



Cystic Fibrosis Trust

Annual Data Report 2004

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1. Data Returns - 2004

This report includes demographic and clinical data submitted by over sixty Specialist CF Centres and CF clinics from all over the United Kingdom

2. Summary of the UK Cystic Fibrosis Database

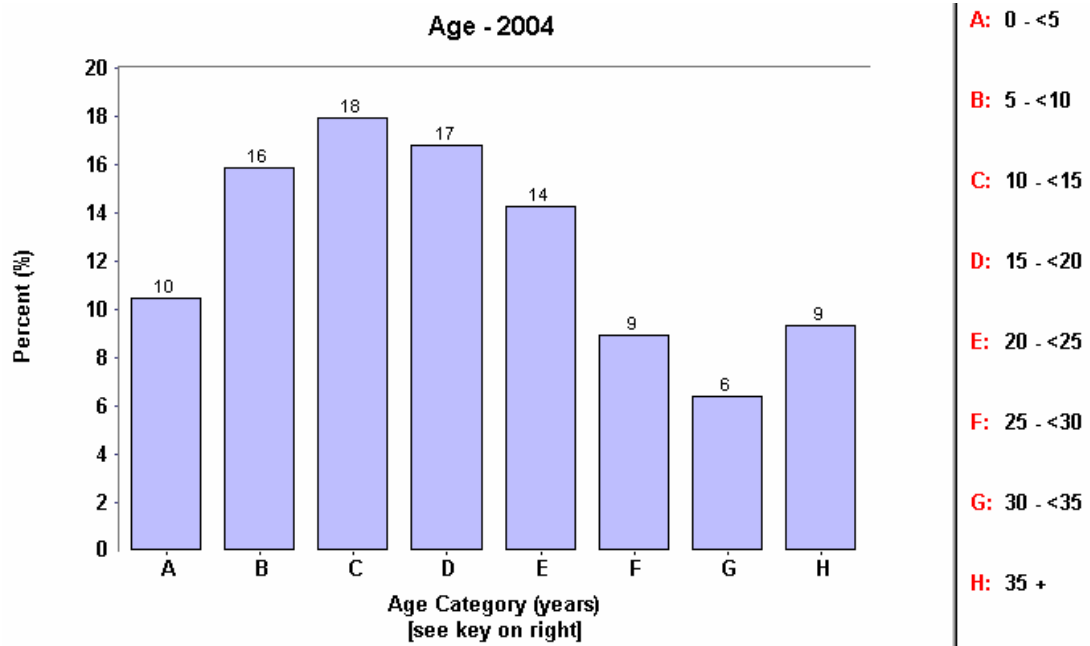
		2002	2003	2004
CF patients registered		6932	6861	7046
CF patients with complete clinical data		5301	4875	5561
Age in years	(mean)	16	17.8	18
Age in years	(median)	17.4	16.1	16.4
Newly diagnosed patients		159	142	164
Age at diagnosis in years	(mean)	2.7	3.0	3.0
Age at diagnosis in months	(median)	5	5	5
Adults (16 years and over) %		50.1	50.8	51.4
Males (%)		53.9	53.8	53.4
Genotyped (%)		95	95	95
Total deaths reported		94	103	123
Age at death in years	(mean)	23.4	26	27.6
Age at death in years	(median)	23	24.2	25.6

Section 3:

All UK Patients

Summary

3.1 Age Profile for all patients - 2004

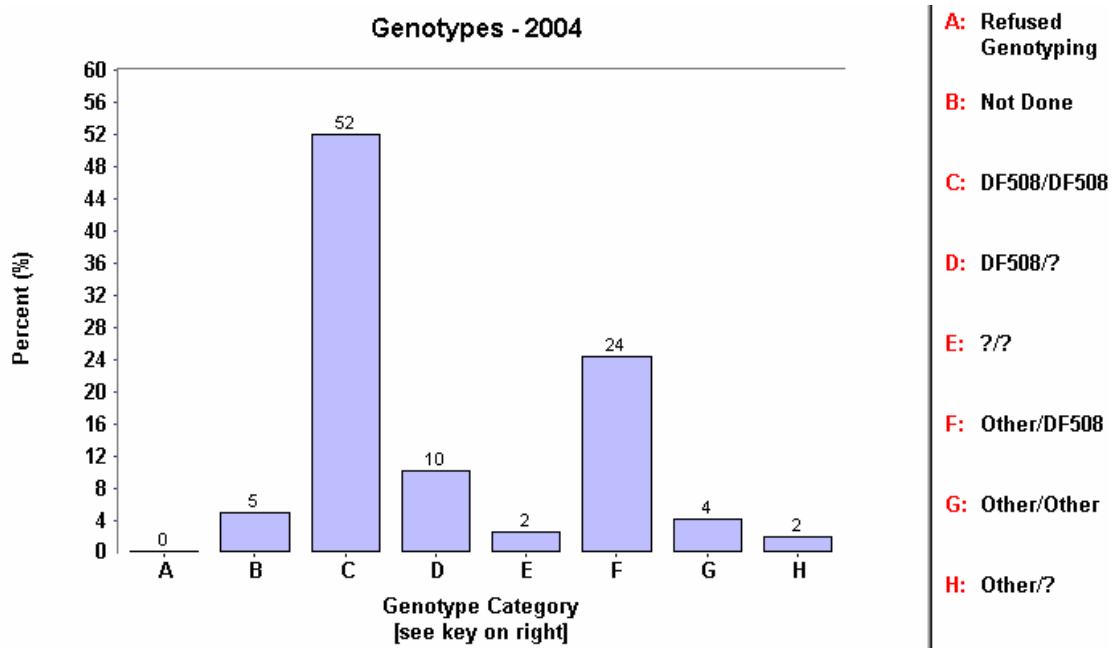


Age	0 - <5	5 - <10	10 - <15	15 - <20	20 - <25	25 - <30	30 - <35	35+	Total
Number of patients	736	1118	1264	1186	1005	630	451	656	7046

(Total number of patients: 7046)

This graph shows the age profile of all patients registered. If a patient has been recorded as deceased, transferred or reverse-diagnosed, he/she is not included. The age of a patient is calculated as at 31st December in the year of analysis.

3.2 Genotypes for all patients - 2004



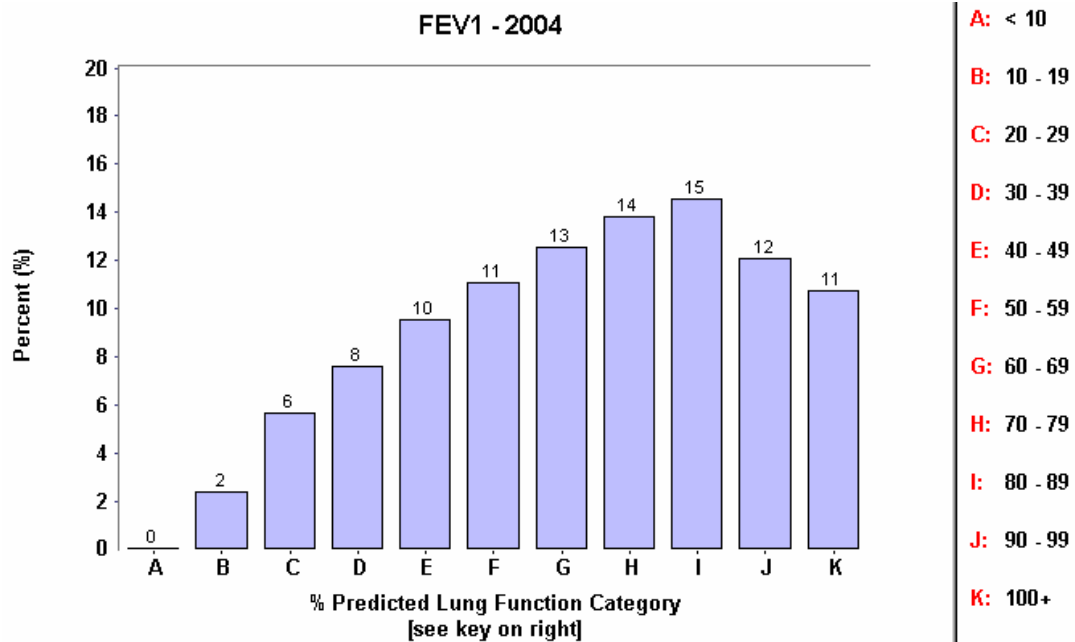
Genotype category	Patient refused	Not done	DF508 / DF508	DF508 / ?	? / ?	DF508 / other	Other / other	Other / ?	Total
Number of patients	8	382	4069	796	194	1902	317	149	7817

(Total number patients: 7817)

This graph shows the genotype profile for all patients registered by the end of 2004. The genotypes are taken from the Biography Form.

Any identified allele that is not "DeltaF508" is aggregated into "Other". Any genotypes entered as "?" are "NOT IDENTIFIED" or "UNKNOWN".

3.3 FEV1 for all patients - 2004



FEV1%	< 10	10 - 19	20 - 29	30 - 39	40 - 49	50 - 59	60 - 69	70 - 79	80 - 89	90 - 99	100+	Total
Number of patients	3	123	289	390	489	569	644	709	749	621	553	5139

(Total number of patients: 5139)

This graph shows patients classified by percent predicted FEV1.

The age of a patient is calculated as at the date of visit. If there is more than one visit over the analysis year then the most recent readings are used.

3.4 Patients with at least 1 Pseudomonas aeruginosa isolated - 2004

Age	0 - <5	5 - <10	10 - <15	15 - <20	20 - <25	25 - <30	30 - <35	35+	Total
Patients with <i>P.aeruginosa</i>	55	125	278	505	552	335	223	306	2379
Age specific prevalence (%)	10	13	27	50	62	59	56	53	40
Number of patients in age band	565	942	1042	1012	889	568	398	572	5988

(Total number of patients with snapshot data: 5988, of which 2379 (40%) had *P. aeruginosa* isolated at least once)

This table shows the patients divided into age categories for *P. aeruginosa* as recorded on the snapshot form.

The age of the patient is calculated at the time of the bacteriology culture. Percent prevalence is calculated in each category, e.g. number of 20-25 year olds who have *P. aeruginosa* / total number of 20-25 year olds. The age of the cohort is as of 31st December of the analysis year. E.g. If there are 6 patients with *P. aeruginosa* in the 20-25 age range, and 10 patients altogether aged 20-25, the age-specific prevalence is $6/10 \times 100$ for the age range 20-25 years.

3.5 Patients with 3 or more *Pseudomonas aeruginosa* isolates - 2004

Age	Number of patients with chronic <i>Pseudomonas</i> infection	Age specific prevalence (%)	Number of patients in age band
0 - <5	46	9	504
5 - <10	148	16	906
10 - <15	295	30	974
15 - <20	486	52	940
20 - <25	545	64	849
25 - <30	349	64	549
30 - <35	218	58	376
35 +	279	51	549
Sub Tot	2366	42	5647

*(Total number of patients with annual review data: 5647, of which 2366 (42%) had chronic *Pseudomonas* infection).*

*Patients are counted if they have "Chronic *Pseudomonas*" checked at the time of Annual Review.*

3.6 Glucose tolerance for all patients - 2004

Age									A	B
	0 - <5	5 - <10	10 - <15	15 - <20	20 - <25	25 - <30	30 - <35	35+	Total: all ages	Total: 10 yrs & over
Not done	477 (96%)	835 (93%)	652 (67%)	427 (45%)	320 (37%)	208 (38%)	145 (38%)	234 (42%)	3298 (58%)	1986 (47%)
Normal	19 (4%)	46 (5%)	241 (25%)	313 (33%)	260 (30%)	151 (27%)	70 (18%)	117 (21%)	1217 (22%)	1152 (27%)
Intolerant	1 (0%)	5 (1%)	39 (4%)	52 (6%)	64 (7%)	32 (6%)	22 (6%)	18 (3%)	233 (4%)	227 (5%)
Diabetic	2 (0%)	12 (1%)	38 (4%)	147 (16%)	213 (25%)	159 (29%)	143 (38%)	185 (33%)	899 (16%)	885 (21%)
Total	499	898	970	939	857	550	380	554	5647	4250

(Total number of patients: 5647, of which 4250 aged 10 years or over)

This table shows the categories patients fall into for glucose tolerance. Patients are selected if they have attended for annual review in the year being analysed.

