

# Cystic Fibrosis our focus

## **Kings College Hospital and paediatric network**

King's College Hospital (KCH) has a well-established cystic fibrosis (CF) service, caring for approximately 200 children with CF, around 50 of whom solely attend KCH because they live locally or have complex problems. The KCH/South East network of hospitals, which provides both inpatient and outpatient care for the remaining children, includes University Hospital Lewisham, Royal Alexandra Children's Hospital Brighton, Medway Maritime Hospital, Maidstone & Tunbridge Wells Hospitals, Eastbourne District General Hospital & Conquest Hospital Hastings, William Harvey Hospital, Ashford and Kent and Canterbury & QEQM (Margate) Hospitals. Lewisham and Brighton undertake more complete care, including annual reviews. The others function more dependently on King's as a managed clinical network. The large geographical area covered by the network poses travel implications for some families when visiting the centre. The patient survey feedback is largely positive and reflects the level of commitment of the CF team but does highlight some areas for consideration, such as infection control and the transition process.

The peer review panel has identified the cohesion and commitment of the team to clinical care as an area of good practice, alongside the accessibility and supportiveness of the KCH team to network clinics. The peer review panel also highlighted the standard of the annual KCH CF education day, providing continued professional development for members of the network.

Service users identified accessibility, availability of team members and outpatient cross-infection/segregation measures as areas of good practice. They highlighted car parking, food and inpatient ward facilities (resulting in a lapse in segregation in one instance) as areas for improvement.

The peer review panel has made recommendations that the three key points in the patient/family pathway (newborn screening, annual review and transition) are reviewed to ensure an integrated and equitable model applies to all clinics more consistently in the network. It also recommends that infection control procedures are reviewed to minimise further the opportunities for patient contact and cross-infection at KCH. Current bed-management policies at KCH make admissions unnecessarily cumbersome for families and staff. They should be streamlined to reduce delays in admissions for ill children. Having dedicated beds for patients with CF could be considered.

Other areas for further consideration might include providing an opportunity for network professionals to meet and develop shared goals and standards, and benchmarking the community support roles undertaken by the multidisciplinary team.