Modelling future trends in cystic fibrosis demography using the French Cystic Fibrosis Registry: update and sensitivity analysis

To the Editor:

Working with a group of investigators from the European Respiratory Society (ERS)/European Cystic Fibrosis Society (ECFS) task force for the "Provision of care in adults with cystic fibrosis (CF)" [1], we have previously modelled future trends in CF demography in European countries by calculating flows of patients entering and exiting CF cohorts in each country [2]. In that report, we used individual country data contained in the ECFS Patient Registry and were able to calculate demographic forecasts for several European Countries, including France [2]. These forecasts, which were based on the assumption that major demographic trends remained stable over time, suggested that a major increase in the number of CF adults was expected in western European countries by 2025 [1, 2]. In France, our forecast predicted an increase by 45.5% in the CF population between 2010 and 2025, corresponding to an increase by 18.4% in the paediatric population and an increase by 75.7% in the adult population [2].

In this follow-up report, we evaluate the accuracy of our methodology by comparing our previously published 2015 forecasts for France, which were obtained by applying 2003–2009 demographic flows to data from the 2009 French CF Registry [2], with the recently available 2015 data collected by the Registry. The comparison of published forecast *versus* observed data for 2015 confirms that our forecasted increase by +27.4% was rather accurate as the observed data showed an increase by +29.3% (n=797) in adult patients between 2010 and 2015 (table 1). For the paediatric population, our forecast predicted an increase by 8.3%, whereas the observed 2015 data showed that the CF paediatric population remained stable between 2010 and 2015. This overestimation in the forecasted number of paediatric patients was related to a decrease in the number of new CF paediatric cases/year captured by the Registry from 267 per year in the 2003–2010 period to 187 per year in the 2011–2015 period. This reduction in the number of new paediatric CF cases was in part related to a reduction in the incidence of CF diagnosed by systematic neonatal screening (incidence rates, 2002–2005: 1 in 4349, mean 211 cases per year; 2006–2010: 1 in 4908, mean 166 cases per year; 2011–2015: 1 in 5676, mean 143 cases per year) [3, 4]. The decrease in the overall number of new diagnoses of paediatric CF patients was in part the result of a true decrease in CF incidence, presumably because of genetic counselling after the diagnosis of a CF case, and to an increase in the registry coverage rate before 2006, which may have resulted in capturing previously diagnosed cases of paediatric CF that had not been reported to the registry. In the Discussion of our previous manuscript, we had already suggested the possibility that our forecast may result in an overestimation of the growth of the paediatric population in the case of a decrease in the incidence of paediatric CF [2].

Based on these findings, we now update our forecast for 2025 in France using the flow method on the French CF Registry 2015 data. In our main analysis we applied the mean flows calculated in the 2006–2015 period to the 2015 data. These data confirm our previous forecast, suggesting an increase by 75.2% in the adult CF population between 2010 and 2025 while the paediatric population will remain roughly stable. In this latter analysis, we chose to apply flows calculated from 2006 to 2015 (over 9 years) to limit the effects of year-to-year variations in flows. However, this analysis is based on the assumption that flows remain constant between the observation period and the forecast period, which was not the case between

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TABLE 1 Comparison of demographic forecast and observed data for 2015 and update in the 2025 forecast of the cystic fibrosis (CF) paediatric and adult population in France

Patients	French CF Registry 2010 data (observed) [2]	Forecast for 2015 using the French CF Registry 2010 data (modelled) [2]		French CF Registry 2015 data (observed) [5]		Forecast for 2025 using the French CF Registry 2015 data (modelled using mean 2006–2015 flows)		Forecast for 2025 using the French CF Registry 2015 data (modelled using mean 2011–2015 flows)	
	Number	Number	Increase from 2010 %	Number	Increase from 2010 %	Number	Increase from 2010 %	Number	Increase from 2010 %
All	5758	6760	17.4	6553	13.8	7908	37.3	7935	37.8
Paediatric	3040	3295	8.3	3038	0	3147	3.5	3094	1.8
Adults	2718	3465	27.4	3515	29.3	4761	75.2	4841	78.1
Adults %	47.2	51.3	4.1	53.6	6.4	60.2	13.0	61.0	13.8

the 2003–2009 period and the 2011–2015 period, as the prognosis of CF kept improving and the incidence decreased. Thus, as a sensitivity analysis, we further calculated the forecast for France in 2025, applying mean flows calculated in the 2011–2015 period to the 2015 data. This analysis suggested that the increase in the CF adult population may be even greater than reported in our previous manuscript (table 1).

In conclusion, comparison of our previously published forecast with observed data collected by the French CF Registry confirmed that the adult population is growing fast in France. This will require increased support to adult CF centres and further strategic planning for healthcare provision over the next 15 years. At the same time, the size of the French paediatric CF population has stabilised, which indicates the need to maintain appropriate support for paediatric CF centres. Similar comparisons can be made in other European countries when data become available to perform similar comparisons to enable targeted planning in each country. Regular updates in these demographic forecasts will help in offering appropriate funding for the care of both children and adults with CF in each country.

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