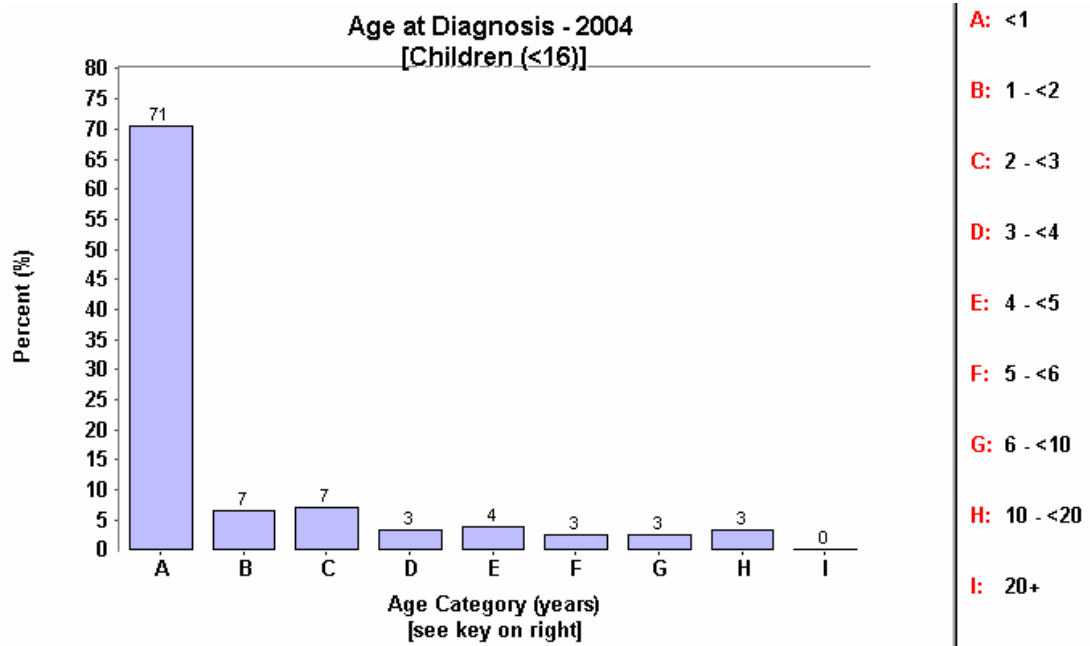
The data have been split for age groups in 5-year bands (age as at 31st December in the year being analysed). Percentages are calculated for glucose tolerance test results within each age band. Overall percentages of glucose tolerance testing (not done, normal, intolerant or diabetic) are also shown for all ages (column A) and for patients aged 10 years or over (column B).

Section 4:

UK Children

Overview

4.1 Age at diagnosis for children (<16) diagnosed in 2004



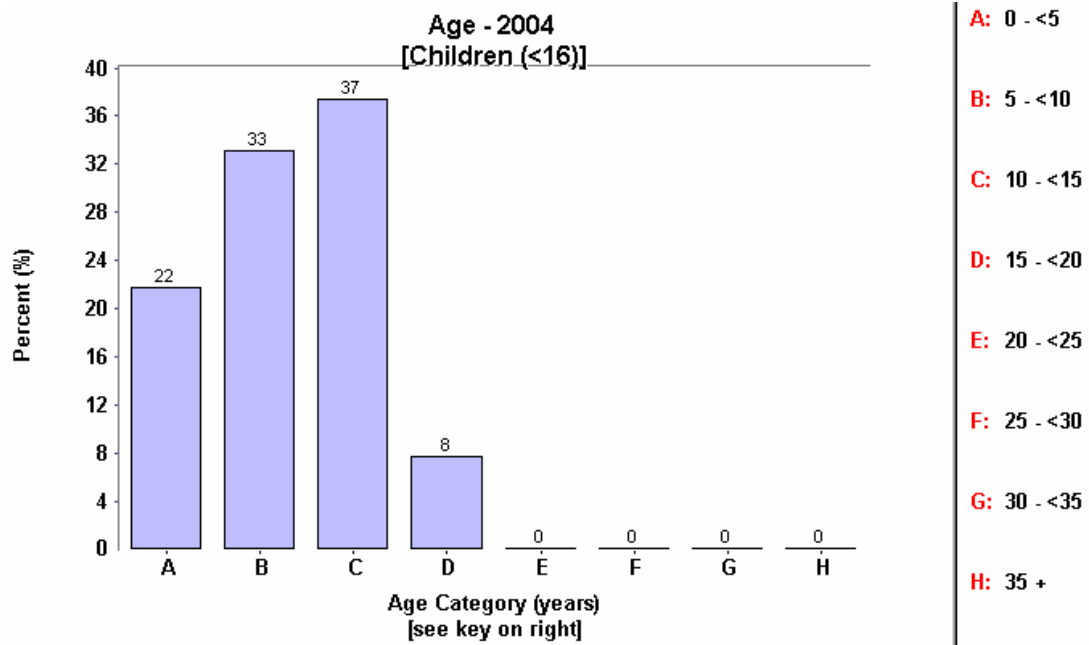
Age at diagnosis	<1	1 - <2	2 - <3	3 - <4	4 - <5	5 - <6	6 - <10	10 - <16	Total
Number diagnosed	108	10	11	5	6	4	4	5	153

(Total number of new diagnoses: 153)

This graph shows newly diagnosed children under 16 years old divided into the age categories at which diagnosis was made. The data shown is only for those patients who were diagnosed in the current analysis year.

Column H only shows patients in the age range 10 - <16. Column I is not applicable.

4.2 Age profile for children (<16) - 2004



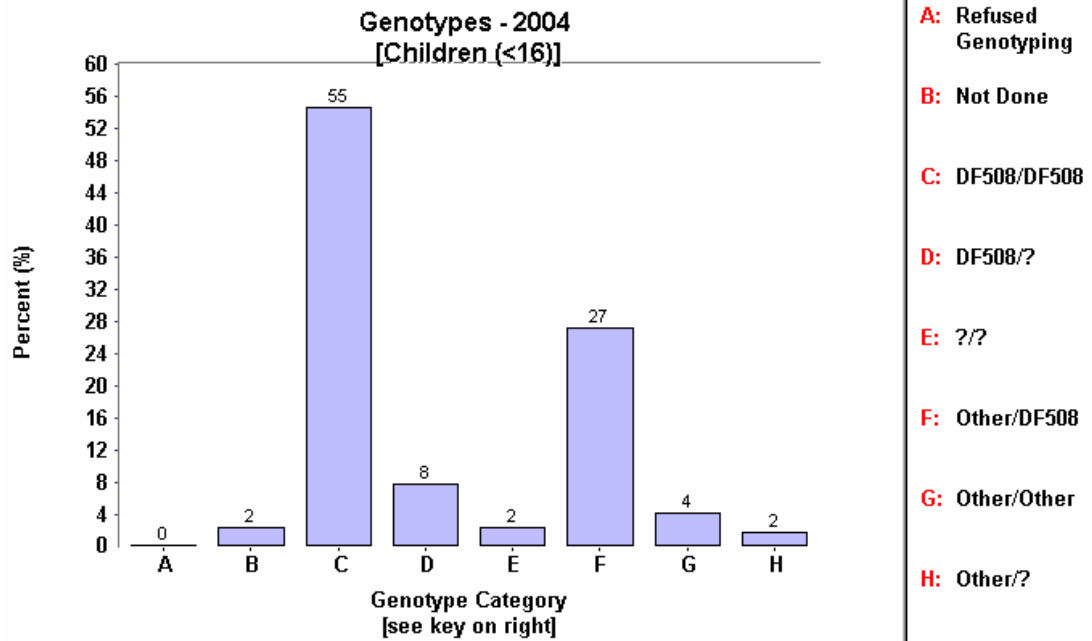
Age	0 - <5	5 - <10	10 - <15	15 - <16	Total
Number of patients	736	1118	1264	258	3376

(Total number of patients: 3376)

This graph shows the age profile of all patients registered who were under 16 years old in 2004. If a patient has been recorded as deceased, transferred or reverse-diagnosed, he/she is not included. The age of a patient is calculated as at 31st December in the year of analysis.

Column D only shows data for 15 year olds.

4.3 Genotypes for children (<16) - 2004



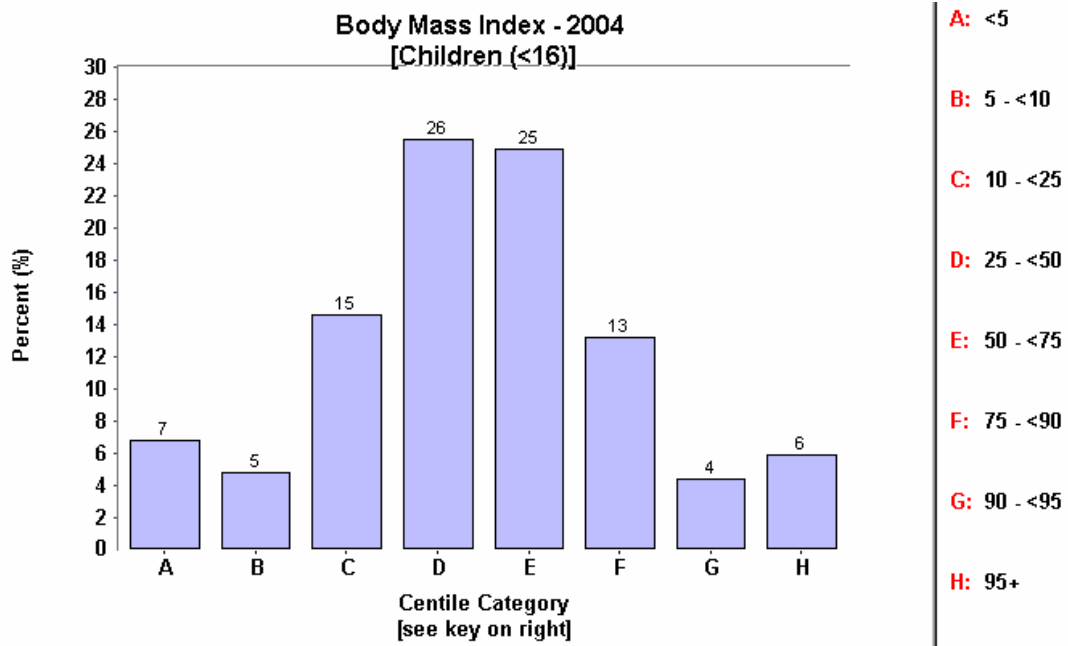
Genotype category	Patient refused	Not done	DF508/DF508	DF508/?	? / ?	DF508/other	Other/other	Other/ ?	Total
Number of patients	2	81	1852	263	76	919	142	55	3390

(Total number of patients: 3390)

This graph shows the genotype profile for all patients under 16 years old who had been registered by the end of 2004. The genotypes are taken from the entries on the biography form.

Any identified allele that is not "DeltaF508" is aggregated into "Other". Any genotypes entered as "?" are "NOT IDENTIFIED" or "UNKNOWN".

