

# Cystic Fibrosis our focus

## Royal Brompton Hospital and its network clinics

This paediatric network has a well-staffed and experienced multi-disciplinary team (MDT) and cared for 339 children and young people in 2014. Of these, 113 received full care and 200 received shared care across the network. There are 14 network hospitals supported through joint clinics with a MDT from the centre. There are 26 patients at ten associated hospitals as part of a historic arrangement. This number is reducing. Additionally, the centre cares for five patients from Malta. Due to their reputation for CF care, a number of complex patients from across the EU have migrated to the centre. CF Registry data shows that compared with national data, outcomes for lung function, BMI and chronic pseudomonas infections are mid-range. The service often provides a second opinion to other tertiary units within the UK, and their published guidelines are used extensively. Their research activity is world class.

Service users have identified the following areas of good practice: accessibility of health professionals, outpatient facility cleanliness and the availability of team members, although admission and outpatient waiting times, inpatient food and facilities and parking were highlighted as areas requiring improvement.

The review panel have highlighted the world-leading paediatric academic and research track record and the excellent clinical care with a holistic/MDT-centred approach, as well as the accessibility of the staff to shared-care teams, as areas of good practice.

Key recommendations are to improve access to inpatient beds, as highlighted in the previous peer review, and to improve facilities to meet infection control requirements, particularly in inpatient accommodation. The shared-care arrangement network model is likely to be unsustainable owing to the number of clinics, and tariff-split and service level agreements require greater transparency with a clear understanding of delivery expectations. Strategic review of the geographical catchment areas is required to ensure clear network structures and equity of provision and access for children with cystic fibrosis. The development of a forum for two-way communication across the network between centres and clinics is required, and some inpatient services for those not admitted to Royal Brompton Hospital are variable/absent, eg psychology and social work.