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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

<table>
<thead>
<tr>
<th></th>
<th>2002</th>
<th>2003</th>
<th>2004</th>
</tr>
</thead>
<tbody>
<tr>
<td>CF patients registered</td>
<td>6932</td>
<td>6861</td>
<td>7046</td>
</tr>
<tr>
<td>CF patients with complete clinical data</td>
<td>5301</td>
<td>4875</td>
<td>5561</td>
</tr>
<tr>
<td>Age in years (mean)</td>
<td>16</td>
<td>17.8</td>
<td>18</td>
</tr>
<tr>
<td>Age in years (median)</td>
<td>17.4</td>
<td>16.1</td>
<td>16.4</td>
</tr>
<tr>
<td>Newly diagnosed patients</td>
<td>159</td>
<td>142</td>
<td>164</td>
</tr>
<tr>
<td>Age at diagnosis in years (mean)</td>
<td>2.7</td>
<td>3.0</td>
<td>3.0</td>
</tr>
<tr>
<td>Age at diagnosis in months (median)</td>
<td>5</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Adults (16 years and over) %</td>
<td>50.1</td>
<td>50.8</td>
<td>51.4</td>
</tr>
<tr>
<td>Males (%)</td>
<td>53.9</td>
<td>53.8</td>
<td>53.4</td>
</tr>
<tr>
<td>Genotyped (%)</td>
<td>95</td>
<td>95</td>
<td>95</td>
</tr>
<tr>
<td>Total deaths reported</td>
<td>94</td>
<td>103</td>
<td>123</td>
</tr>
<tr>
<td>Age at death in years (mean)</td>
<td>23.4</td>
<td>26</td>
<td>27.6</td>
</tr>
<tr>
<td>Age at death in years (median)</td>
<td>23</td>
<td>24.2</td>
<td>25.6</td>
</tr>
</tbody>
</table>
Section 3:

All UK Patients

Summary
3.1 Age Profile for all patients - 2004

<table>
<thead>
<tr>
<th>Age</th>
<th>0 - &lt;5</th>
<th>5 - &lt;10</th>
<th>10 - &lt;15</th>
<th>15 - &lt;20</th>
<th>20 - &lt;25</th>
<th>25 - &lt;30</th>
<th>30 - &lt;35</th>
<th>35+</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of patients</td>
<td>736</td>
<td>1118</td>
<td>1264</td>
<td>1186</td>
<td>1005</td>
<td>630</td>
<td>451</td>
<td>656</td>
<td>7046</td>
</tr>
</tbody>
</table>

(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

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

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

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

(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*100 for the age range 20-25 years.
### 3.5 Patients with 3 or more Pseudomonas aeruginosa isolates - 2004

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

(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

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).

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

<table>
<thead>
<tr>
<th>Age</th>
<th>0 - &lt;5</th>
<th>5 - &lt;10</th>
<th>10 - &lt;15</th>
<th>15 - &lt;20</th>
<th>20 - &lt;25</th>
<th>25 - &lt;30</th>
<th>30 - &lt;35</th>
<th>35+</th>
<th>Total: all ages</th>
<th>Total: 10 yrs &amp; over</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not done</td>
<td>477 (96%)</td>
<td>835 (93%)</td>
<td>652 (67%)</td>
<td>427 (45%)</td>
<td>320 (37%)</td>
<td>208 (38%)</td>
<td>145 (38%)</td>
<td>234 (42%)</td>
<td>3296 (58%)</td>
<td>1986 (47%)</td>
</tr>
<tr>
<td>Normal</td>
<td>19 (4%)</td>
<td>46 (5%)</td>
<td>241 (25%)</td>
<td>313 (33%)</td>
<td>260 (30%)</td>
<td>151 (27%)</td>
<td>70 (18%)</td>
<td>117 (21%)</td>
<td>1217 (22%)</td>
<td>1152 (27%)</td>
</tr>
<tr>
<td>Intolerant</td>
<td>1 (0%)</td>
<td>5 (1%)</td>
<td>39 (4%)</td>
<td>52 (6%)</td>
<td>64 (7%)</td>
<td>32 (6%)</td>
<td>22 (6%)</td>
<td>18 (3%)</td>
<td>233 (4%)</td>
<td>227 (5%)</td>
</tr>
<tr>
<td>Diabetic</td>
<td>2 (0%)</td>
<td>12 (1%)</td>
<td>38 (4%)</td>
<td>147 (16%)</td>
<td>213 (25%)</td>
<td>159 (29%)</td>
<td>143 (38%)</td>
<td>185 (33%)</td>
<td>899 (16%)</td>
<td>885 (21%)</td>
</tr>
<tr>
<td>Total</td>
<td>499</td>
<td>898</td>
<td>970</td>
<td>939</td>
<td>857</td>
<td>550</td>
<td>380</td>
<td>554</td>
<td>5647</td>
<td>4250</td>
</tr>
</tbody>
</table>

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Section 4:

UK Children

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

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.

(Total number of new diagnoses: 153)
4.2 Age profile for children (<16) - 2004

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

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".

(Total number of patients: 3390)
4.4 Body Mass Index centile for children (<16) - 2004

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

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

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.