4.4 Body Mass Index centile for children (<16) - 2004



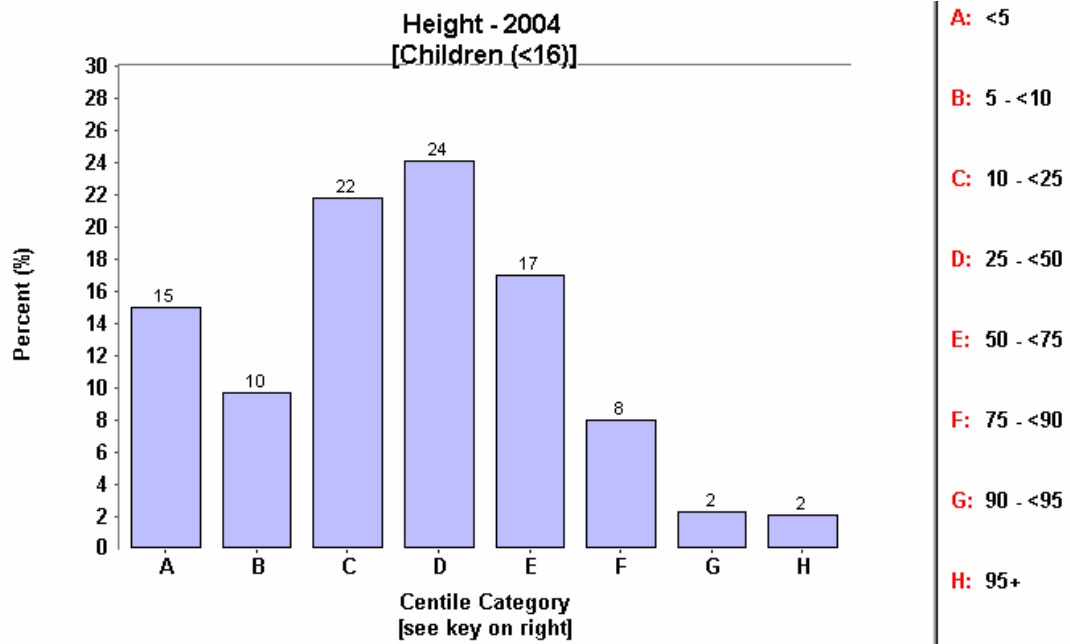
BMI centile	<5	5 - <10	10 - <25	25 - <50	50 - <75	75 - <90	90 - <95	95+	Total
Number of patients	183	129	395	692	675	357	118	160	2709

(Total number of patients: 2709)

This graph shows the BMI values for the CF population under 16 years old. The population is compared against standard UK growth tables.

The age of a patient is calculated as at the date of visit. For patients with more than one clinic visit per year, the last clinic visit for the year is selected for the graph.

4.5 Height centile for children (<16) - 2004



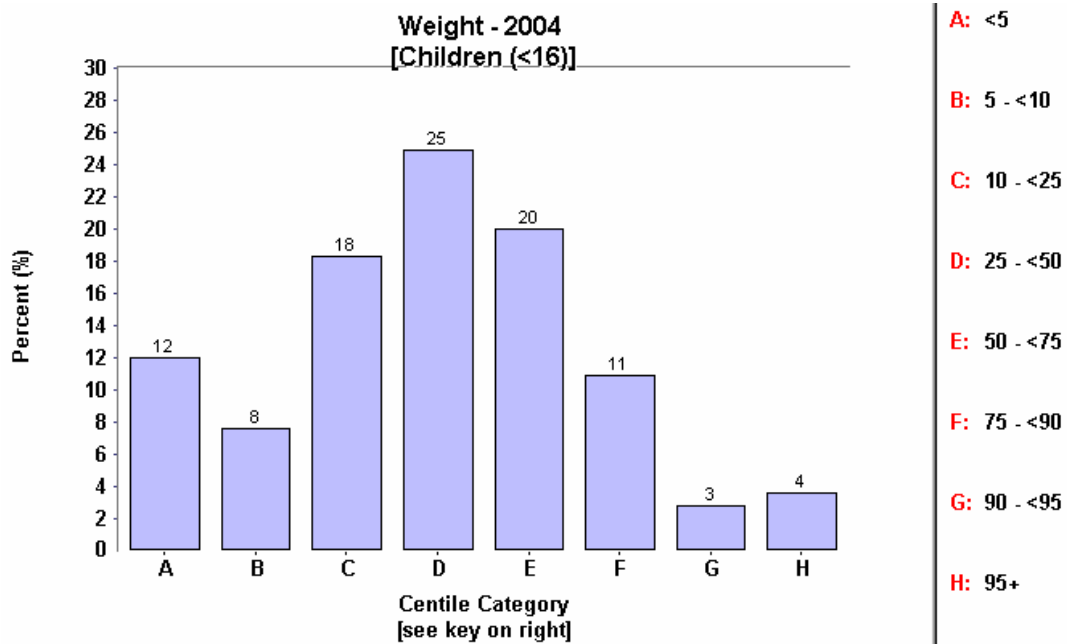
Height centile	<5	5 - <10	10 - <25	25 - <50	50 - <75	75 - <90	90 - <95	95+	Total
Number of patients	406	263	591	653	462	217	60	57	2709

(Total number of patients: 2709)

This graph shows the height values for the CF population under 16 years old. The population is compared against standard UK growth tables.

The age of a patient is calculated as at the date of visit. For patients with more than one clinic visit per year, the last clinic visit for the year is selected for the graph.

4.6 Weight centile for children (<16) - 2004



Weight centile	<5	5 - <10	10 - <25	25 - <50	50 - <75	75 - <90	90 - <95	95+	Total
Number of patients	324	206	496	675	542	294	76	96	2709

(Total number of patients: 2709)

This graph shows the weight values for the CF population under 16 years old. The population is compared against standard UK growth tables.

The age of a patient is calculated as at the date of visit. For patients with more than one clinic visit per year, the last clinic visit for the year is selected for the graph.

4.7 Glucose tolerance for children (<16) - 2004

Actual numbers (percentage) of patients in each age group are shown below:

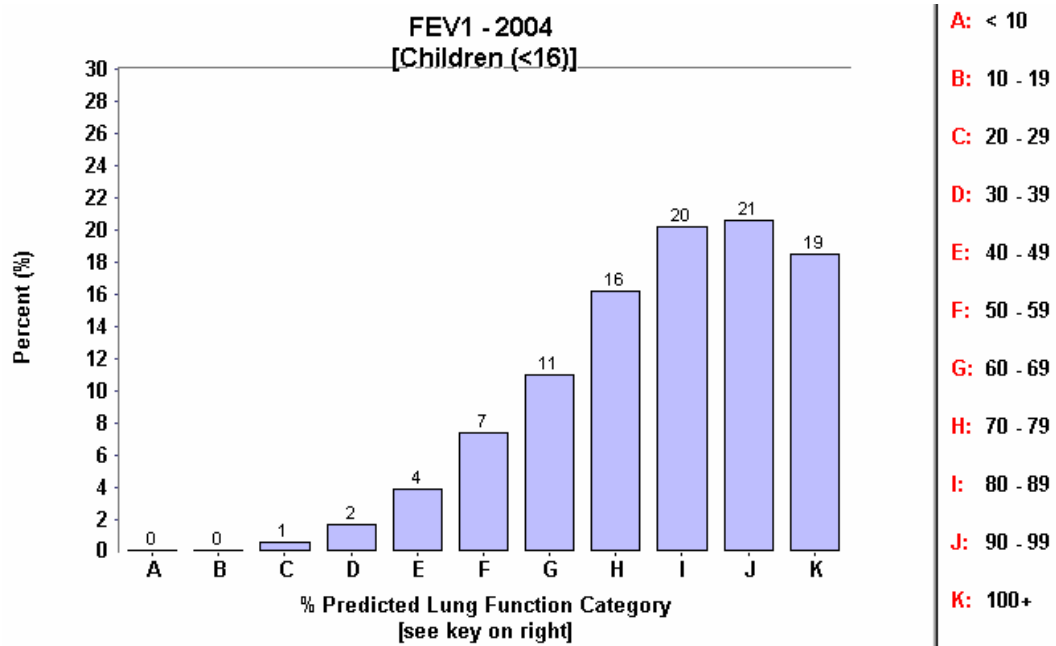
Age					A	B
	0 - <5	5 - <10	10 - <15	15 - <16	Total: All Ages	Total: 10 yrs & over
	477 (96%)	835 (93%)	652 (67%)	94 (52%)	2058 (81%)	746 (65%)
<i>Not done</i>						
Normal	19 (4%)	46 (5%)	241 (25%)	56 (31%)	362 (14%)	297 (26%)
Intolerant	1 (0%)	5 (1%)	39 (4%)	15 (8%)	60 (2%)	54 (5%)
Diabetic	2 (0%)	12 (1%)	38 (4%)	17 (9%)	69 (3%)	55 (5%)
Total	499	898	970	182	2549	1152

(Total number of patients: 2549, of which 1152 aged 10 years or over)

This table shows the categories patients fall into for glucose tolerance. Patients are selected if they are under 16 years old and have attended for annual review in the year being analysed.

The data have been split for age groups in 5-year age bands (age as at 31st December in the year being analysed). Percentages are calculated for glucose tolerance test results within each age band. Overall percentages of glucose tolerance testing (not done, normal, intolerant or diabetic) are also shown for all ages (column A) and for patients aged 10 years and over (column B).

4.8 FEV1 for children (<16) - 2004



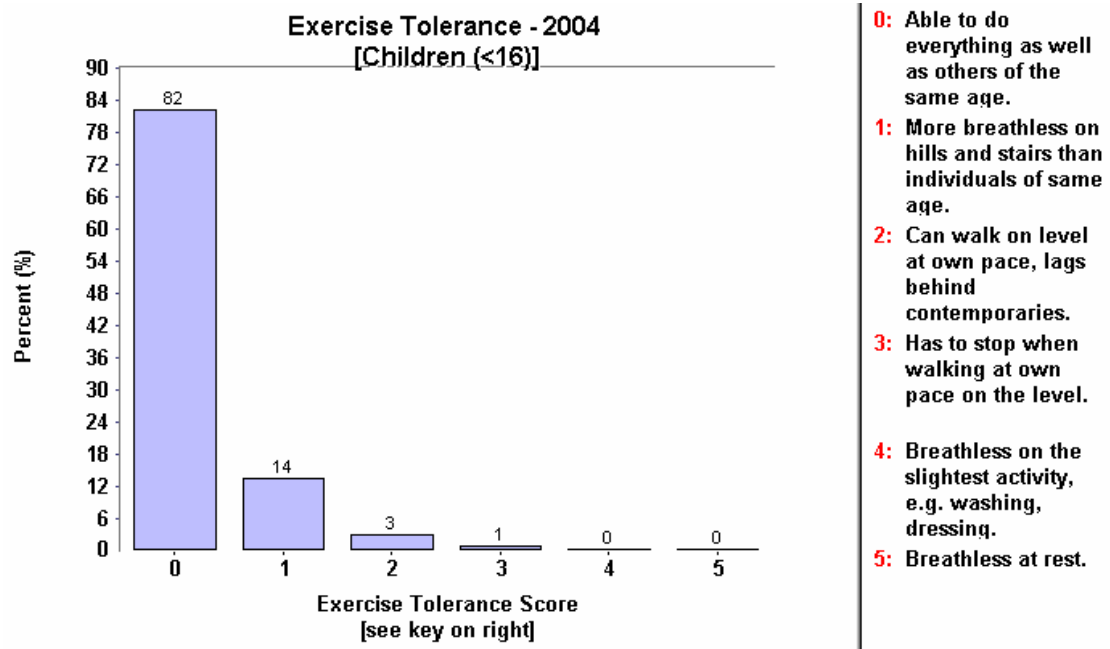
FEV1 %	<10	10 - 19	20 - 29	30 - 39	40 - 49	50 - 59	60 - 69	70 - 79	80 - 89	90 - 99	100+	Total
Number of patients	0	1	10	32	75	144	215	316	396	403	362	1954

(Total number of patients: 1954)

This graph shows patients under 16 years old classified by percent predicted FEV1.

The age of a patient is calculated as at the date of visit. If there is more than one visit over the analysis year then the most recent readings are used.

