News Release

Dramatic rise expected in adults living with cystic fibrosis

The number of people living with cystic fibrosis into adulthood is expected to increase dramatically by 2025, prompting calls for the development of adult cystic fibrosis services to meet the demand.

People living with cystic fibrosis have previously had low life expectancy, but improvements in treatments and care in the last three decades have led to an increase in survival with almost all children now living to around 40 years.

In the first study of its kind, published in the *European Respiratory Journal* on 19 March 2015, researchers have provided forecasts for the number of adults living with the disease in 34 different European countries by the year 2025.

Professor Pierre-Régis Burgel, an author of the study from Cochin Hospital, Paris, said: "The estimations we have made show very positive news for cystic fibrosis patients as the average survival age is increasing. We are now concerned that there are insufficient specialist centres to provide optimal care to adults with the disease. Healthcare systems will need to adapt to this change, particularly in countries with less well-established adult services."

The researchers divided the countries into four groups based on the availability of data, and where no data existed, on the economic state of the country. Using these measurements, predictions were made to estimate the levels of adults with cystic fibrosis by the year 2025.

The results showed that in the 16 countries where reliable data exists, the number of adults with cystic fibrosis is expected to increase by approximately 75%. Within the 6 countries with the most reliable data, the Netherlands and the UK are expected to see the largest rises with 96.1% and 79.3% increases respectively. <u>Download a graph showing the predicted percentage increases in these 16 countries.</u>

Many cystic fibrosis centres are focused on paediatric care therefore if trends continue as predicted, adults living with the disease may not be able to access the specialist care they need.

The research is part of a joint task force between the European Respiratory Society (ERS) and the European Cystic Fibrosis Society (ECFS). The members of the task force are now calling on healthcare professionals and policymakers to be aware of these expected increases and to develop adult services to meet this demand.

Notes to editors:

Download further information on the methods and data.

Title: Future trends in cystic fibrosis demography in 34 European countries **Authors:** P-R Burgel, G Bellis, H Olesen, L Viviani, A Zolin, F Blasi, J S Elborn on behalf of the ERS/ECFS task force on "the provision of care for adults with cystic fibrosis in Europe"

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- When the embargo lifts, the paper can be viewed on the <u>European</u> <u>Respiratory Journal website</u>.
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