

Cystic Fibrosis our focus

Southampton Regional Centre and Local District Hospitals 'Central South Coast' Paediatric Cystic Fibrosis Network

The Central South Coast paediatric cystic fibrosis network comprises the regional specialist centre at Southampton Children's Hospital (SCH), nine UK network clinics and patients from Jersey and Guernsey. The network provides care for around 220 patients, with 55 attending the regional centre at Southampton Children's Hospital and around 160 primarily receiving care at network clinics.

The number of joint network clinics has increased to around 80 per year to ensure patients are seen at least twice a year by the Southampton-based specialist multidisciplinary team (MDT). The regional centre gives a generous proportion (70%) of CF tariff to network clinics to strengthen local MDTs. While local MDTs are very committed to providing good care for their patients, many staff have little or no recognised time for CF in their job plans. They often work well beyond their contracted hours.

Service users identified the availability of team members, the measures for cross-infection control and the continuity of staff as areas of excellence. Areas for improvement identified included car parking and waiting times.

The review panel identified the well-established network service, the transition programme, which is supported by a close relationship with the UHS adult CF service, and the active research programme as good practice examples. The majority of the network clinics are signed up to the TORPEDO-CF study.

The panel made a number of recommendations, including a review of the practicality of sustaining a relatively high number of network clinics, and increasing bed capacity at Southampton Children's Hospital to ensure that admissions for local patients and from network clinics are timely and well managed. Southampton clinicians and contracts/service managers must continue working with their counterparts in network clinics to ensure that staffing levels and the Cystic Fibrosis Trust's Standards of Care are met through the tariff provided.

Other recommendations include increasing the amount of time for centre pharmacists to support network clinics, and an increase in psychology and social work support across the region. Administrative staff posts should be secure, and consideration given to a dedicated service manager position.