4.9 Exercise tolerance for children (<16) - 2004

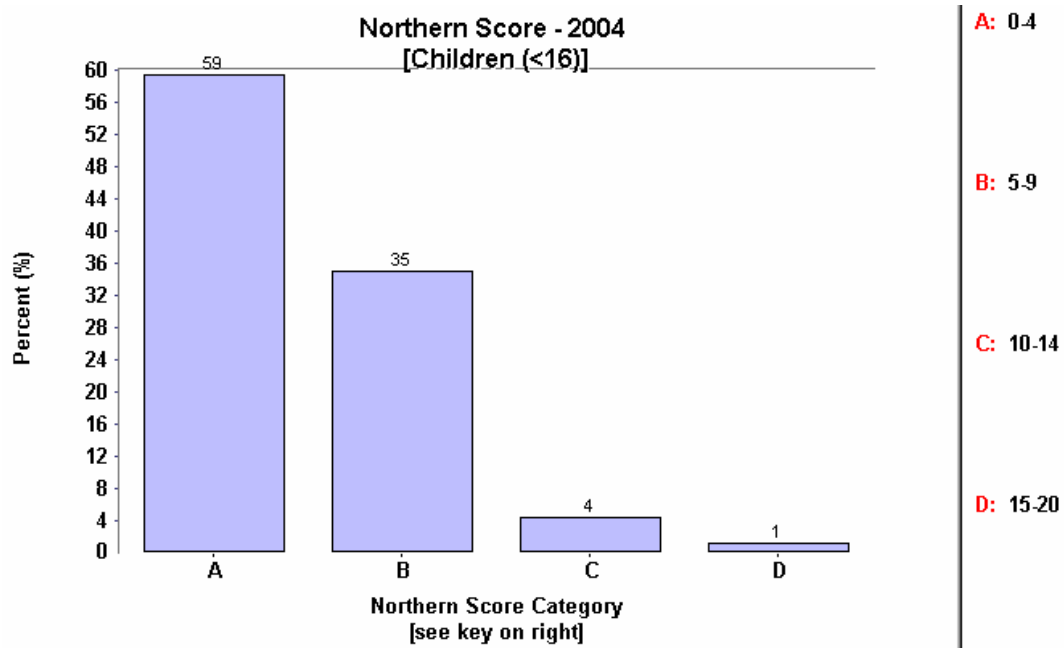


Exercise tolerance score	0	1	2	3	4	5	Total
Number of patients	1864	306	67	18	3	3	2261

(Total number of patients: 2261)

This graph shows patients under 16 years old categorised by their exercise tolerance. The patient is classified according to the worst score (i.e. maximum value) over the analysis year.

4.10 Northern chest X-ray score for children (<16) - 2004



Northern score	0 - 4	5 - 9	10 - 14	15 - 20	Total
Number of patients	913	538	67	17	1535

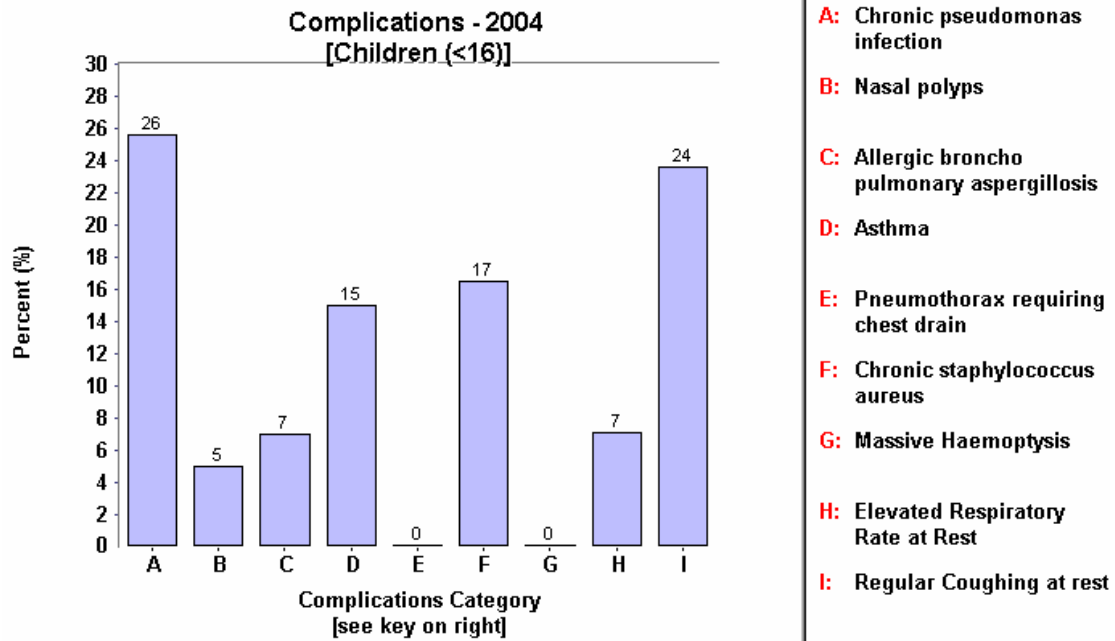
(Total number of patients: 1535)

This graph shows the Northern chest X-ray score categories for the CF population under 16 years old. It excludes any scores recorded as 'x' (not done) or '?' (unknown). Patients are selected if they have attended for annual review in the year being analysed.

This score is calculated by the clinician by awarding 0 - 4 points (as below) for each quadrant of the X-ray and up to 4 discretionary points for focal lesions etc.

- 0: Normal: No CF lung disease evident
- 1: Mild: Minimal increase in linear markings and/or nodular-cystic lesion up to 0.5cm diameter
- 2: Moderate: More pronounced linear markings and/or more widespread nodular-cystic lesions
- 3: Severe: Prominent increase in linear markings, profuse nodular-cystic lesions, large areas of collapse/consolidation
- 4: Very severe: Little or no area of normal seen, dense infiltration

4.11 Complications (chest) for children (<16) - 2004



Chest complication	A	B	C	D	E	F	G	H	I	Total
Number of patients	565	109	154	330	2	364	2	157	522	2205

(Total number of complications: 2205 for 2569 patients)

This graph shows the details of chest complications. Patients are selected if they are less than 16 years old and have attended for annual review in the year being analysed. Patients are counted once for each chest complication.

4.12 Children (<16) with at least 1 Burkholderia cepacia isolated - 2004

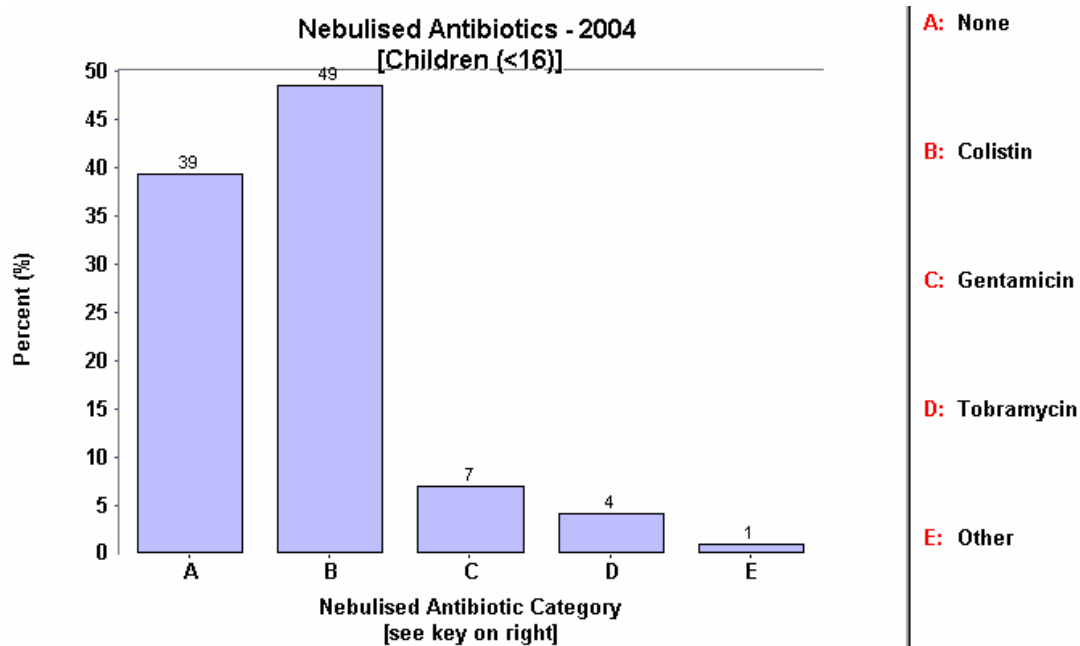
Age	0 - <5	5 - <10	10 - <15	15 - <16	Total
Patients with <i>B.cepacia</i>	2	8	18	5	33
Age specific prevalence (%)	<1	1	2	2	1
Number of patients in age band	565	942	1042	204	2753

(Total number of patients with snapshot data: 2753, of which 33 (1%) had *B. cepacia* isolated at least once)

This table shows patients under 16 years old divided into age categories for *B. cepacia* as recorded on the snapshot form.

The age of the patient is calculated at the time of the bacteriology culture. Percent prevalence is calculated in each category, e.g. number of 0-5 year olds who have *B. cepacia* / total number of 0-5 year olds. The age of the cohort is as of 31st December of the analysis year. E.g. If there are 6 patients with *B. cepacia* in the 0-5 age range, and 10 patients altogether aged 0-5, the age-specific prevalence is $6/10 \times 100$ for the age range 0-5 years.

4.13 Nebulised antibiotics for children (<16) - 2004



Nebulised antibiotics	None	Colistin	Gentamicin	Tobramycin	Other	Total
Number of patients	1106	1361	194	117	25	2803

(Total: 2803, given to 2569 children)

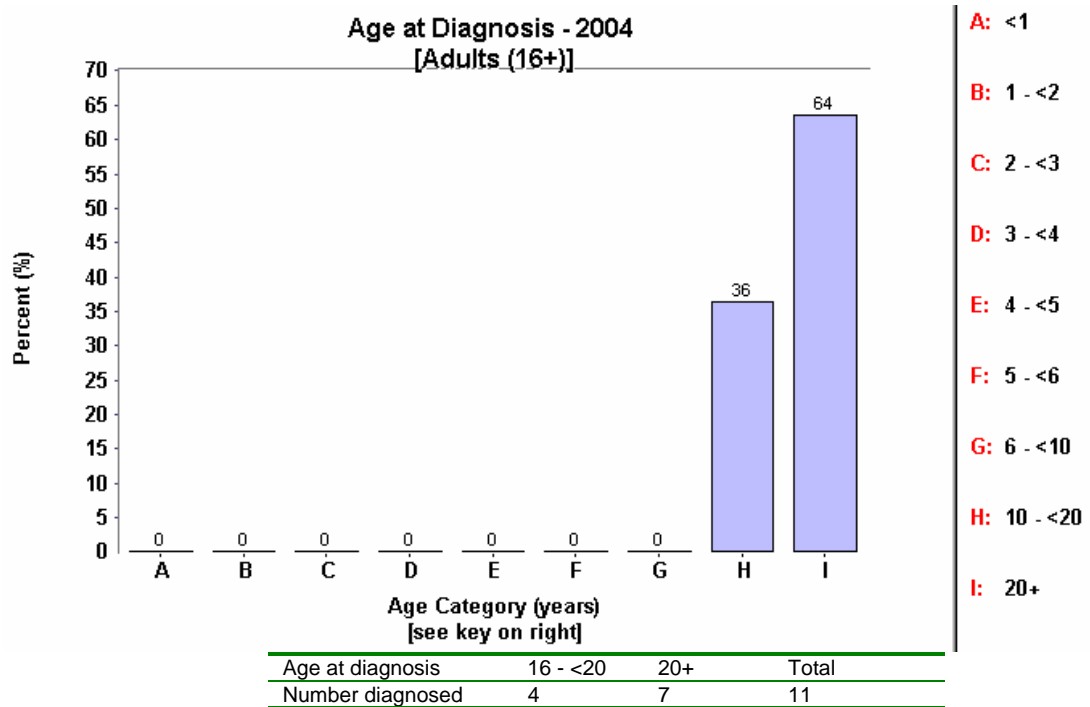
This graph shows the nebulised antibiotics received by patients under 16 years old. Patients are selected if they have attended for annual review in the year being analysed. Patients are counted once for each nebulised antibiotic that they have received.