(Total number of patients: 2709)
### 4.7 Glucose tolerance for children (<16) - 2004

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

<table>
<thead>
<tr>
<th>Age</th>
<th>0 - &lt;5</th>
<th>5 - &lt;10</th>
<th>10 - &lt;15</th>
<th>15 - &lt;16</th>
<th>Total: All Ages</th>
<th>Total: 10 yrs &amp; over</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>477 (96%)</td>
<td>835 (93%)</td>
<td>652 (67%)</td>
<td>94 (52%)</td>
<td>2058 (81%)</td>
<td>746 (65%)</td>
</tr>
<tr>
<td>Not done</td>
<td>Normal</td>
<td>19 (4%)</td>
<td>46 (5%)</td>
<td>241 (25%)</td>
<td>56 (31%)</td>
<td>362 (14%)</td>
</tr>
<tr>
<td></td>
<td>Intolerant</td>
<td>1 (0%)</td>
<td>5 (1%)</td>
<td>39 (4%)</td>
<td>15 (8%)</td>
<td>60 (2%)</td>
</tr>
<tr>
<td></td>
<td>Diabetic</td>
<td>2 (0%)</td>
<td>12 (1%)</td>
<td>38 (4%)</td>
<td>17 (9%)</td>
<td>69 (3%)</td>
</tr>
<tr>
<td>Total</td>
<td>499</td>
<td>898</td>
<td>970</td>
<td>182</td>
<td>2549</td>
<td>1152</td>
</tr>
</tbody>
</table>

(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

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

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.

<table>
<thead>
<tr>
<th>Exercise tolerance score</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of patients</td>
<td>1864</td>
<td>306</td>
<td>67</td>
<td>18</td>
<td>3</td>
<td>3</td>
<td>2261</td>
</tr>
</tbody>
</table>

(Total number of patients: 2261)
4.10 Northern chest X-ray score for children (<16) - 2004

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

(Total number of patients: 1535)
4.11 Complications (chest) for children (<16) - 2004

<table>
<thead>
<tr>
<th>Chest complication</th>
<th>A</th>
<th>B</th>
<th>C</th>
<th>D</th>
<th>E</th>
<th>F</th>
<th>G</th>
<th>H</th>
<th>I</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of patients</td>
<td>565</td>
<td>109</td>
<td>154</td>
<td>330</td>
<td>2</td>
<td>364</td>
<td>2</td>
<td>157</td>
<td>522</td>
<td>2205</td>
</tr>
</tbody>
</table>

(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

<table>
<thead>
<tr>
<th>Age</th>
<th>0 - &lt;5</th>
<th>5 - &lt;10</th>
<th>10 - &lt;15</th>
<th>15 - &lt;16</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients with <em>B. cepacia</em></td>
<td>2</td>
<td>8</td>
<td>18</td>
<td>5</td>
<td>33</td>
</tr>
<tr>
<td>Age specific prevalence (%)</td>
<td>&lt;1</td>
<td>1</td>
<td>2</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Number of patients in age band</td>
<td>565</td>
<td>942</td>
<td>1042</td>
<td>204</td>
<td>2753</td>
</tr>
</tbody>
</table>

(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*100 for the age range 0-5 years.
4.13 Nebulised antibiotics for children (<16) - 2004

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.

(Total: 2803, given to 2569 children)

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Section 5:

UK Adults

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

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.

(Total number of new diagnoses: 11)
### 5.2 Age profile for adults (16+) - 2004

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.

#### (Total number of patients: 3670)

<table>
<thead>
<tr>
<th>Age</th>
<th>16 - &lt;20</th>
<th>20 - &lt;25</th>
<th>25 - &lt;30</th>
<th>30 - &lt;35</th>
<th>35+</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of patients</td>
<td>928</td>
<td>1005</td>
<td>630</td>
<td>451</td>
<td>656</td>
<td>3670</td>
</tr>
</tbody>
</table>

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5.3 Genotypes for adults (16+) - 2004

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".

(Total number of patients: 4427)
5.4 Body Mass Index centile for adults (16+) - 2004

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

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.

(Total number of patients: 3206)
5.6 Weight centile for adults (16+) - 2004

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.

(Total number of patients: 3206)
5.7 Glucose tolerance for adults (16+) - 2004

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

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

(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.
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

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.

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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

(Total number of patients: 1786)
5.11 Complications (chest) for adults (16+) - 2004

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.

(Total number of complications: 4357 for 3078 patients)
5.12 Adults (16+) with at least 1 Burkholderia cepacia isolated - 2004

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

(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*100 for the age range 0-5 years.
5.13 Nebulised antibiotics for adults (16+) - 2004

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.

(Total: 3361, given to 3078 adults)
Section 6:

Comparison of Outcomes for Specialist CF Centres
6.1 Percentage of patients < 10th height centile – Paediatric Centres

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

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.

(Average for all paediatric centres – 20%
Range – 32% to 12%
Total number of paediatric centres – 20)
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 < 10\textsuperscript{th} height centile – Adult Centres

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.

(Average for all adult centres – 23%
Range – 29% to 16%
Total number of adult centres – 17)
6.6 Percentage of patients < 10\textsuperscript{th} weight centile – Adult Centres

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.

(Average for all adult centres – 29%  
Range – 36% to 19%  
Total number of adult centres – 17)
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

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.