

Short Communication

## Limitations to providing adult cystic fibrosis care in Europe: Results of a care centre survey



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on behalf of the ERS/ECFS task force: The provision of care for adults with cystic fibrosis in Europe

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### Abstract

**Background:** There are a growing number of adults in Europe with a projected increase of 75% over the next decade. There is concern that provision of care will not be sufficient to meet needs. We aimed to establish the level of CF service throughout Europe.

**Methods:** An online survey designed by clinicians and patient representatives to explore level of service.

**Results:** Training opportunities for clinicians and resources (physical and manpower) to provide care to adults with CF are limited in Europe. Although specific adult CF care has been identified, teams continue to be supported by paediatric colleagues and many adults are still being admitted to paediatric wards. In some centres, service delivery, particularly infection control and access to some CF medication is insufficient and in many places poor personnel resources limits access to comprehensive multidisciplinary teams.

**Conclusions:** This survey shows an urgent need for the development of resources for adult CF care, in both physical space and appropriately trained clinicians.

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**Keywords:** Cystic fibrosis; Service provision; Adults; Eastern Europe; Western Europe

Median survival in cystic fibrosis (CF) is improving. In many countries there are few childhood deaths due to therapeutic innovation, early and aggressive therapy, and specialised CF centre care resulting in increasing numbers of adults with CF

(>18 years: 51% of 38,985 patients registered on the 2013 ECFS Patient Registry (ECFSPR)). Over the past 15 years data from CF registries report an increase in the proportion of adults from 29% to 60%, with up to 71% working or studying [1–8].

In the last year the European Respiratory Society/European CF Society (ERS/ECFS) Taskforce on the provision of care for adults with CF in Europe published two papers. The first predicted that the number of people with CF living into adulthood could increase by 75% by 2025 [9]. The second identified the resources needed

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to provide specific care for adults with CF, and reviewed the requirements for a curriculum for physicians [10]. Clinicians working in CF are aware and concerned that increasing survival is not proportionately matched with an increase in resources. The Taskforce therefore sought to review the current provision of adolescent and adult (> 16 years) CF care in Europe using a survey sent to European CF centres (recognised as such within countries). The survey consisted of 48 questions; a combination of both multiple choice and open ended and divided into two themes: managerial (recognition as a CF Centre, funding sources, whether they were adult only centres, benchmarking/guidelines/registry, access to a transplant centre, and available medication). The second theme was clinical (practical) and covered areas such as access to an adult pulmonologist and a comprehensive CF multidisciplinary team, admission and urgent reviews, cross infection and access to support at home and end of life (Supplemental Table 1). Three hundred surveys were distributed with a 33% response rate (n = 86 separate replies from Western Europe, n = 12 separate replies from Eastern Europe) (Table 1). Limited contact details and a paucity of adult CF centres in Eastern Europe resulted in a bias to responses from Western Europe. To determine if the survey was representative, data on CF centre numbers from ECFSPR 2010 were compared with the number of survey replies [6]. Replies from this survey represent about one fifth of all European CF centres, including paediatric centres contributing data to the ECFSPR.

The survey shows that CF centres in Europe receive funding from a variety of sources including governments, charities, research funds and private incomes (Fig. 1). Although 86% of centres report as being recognised by governments as specialist CF centres, only one third receive direct government funding (35%) with 37% of respondents stating other funding sources which mainly included patient organisations and research money. Nevertheless, despite poor financial support, there were a number

of positive findings with most centres identifying adult-specific CF care where patients have access to one or more adult pulmonologists (94%), CF multidisciplinary (MDT) teams holding regular meetings (80%), annual assessments (89%), CF-specific clinics (96%), and access to home intravenous (IV) therapy (94%). Importantly for adult CF care, >90% of centres have access to specialities associated with the co-morbidities of CF and, whilst few centres were co-located with a lung transplant service, most have access to a transplant centre (94%).

Less positive were responses around infection control with only 77% admitting patients to a single room and 48% using a single room during outpatient appointments (Fig. 1). Fewer centres practiced a total segregation policy (where the patient stays in a room and the CF MDT carry out individual consultations ~15%). A small number of centres ask patients to wear masks when attending the hospital (inpatients 32%, clinic attenders 41%).

Funding for medication was variable although six common drugs (Azithromycin (93%), pancreatic enzymes (100%), Colistimethate sodium (96%), Dornase alpha (98%), hypertonic saline (87%), and Tobramycin for nebulisation (97%)) appear to be at least partially funded with most being fully funded (85%) (Fig. 1). A number of respondents added comments about limited or no access to Aztreonam for inhalation (Cayston), Mannitol (Bronchitol), dry-power Tobramycin for inhalation (TOBI Podhaler), dry-powder Colistimethate sodium (Colobreathe), Ivacaftor (Kalydeco), and vitamins.

There is little formalised training for junior doctors in adult CF care across Europe, with only 69% reporting available training, which was generally *ad hoc*.

## 1. Discussion

This survey provides some information regarding adult CF care in Europe yet, because of the imbalance of responses it is difficult to truly assess the situation, particularly in Eastern Europe. It is clear that most centres provide an adult service with an MDT team and home IV therapy, although this may be led by the west where adult patient numbers are greater [11].

Fixed physical resources can limit care, particularly with the challenge of rapidly increasing numbers of adults. Managing a CF service in a busy hospital is demanding when single-room accommodation and access to outpatient facilities conflict with the needs of other patient cohorts. To develop an adult specific CF service, unique, rather than shared space, is critical. This survey documented that >50% of CF centres are admitting adults to paediatric wards, only 74% of centres always admit to single rooms, and a third of centres asked adults to share rooms, raising concerns about the potential for cross-infection. Outpatient resources are even more restricted, with <50% able to access a single room for the complete assessment of individual patients. This aspect of care is particularly important as several common CF pathogens can be potentially transmitted between patients with CF, including *Burkholderia cepacia* complex, MRSA, shared strain *Pseudomonas aeruginosa* and potentially *Mycobacterium abscessus* infection [12].

Despite the limitations of physical and financial resources, CF centres throughout Europe are trying to provide optimum

Table 1  
Number of replies from European countries.

Country	Number of replies
Austria	n = 3
Belgium	n = 6
Czech Republic	n = 3
Denmark	n = 1
Estonia	n = 2
France	n = 12
Germany	n = 16
Hungary	n = 1
Italy	n = 5
Lithuania	n = 1
Netherlands	n = 3
Norway	n = 2
Spain	n = 21
Slovakia	n = 2
Slovenia	n = 1
Sweden	n = 2
Switzerland	n = 2
Ukraine	n = 2
United Kingdom	n = 13
Total	n = 98

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