Section 5:

UK Adults

Overview

5.1 Age at diagnosis for adults (16+) diagnosed in 2004

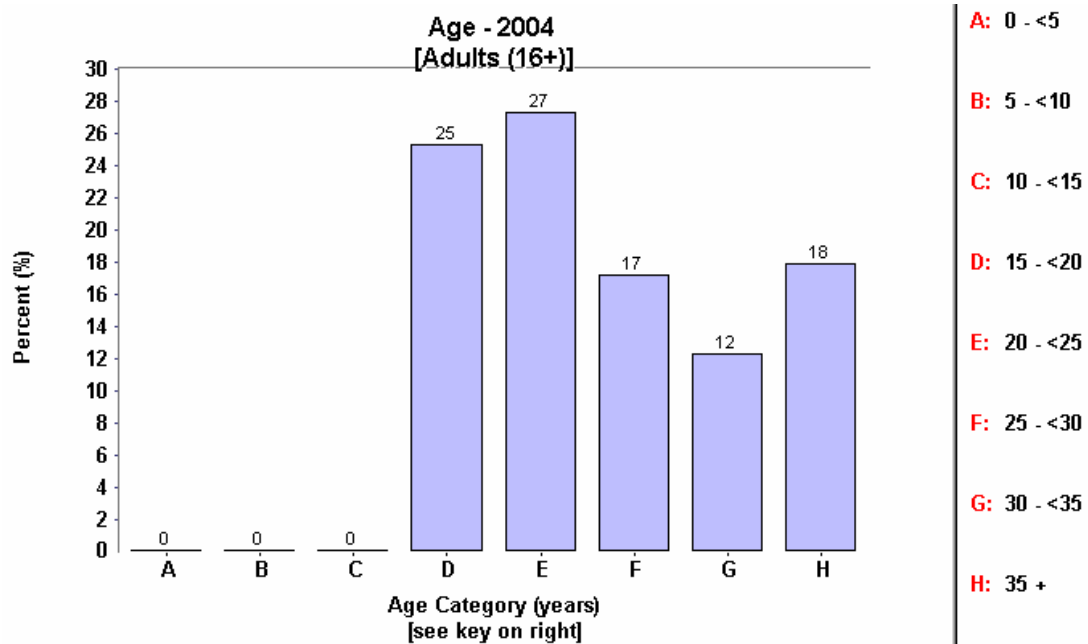


(Total number of new diagnoses: 11)

This graph shows newly diagnosed adults aged 16 years or over divided into the age categories at which diagnosis was made. The data shown is only for those patients who were diagnosed in the current analysis year.

Column H only shows patients in the age range 16 - <20. Columns A to G are not applicable.

5.2 Age profile for adults (16+) - 2004



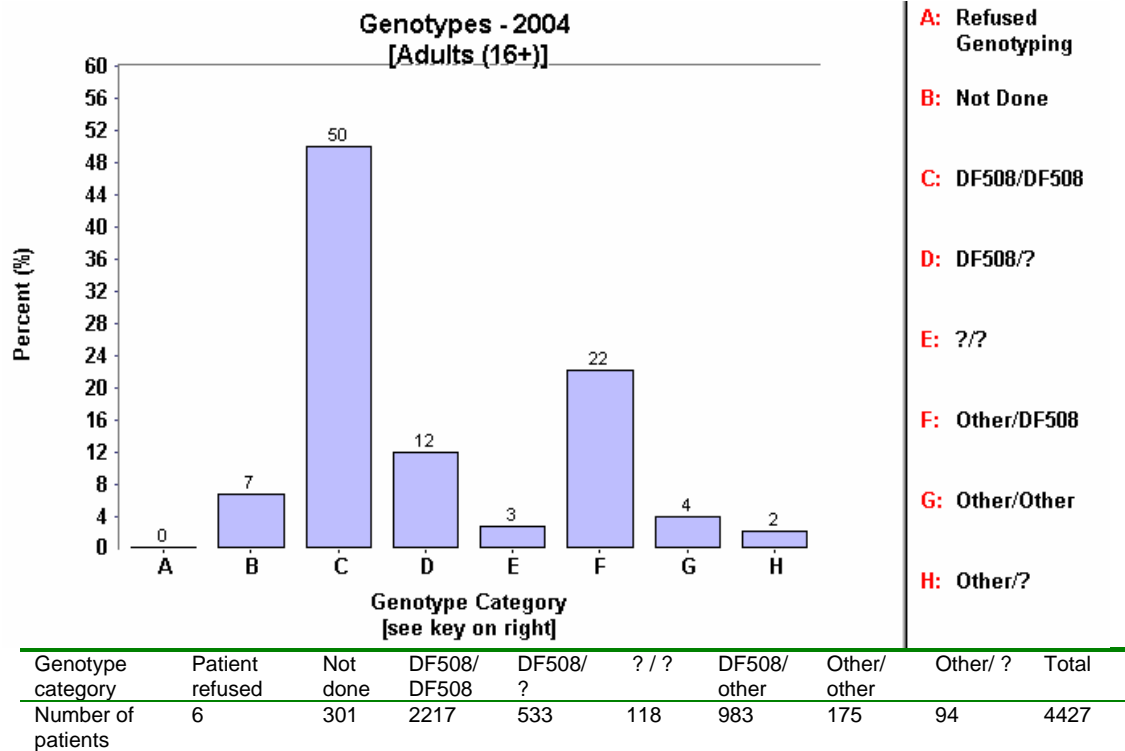
Age	16 - <20	20 - <25	25 - <30	30 - <35	35+	Total
Number of patients	928	1005	630	451	656	3670

(Total number of patients: 3670)

This graph shows the age profile of all patients registered who were 16 years or over in 2004. If a patient has been recorded as deceased, transferred or reverse-diagnosed, he/she is not included. The age of a patient is calculated as at 31st December in the year of analysis.

Column D only shows data for patients aged 16 years or over.

5.3 Genotypes for adults (16+) - 2004

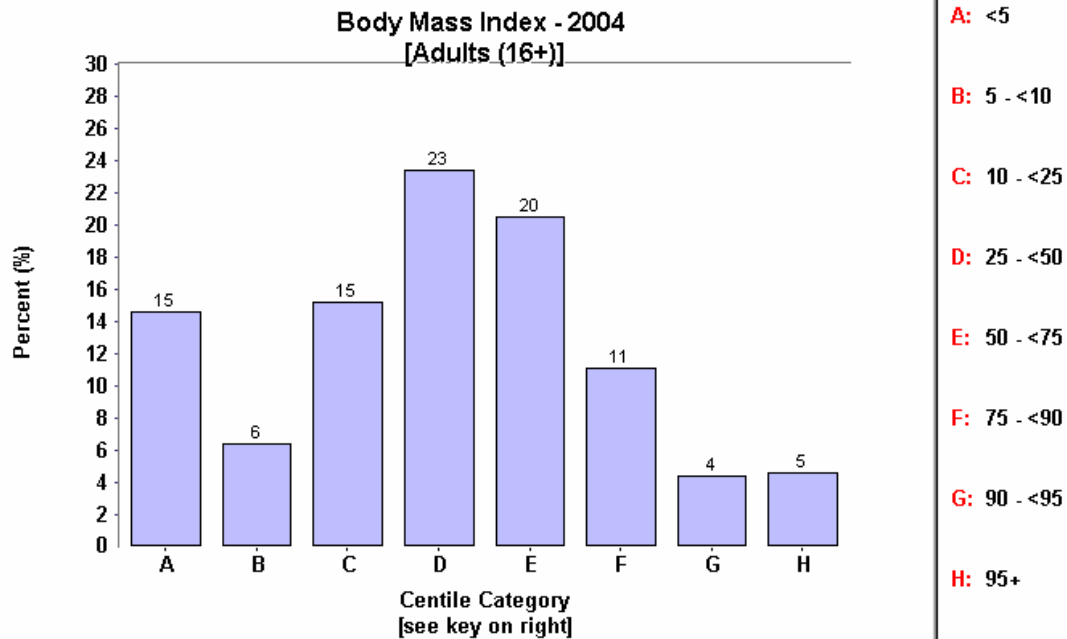


(Total number of patients: 4427)

This graph shows the genotype profile for all patients aged 16 years or over who had been registered by the end of 2004. The genotypes are taken from the entries on the biography form.

Any identified allele that is not "DeltaF508" is aggregated into "Other". Any genotypes entered as "?" are "NOT IDENTIFIED" or "UNKNOWN".

5.4 Body Mass Index centile for adults (16+) - 2004



BMI centile	<5	5 - <10	10 - <25	25 - <50	50 - <75	75 - <90	90 - <95	95+	Total
Number of patients	467	203	487	751	657	355	139	147	3206

BMI value	<15	15 -16.9	17-18.9	19-20.9	21-22.9	23-24.9	25-26.9	27-28.9	≥29	Total
Number of patients	22	153	508	844	801	477	226	102	73	3206
	(1%)	(5%)	(16%)	(26%)	(25%)	(15%)	(7%)	(3%)	(2%)	(100%)

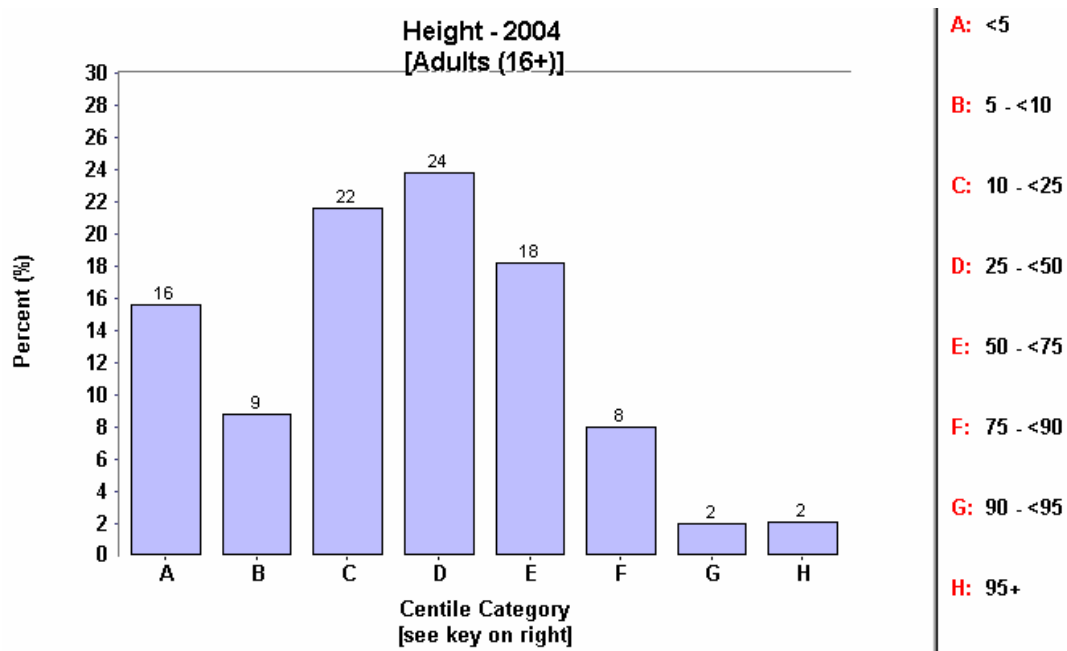
(Total number of patients: 3206)

This graph shows the BMI values for the CF population aged 16 years or over. The population is compared against standard UK growth tables.

The age of a patient is calculated as at the date of visit. For patients with more than one clinic visit per year, the last clinic visit for the year is selected for the graph.

Actual BMI values are provided in the second table.

