336 Predicting future treatment needs from annual review data

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Objectives: From April 2012, UK centres will be funded based on treatment patients needed the 12 months leading up to annual review the previous calendar year. Thus, funding will be based on data 3–15 months old, potentially underestimating patients' health needs. We investigated whether data from the previous calendar year (only 3 months old) were better at predicting subsequent treatment needs.
Methods: The following data were collected retrospectively from all patients treated at our centre from 2008 to 2011: number of in-patient days (IP days), number of days of iv antibiotics (IV days), and month of annual review. Wilcoxon matched-pairs signed-rank and Kolgorov–Smirnov tests were used to test whether data from the previous calendar year were better than annual review data from that year at predicting treatment needs the following calendar year.
Results: 103 patient-years (41 patients) were analyzed. IP days differed by a mean 2.9 days (range −66 to +132) from the previous calendar year, compared to a mean 3.5 days (range −100 to +144) from annual review. IV days differed by a mean 3.2 days (range −97 to +178) compared to a mean 5.1 days (range −78 to +218). Differences in the means were not significant ($p = 0.33$, Wilcoxon). When data were analyzed to look at the variation in treatment band there was no significant difference.
Conclusion: Though treatment needs for some individuals changed dramatically from year to year, overall the treatment needs of patients in a given calendar year were reasonably predicted by the treatment given as measured at patients' previous annual reviews. There would be no benefit in using calendar year data rather than annual review data.

337 Changing incidence and thresholds for pulmonary exacerbation treatment, North America 1995–2005

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Background: Intravenous (IV) antibiotic (ABX) treatments for CF pulmonary exacerbations (PEx) are associated with poor lung function. We studied how changes in CF pulmonary health have affected PEx treatment incidence.
Methods: IV and oral/inhaled (nonIV) ABX PEx treatment incidence from 1995–2005 stratified by age group (<6, 6–12, 13–17, ⩾18 yr) was calculated from the Epidemiologic Study of CF. Modified sign/symptom scores (range 0–4) associated with PEx treatment [Rabin et al., Ped. Pulm. 2004; 37: 400] were calculated.
Results: 213,054 PEx ABX treatments occurred over 185,981 patient years (pt-yr) studied. ABX treatment (Tx) incidence fell 0.07/yr ($R^2 = 0.85$; $P < 0.001$) from 1.68 Tx/pt-yr in the ⩾18 yr group and 0.04/yr ($R^2 = 0.74$; $P < 0.001$) in the 13–17 yr group, while rising 0.03/yr from 0.55 Tx/pt-yr ($R^2 = 0.63$; $P = 0.004$) in the <6 yr group, the latter due to a 0.04/yr ($R^2 = 0.64$; $P = 0.001$) nonIV ABX treatment increase. Tx incidence was unchanged in the 6–12 yr group. 30,337 PEx were evaluable for Rabin clinical score. Mean clinical scores at nonIV ABX treatment dropped 0.01–0.02 units/yr (R^2 range 0.34–0.77; $P < 0.001$ to $P = 0.06$); IV ABX treatment score changes showed no pattern by age, with <6 yr group mean scores dropping 0.03 units/yr ($R^2 = 0.45$; $P = 0.02$).
Conclusions: PEx ABX treatment incidence changed significantly from 1995–2005, with children receiving more ABX treatments and adults receiving fewer. Clinical thresholds for intervention declined over the 11-year study period for nonIV ABX treatment in all age groups, and for IV ABX treatment in patients aged <6. These data underscore the importance of including nonIV ABX treatments and treatment thresholds in PEx analyses.

338 Improved life expectancy in cystic fibrosis patients: real progress or reduced measurement bias?

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Objectives: To calculate life expectancy at birth of cystic fibrosis patients in France (period 1994–2008) and to interpret trends by distinguishing between the improvement attributable to progress in healthcare and that explained by better observation and measurement conditions.
Methods: The study population is that of the French Cystic Fibrosis Registry (RFM) which has recorded individual clinical data on patients since 1992: diagnosis, vital status, anthropometry and spirometry, bacteriology, morbidity and therapeutic management.
Mortality was analysed on a cross-sectional basis, using the standard demographic method of period life tables, taking account of populations and deaths in the RFM by three-year period: 1993–1994–1995, ... 2007–2008–2009. Each table provided the series of five-year probabilities of dying at different ages, and life expectancies at each age.
The RFM mortality data were compared with the life tables of the French population giving, for the past, the same life expectancies at birth.
Conclusions: The increase in life expectancy of cystic fibrosis patients, from 29.4 years in 1994 to 48.8 years in 2008, can be explained by two factors:
– improved patient survival: at the adult ages when the majority of cystic fibrosis deaths occur (15–35 years), the risks of dying in 2008 were lower than in the past.
– improved coverage of the RFM, linked to the introduction of neonatal screening in 2002 and a reorganization of healthcare management for CF patients: this led to the inclusion of a growing number of adults and of asymptomatic newborns who were previously unobserved and whose presence has contributed to lowering the age-specific risks of dying.

339 Increased proportion of CF patients with normal FEV_1 over an 11-years nation-wide study: have patient characteristics changed?

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Background: Normal FEV_1 ($NFEV_1$) does not exclude early lung disease in CF. $NFEV_1$ patients are of special interest for using more accurate techniques to determine early lung disease. With this survey we aimed to define these patients and looked if their characteristics changed over time.
Methods: Retrospective analysis of the Belgian CF Registry (BR) focused on patients with FEV_1%pred ⩾85% ($NFEV_1$). Data were collected from the annual reports from 1998 to 2008.
Results: CF population increased in time from 566 in 1998 to 1087 in 2008, with a significant increase in adults from 38.5% to 50.3% ($p < 0.001$). $NFEV_1$ patients increased from 28.5% in 1998 to 42.7% in 2008 ($p < 0.001$). This trend, significant in both females and males, was stronger for $NFEV_1$ males (adjusted odds ratio 1.28, 95% CL 1.15 to 1.42). In 1998, 97.3% of $NFEV_1$ patients had a sweat chloride >60 mmol/L; this proportion decreased steadily to 84% in 2008 ($p < 0.001$). Two known CFTR mutations were detected in 79.3% of the $NFEV_1$ patients in 1998 versus 85.5% in 2008 ($p = 0.002$). For F508del/F508del, proportions decreased in time from 56% in 1998 to 40.4% in 2008 ($p < 0.001$).
Discussion: A significant increase in $NFEV_1$ patients was seen over an 11-year period, with a significant increase in adults. This could be explained by the significant increase in $NFEV_1$ patients with atypical CF. A more detailed genetic analysis of CFTR over 11 years explains the increase in patients with two known CFTR mutations. Separate analysis of the F508del/F508del adults is needed to conclude that improved CF care over 11 years had also its impact on the increased proportion of $NFEV_1$ CF patients.