 – alphabetical order

England Location		Centre/clinic	Clinic ID	Number of patients registered	Number of patients providing data in 2010
Birmingham	<i>Birmingham</i>	Birmingham Heartlands Hospital	27	306	247
	<i>Wolverhampton</i>	New Cross Hospital	2	19	19
Bristol	<i>Bristol</i>	Bristol Royal Infirmary	106	116	81
	<i>Bath</i>	Bath Royal United Hospital	10	23	22
Cambridge		Papworth Hospital	51	261	193
Exeter		Royal Devon & Exeter Hospital	34	77	70
Frimley		Frimley Park Hospital	19	116	103
Hull		Castle Hill Hospital	138	30	3
Leeds	<i>Leeds</i>	St James's University Hospital	42	386	362
	<i>York</i>	York Hospital	120	13	11
Leicester		Glenfield Hospital	142	68	67
Liverpool		Liverpool Heart and Chest Hospital	66	268	247
London - East		London Chest Hospital	92	141	118
London - South East		King's College Hospital	5	137	119

London - South East		University Hospital Lewisham	105	43	41
London - South West		Royal Brompton Hospital	12	703	584
Manchester		Wythenshawe Hospital	102	372	336
Newcastle		Royal Victoria Infirmary	9	226	206
Norwich		Norfolk & Norwich University Hospital	114	59	54
Nottingham		Nottingham City Hospital	101	122	111
Oxford		Churchill Hospital	128	81	66
Plymouth		Derriford Hospital	64	41	40
Portsmouth		Queen Alexandra Hospital	95	20	8
Sheffield		Northern General Hospital	65	135	131
Southampton	<i>Southampton Poole</i>	Southampton General hospital	110	142	133
		Poole Hospital	35	23	21
Stoke-on-Trent		University Hospital of North Staffordshire	74	52	50
Truro		Royal Cornwall Hospital	129	33	31

Northern Ireland

Location		Centre/clinic	Clinic ID	Number of patients registered	Number of patients providing data in 2010
Belfast		Belfast City Hospital	14	223	187

Scotland

Location		Centre/clinic	Clinic ID	Number of patients registered	Number of patients providing data in 2010
Aberdeen		Aberdeen Royal Infirmary	70	50	47
Edinburgh	<i>Edinburgh</i>	Western General Hospital, Edinburgh	44	141	34
	<i>Dundee</i>	Ninewells Hospital, Dundee	21	45	33
	<i>Inverness-split</i>	Raigmore Hospital, Inverness	53	22	20
Glasgow		Gartnavel General Hospital, Glasgow	79	218	188

Wales

Location		Centre/clinic	Clinic ID	Number of patients registered	Number of patients providing data in 2010
Llandough		Llandough Hospital	68	149	130