5.5 Height centile for adults (16+) - 2004



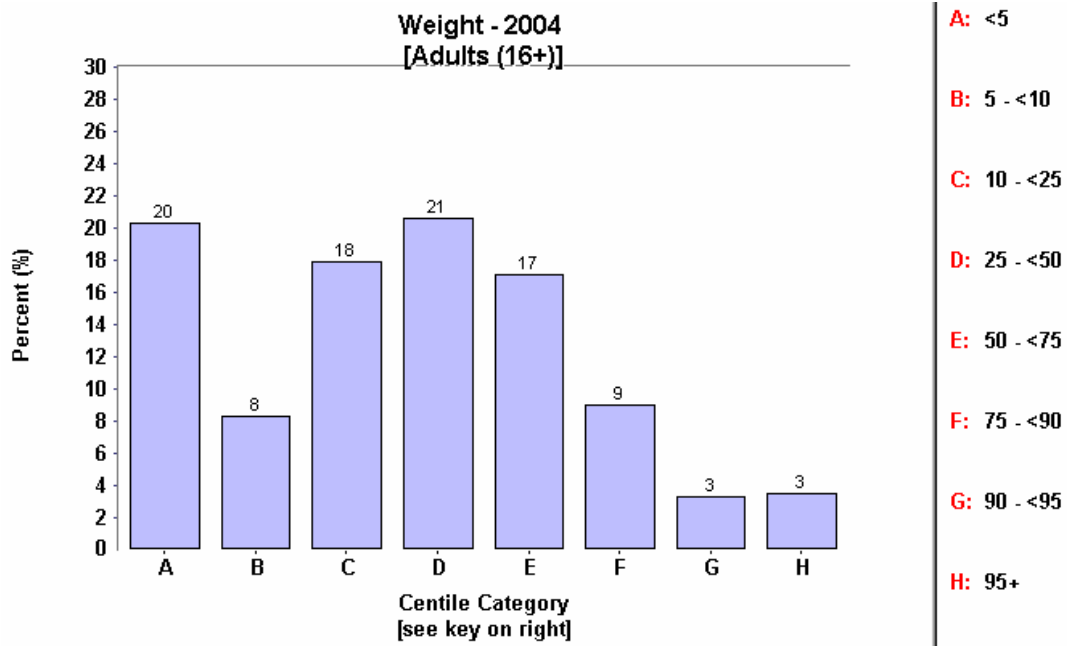
Height centile	<5	5 - <10	10 - <25	25 - <50	50 - <75	75 - <90	90 - <95	95+	Total
Number of patients	500	280	694	764	583	256	64	65	3206

(Total number of patients: 3206)

This graph shows the height values for the CF population aged 16 years or over. The population is compared against standard UK growth tables.

The age of a patient is calculated as at the date of visit. For patients with more than one clinic visit per year, the last clinic visit for the year is selected for the graph.

5.6 Weight centile for adults (16+) - 2004



Weight centile	<5	5 - <10	10 - <25	25 - <50	50 - <75	75 - <90	90 - <95	95+	Total
Number of patients	652	265	575	660	549	289	106	110	3206

(Total number of patients: 3206)

This graph shows the weight values for the CF population aged 16 years or over. The population is compared against standard UK growth tables.

The age of a patient is calculated as at the date of visit. For patients with more than one clinic visit per year, the last clinic visit for the year is selected for the graph.

5.7 Glucose tolerance for adults (16+) - 2004

Actual numbers of patients in each age group are shown below:

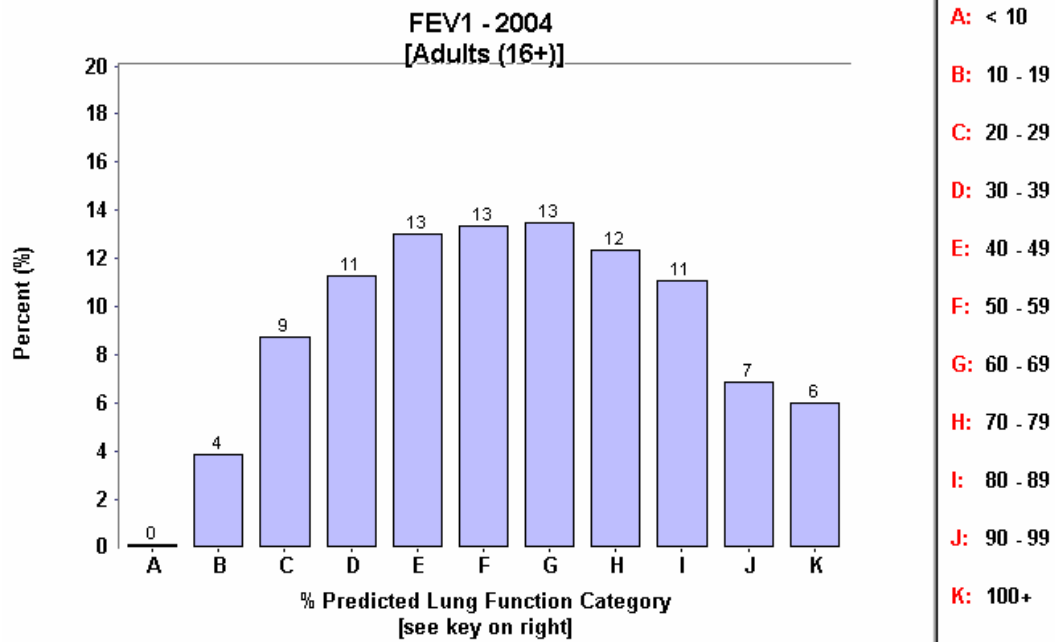
<i>Age groups</i>	<i>16 - <20</i>	<i>20 - <25</i>	<i>25 - <30</i>	<i>30 - <35</i>	<i>35+</i>	<i>Total</i>
	333 (44%)	320 (37%)	208 (38%)	145 (38%)	234 (42%)	1240 (40%)
<i>Not done</i>						
Normal	257 (34%)	260 (30%)	151 (27%)	70 (18%)	117 (21%)	855 (28%)
Intolerant	37 (5%)	64 (7%)	32 (6%)	22 (6%)	18 (3%)	173 (6%)
Diabetic	130 (17%)	213 (25%)	159 (29%)	143 (38%)	185 (33%)	830 (27%)
Total	757	857	550	380	554	3098

(Total number of patients: 3098)

This table shows the categories patients fall into for glucose tolerance. Patients are selected if they are aged 16 years or over and have attended for annual review in the year being analysed.

The data have been split for age groups in 5-year bands (age as at 31st December in the year being analysed). Percentages are calculated for glucose tolerance test results within each age band. Overall percentages of glucose tolerance testing (not done, normal, intolerant or diabetic) are also shown.

5.8 FEV1 for adults (16+) - 2004



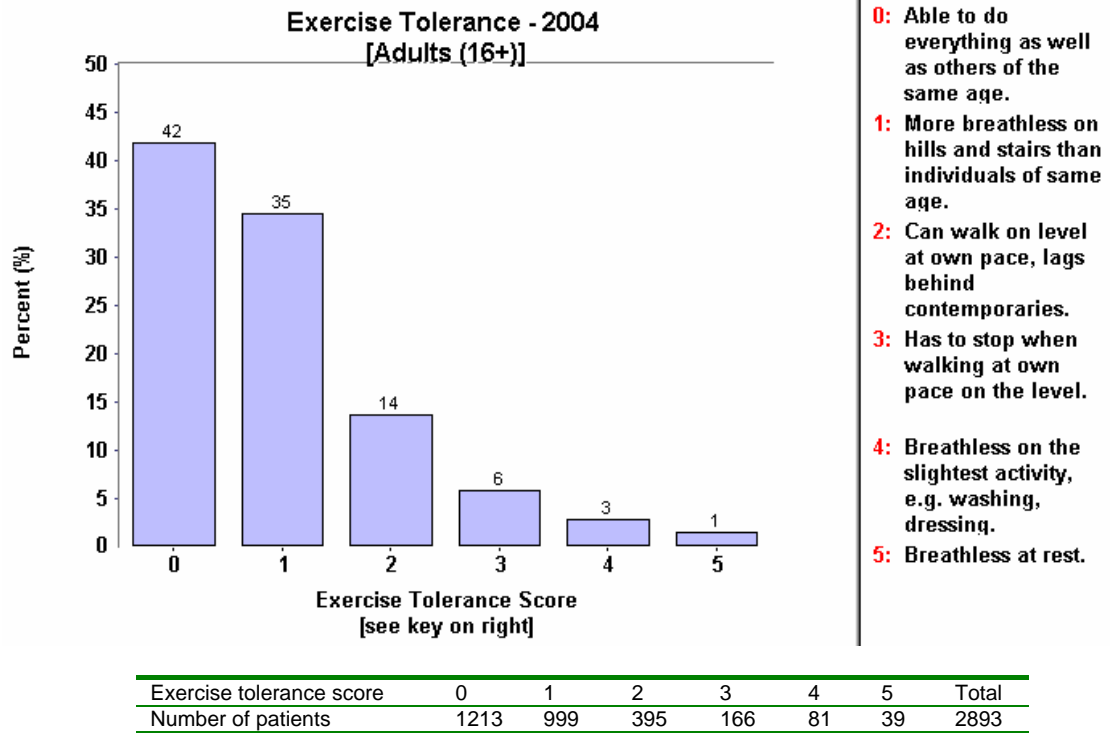
FEV1 %	<10	10 - 19	20 - 29	30 - 39	40 - 49	50 - 59	60 - 69	70 - 79	80 - 89	90 - 99	100+	Total
Number of patients	3	122	279	358	414	425	429	393	353	218	191	3185

(Total number of patients: 3185)

This graph shows patients aged 16 years or over classified by percent predicted FEV1.

The age of a patient is calculated as at the date of visit. If there is more than one visit over the analysis year then the most recent readings are used.

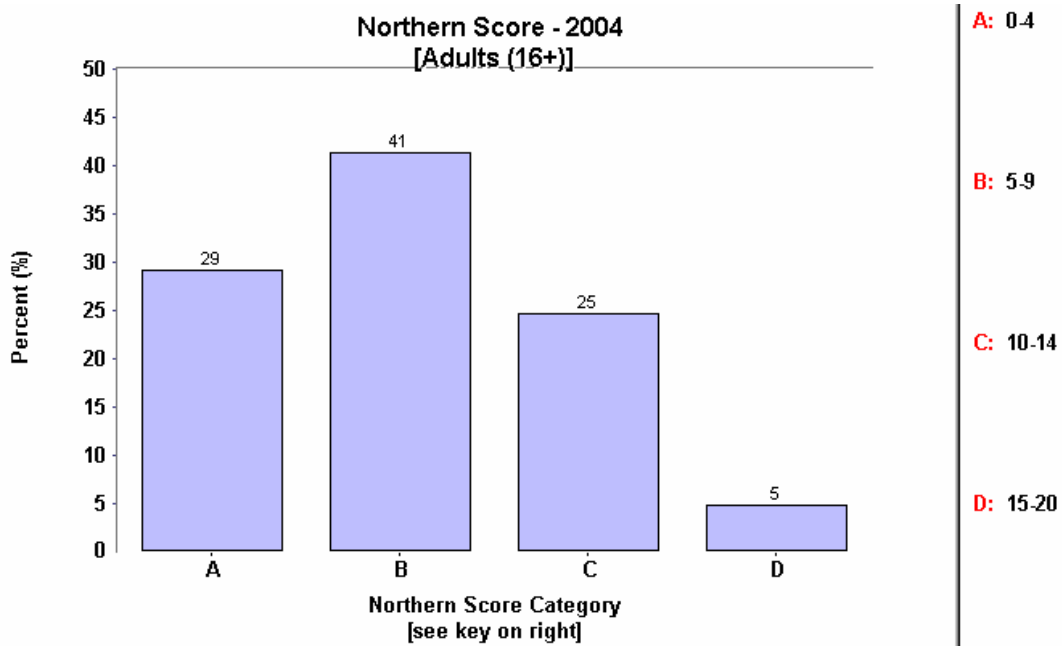
5.9 Exercise tolerance for adults (16+) - 2004



(Total number of patients: 2893)

This graph shows patients aged 16 years or over categorised by their exercise tolerance. The patient is classified according to the worst score (i.e. maximum value) over the analysis year.

5.10 Northern chest X-ray score for adults (16+) - 2004



Northern score	0 - 4	5 - 9	10 - 14	15 - 20	Total
Number of patients	521	740	441	84	1786

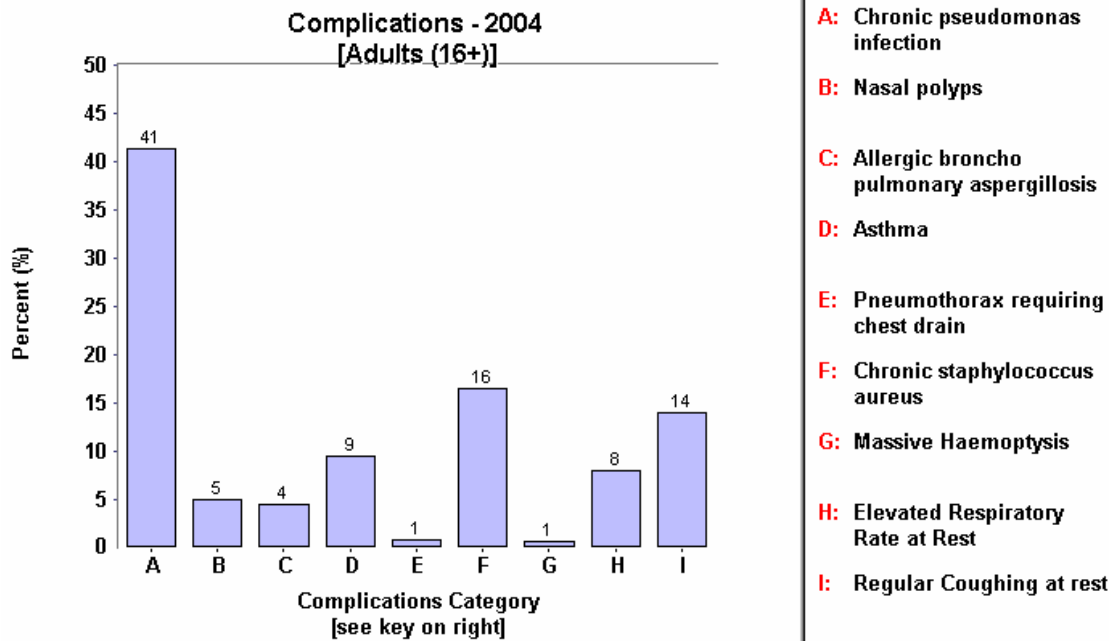
(Total number of patients: 1786)

This graph shows the Northern chest X-ray score categories for the CF population aged 16 years or over. It excludes any scores recorded as 'x' (not done) or '?' (unknown). Patients are selected if they have attended for annual review in the year being analysed.

This score is calculated by the clinician by awarding 0 - 4 points (as below) for each quadrant of the X-ray and up to 4 discretionary points for focal lesions etc.

- 0: Normal: No CF lung disease evident
- 1: Mild: Minimal increase in linear markings and/or nodular-cystic lesion up to 0.5cm diameter
- 2: Moderate: More pronounced linear markings and/or more widespread nodular-cystic lesions
- 3: Severe: Prominent increase in linear markings, profuse nodular-cystic lesions, large areas of collapse/consolidation
- 4: Very severe: Little or no area of normal seen, dense infiltration

5.11 Complications (chest) for adults (16+) - 2004



Chest complication	A	B	C	D	E	F	G	H	I	Total
Number of patients	1801	216	195	410	36	715	27	346	611	4357

(Total number of complications: 4357 for 3078 patients)

This graph shows the details of chest complications. Patients are selected if they are 16 years or over and have attended for annual review in the year being analysed. Patients are counted once for each chest complication.

5.12 Adults (16+) with at least 1 *Burkholderia cepacia* isolated - 2004

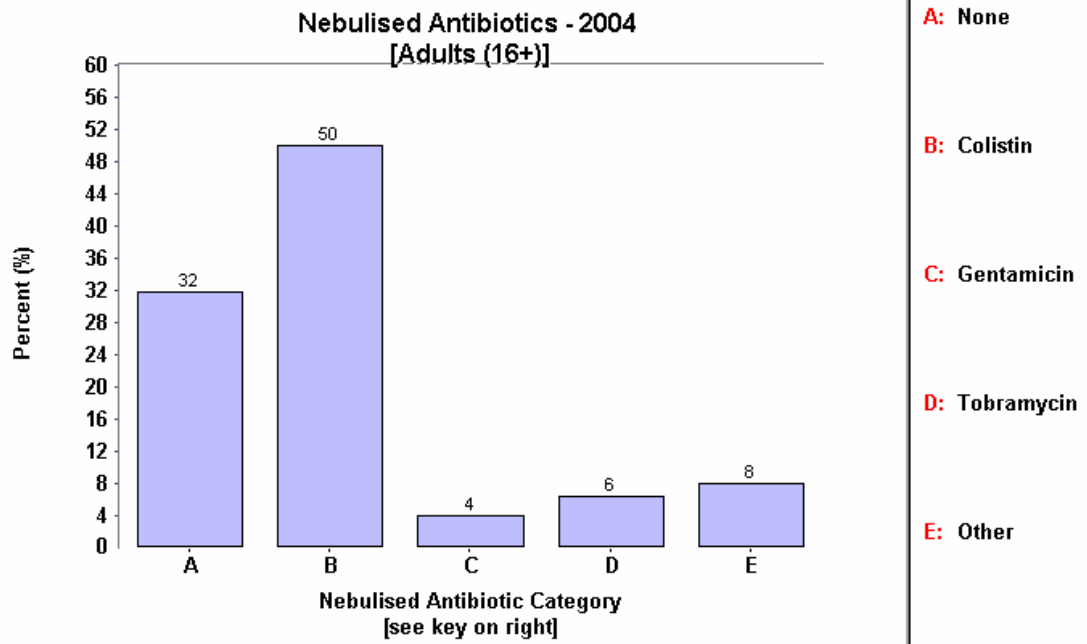
Age	16 - <20	20 - <25	25 - <30	30 - <35	35+	Total
Patients with <i>B.cepacia</i>	30	50	46	23	23	172
Age specific prevalence (%)	4	6	8	6	4	5
Number of patients in age band	808	889	568	398	572	3235

(Total number of patients with snapshot data: 3235, of which 172 (5%) had *B. cepacia* isolated at least once).

This table shows patients aged 16 years or over divided into age categories for *B. cepacia* as recorded on the snapshot form.

The age of the patient is calculated at the time of the bacteriology culture. Percent prevalence is calculated in each category, e.g. number of 0-5 year olds who have *B. cepacia* / total number of 0-5 year olds. The age of the cohort is as of 31st December of the analysis year. E.g. If there are 6 patients with *B. cepacia* in the 0-5 age range, and 10 patients altogether aged 0-5, the age-specific prevalence is $6/10 \times 100$ for the age range 0-5 years.

5.13 Nebulised antibiotics for adults (16+) - 2004



Nebulised antibiotics	None	Colistin	Gentamicin	Tobramycin	Other	Total
Number of patients	1072	1681	132	212	264	3361

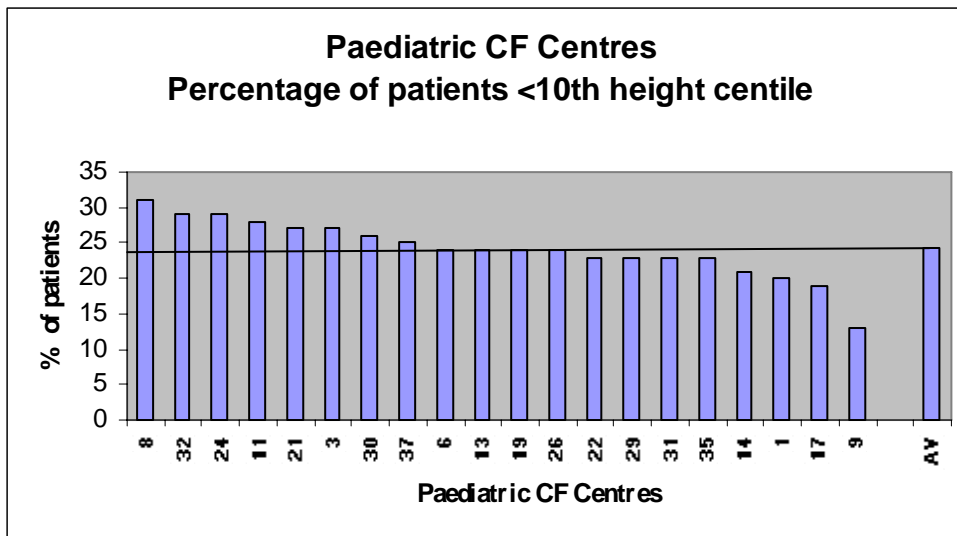
(Total: 3361, given to 3078 adults)

This graph shows the nebulised antibiotics received by patients aged 16 years or over. Patients are selected if they have attended for annual review in the year being analysed. Patients are counted once for each nebulised antibiotic that they have received.

Section 6:

Comparison of Outcomes for Specialist CF Centres

6.1 Percentage of patients < 10th height centile – Paediatric Centres



(Average for all paediatric centres – 24%)

Range – 31% to 13%

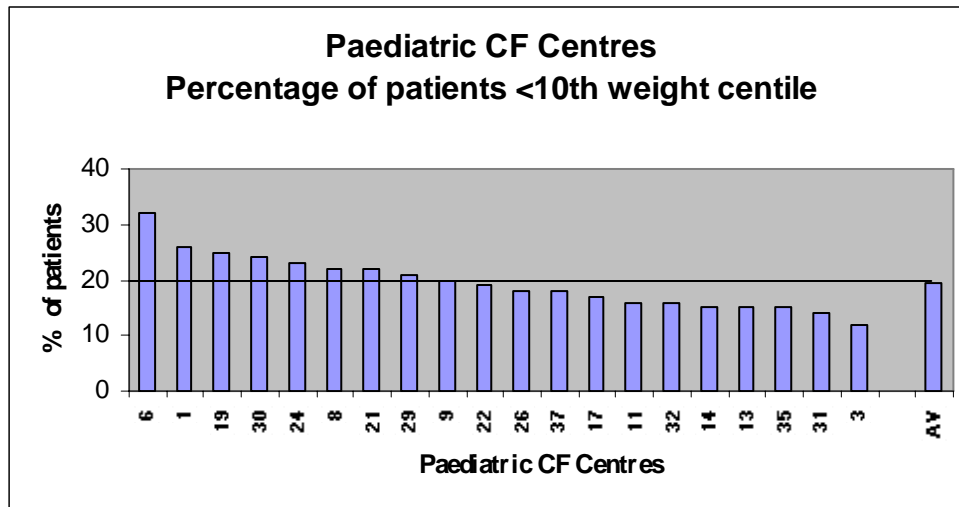
Total number of paediatric centres – 20)

This graph shows the percentage of patients under the tenth centile for height for each paediatric specialist CF centre. Each centre is identified by a unique number. Centres have been included if they returned complete data for at least 40 patients.

The graph shows raw figures as submitted to the UK Cystic Fibrosis Database.

No adjustment has been made for any potential confounders such as staffing, socio-economic profile of the Centre, genotype, proportions of shared care patients seen by the Centre or reported to the Database etc.

6.2 Percentage of patients < 10th weight centile – Paediatric Centres



(Average for all paediatric centres – 20%)

Range – 32% to 12%

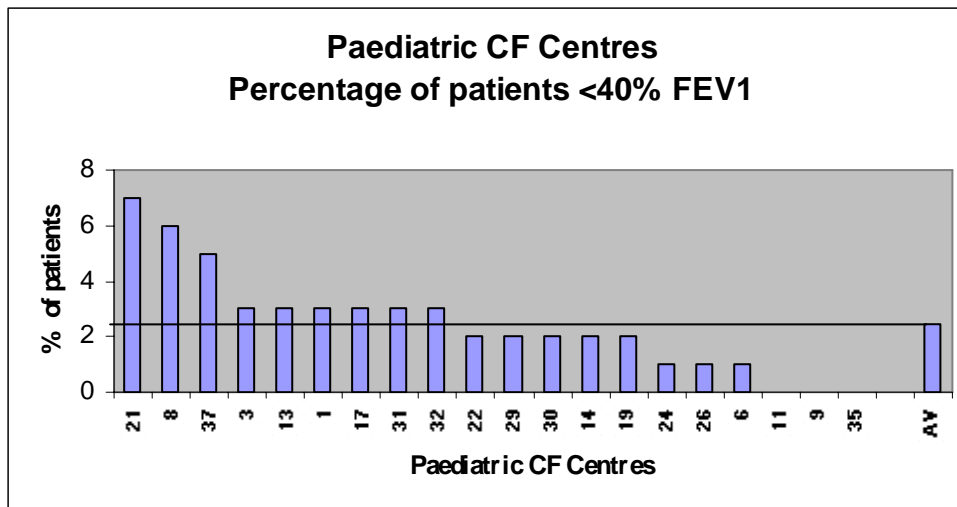
Total number of paediatric centres – 20)

This graph shows the percentage of patients under the tenth centile for weight for each paediatric specialist CF centre. Each centre is identified by a unique number. Centres have been included if they returned complete data for at least 40 patients.

The graph shows raw figures as submitted to the UK Cystic Fibrosis Database.

No adjustment has been made for any potential confounders such as staffing, socio-economic profile of the Centre, genotype, proportions of shared care patients seen by the Centre or reported to the Database etc.

6.3 Percentage of patients with FEV1 < 40% predicted – Paediatric Centres



(Average for all paediatric centres – 2.5%)

Range – 7% to 0%

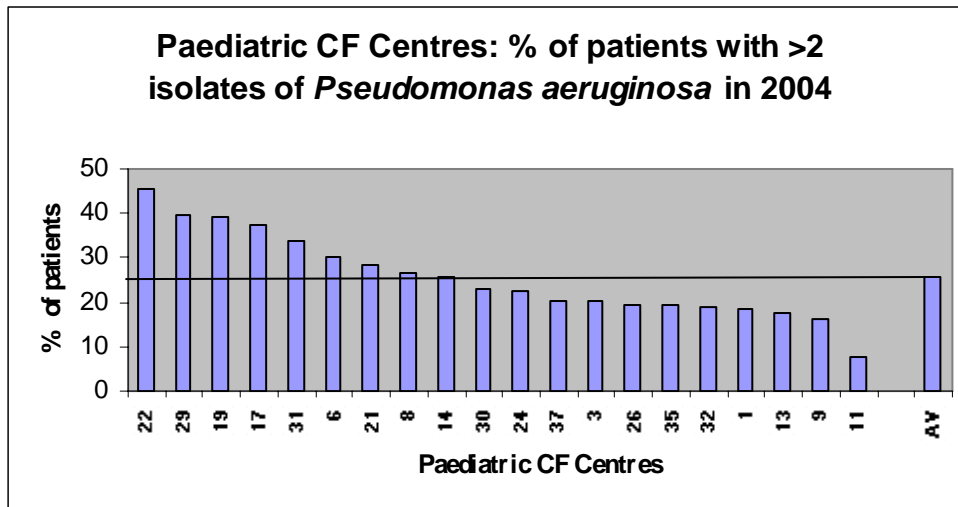
Total number of paediatric centres – 20)

This graph shows the percentage of patients with FEV1 < 40% predicted for each paediatric specialist CF centre. Each centre is identified by a unique number. Centres have been included if they returned complete data for at least 40 patients.

The graph shows raw figures as submitted to the UK Cystic Fibrosis Database.

No adjustment has been made for any potential confounders such as staffing, socio-economic profile of the Centre, genotype, proportions of shared care patients seen by the Centre or reported to the Database etc.

6.4 Percentage of patients with > 2 isolates of *Pseudomonas aeruginosa* in 2004 – Paediatric Centres



(Average for all paediatric centres – 26%)

Range – 45% to 7%

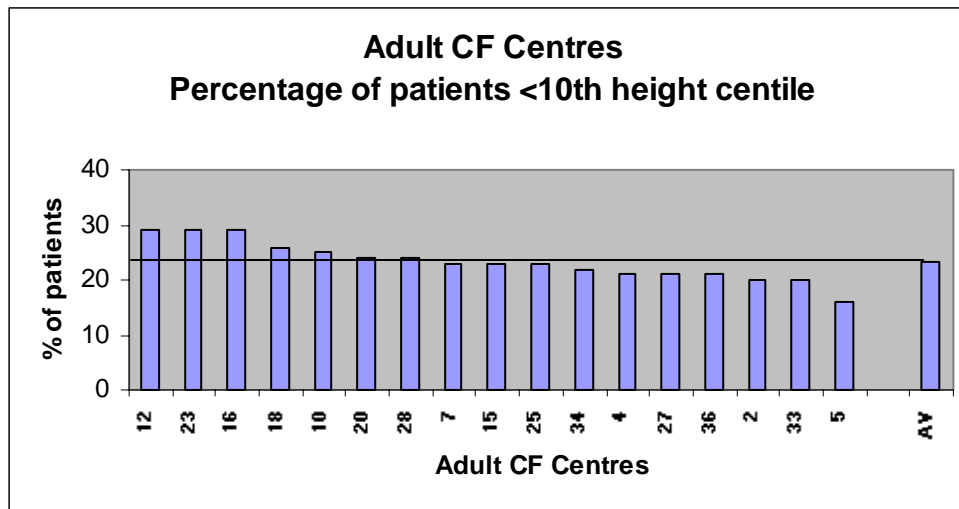
Total number of paediatric centres – 20)

This graph shows the percentage of patients with over 2 isolates of *Pseudomonas aeruginosa* for each paediatric specialist CF centre. Each centre is identified by a unique number. Centres have been included if they returned complete data for at least 40 patients.

The graph shows raw figures as submitted to the UK Cystic Fibrosis Database.

No adjustment has been made for any potential confounders such as staffing, socio-economic profile of the Centre, genotype, proportions of shared care patients seen by the Centre or reported to the Database etc.

6.5 Percentage of patients < 10th height centile – Adult Centres



(Average for all adult centres – 23%)

Range – 29% to 16%

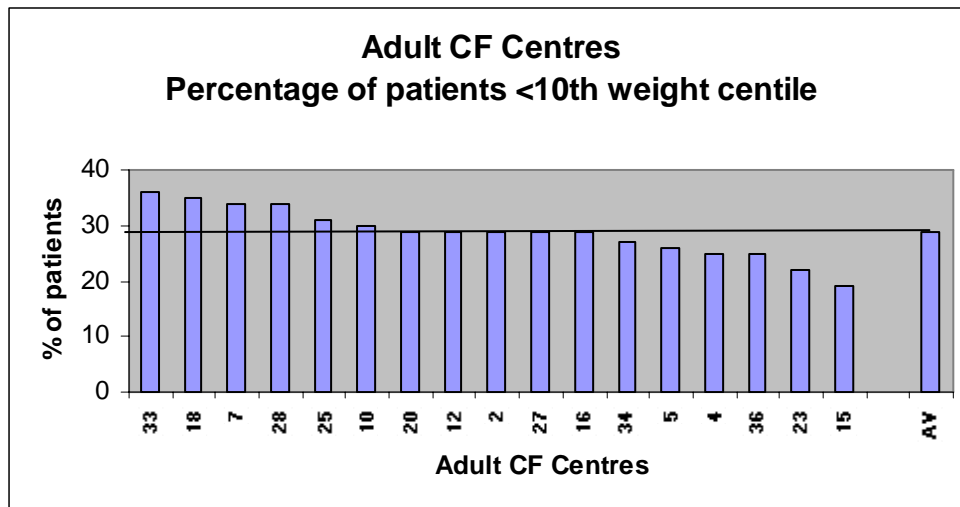
Total number of adult centres – 17)

This graph shows the percentage of patients under the tenth centile for height for each adult specialist CF centre. Each centre is identified by a unique number. Centres have been included if they returned complete data for at least 40 patients.

The graph shows raw figures as submitted to the UK Cystic Fibrosis Database.

No adjustment has been made for any potential confounders such as staffing, socio-economic profile of the Centre, genotype, proportions of shared care patients seen by the Centre or reported to the Database etc.

6.6 Percentage of patients < 10th weight centile – Adult Centres



(Average for all adult centres – 29%

Range – 36% to 19%

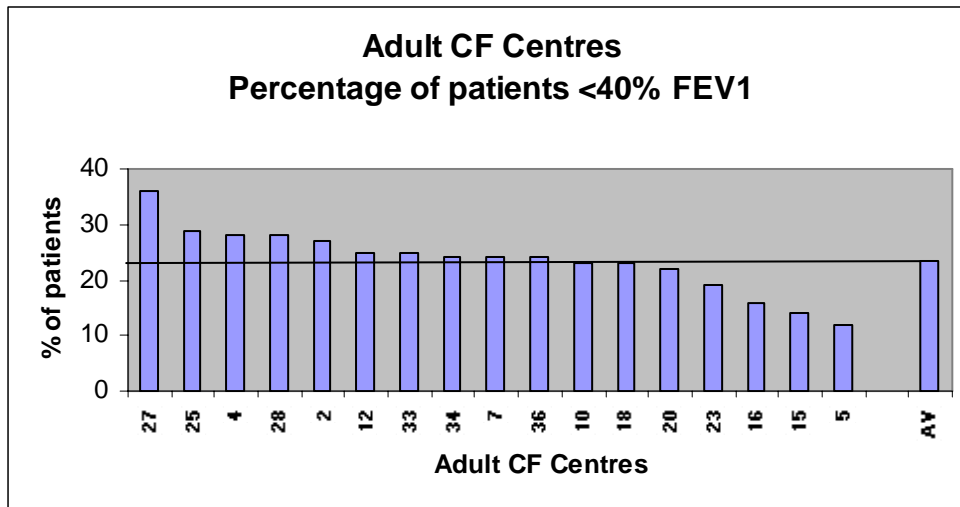
Total number of adult centres – 17)

This graph shows the percentage of patients under the tenth centile for weight for each adult specialist CF centre. Each centre is identified by a unique number. Centres have been included if they returned complete data for at least 40 patients.

The graph shows raw figures as submitted to the UK Cystic Fibrosis Database.

No adjustment has been made for any potential confounders such as staffing, socio-economic profile of the Centre, genotype, proportions of shared care patients seen by the Centre or reported to the Database etc.

6.7 Percentage of patients with FEV1 < 40% predicted – Adult Centres



(Average for all adult centres – 23%)

Range – 36% to 12%

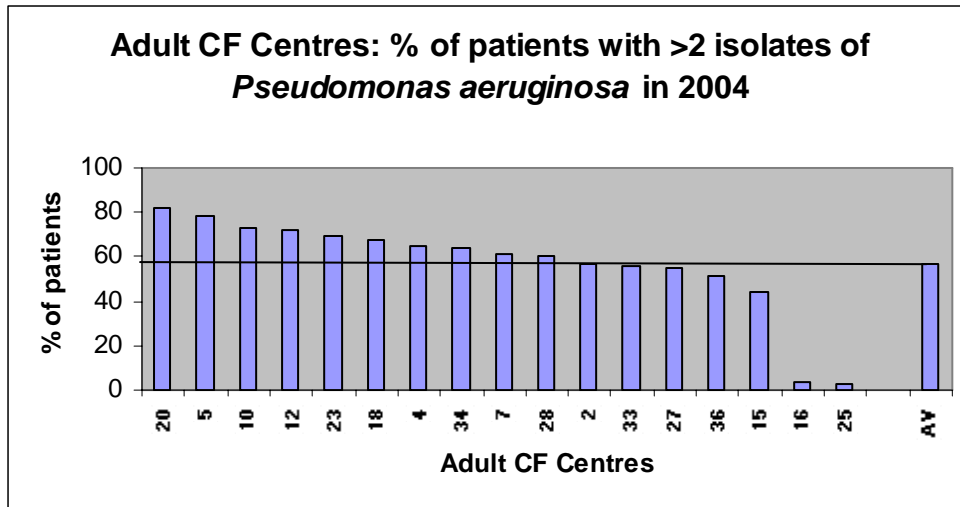
Total number of adult centres – 17)

This graph shows the percentage of patients with FEV1 < 40% predicted for each adult specialist CF centre. Each centre is identified by a unique number. Centres have been included if they returned complete data for at least 40 patients.

The graph shows raw figures as submitted to the UK Cystic Fibrosis Database.

No adjustment has been made for any potential confounders such as staffing, socio-economic profile of the Centre, genotype, proportions of shared care patients seen by the Centre or reported to the Database etc.

6.8 Percentage of patients with > 2 isolates of *Pseudomonas aeruginosa* in 2004 – Adult Centres



(Average for all adult centres – 57%)

Range – 82% to 3%

Total number of adult centres – 17)

This graph shows the percentage of patients with over 2 isolates of *Pseudomonas aeruginosa* for each adult specialist CF centre. Each centre is identified by a unique number. Centres have been included if they returned complete data for at least 40 patients.

The graph shows raw figures as submitted to the UK Cystic Fibrosis Database.

No adjustment has been made for any potential confounders such as staffing, socio-economic profile of the Centre, genotype, proportions of shared care patients seen by the Centre or reported to the Database etc.