

Cystic Fibrosis our focus

The North West Midlands Cystic Fibrosis Centre – Paediatrics

The North West Midlands Cystic Fibrosis Centre's paediatric CF service comprises the CF team at the University Hospital of North Staffordshire (UHNS), with network teams and clinics at Shrewsbury and Telford Hospitals (SaTH) and Burton Hospital.

The service cares for approximately 100 patients (both full and shared care). It serves a large geographic area with significant socioeconomic deprivation and challenging transport links.

User feedback identified the CF team's accessibility and communication, the cross-infection arrangements in outpatients and the overall care from the CF team as areas of excellence. Areas for improvement identified included hospital catering, waiting times and car parking. Good practice examples noted by the peer review panel included team-working across the network, the vertical integration between the adult and paediatric services at UHNS and the staff being active and proactive in the wider CF community. The panel was also impressed with the commitment of the specialist nurses across the network

The panel identified a need for an additional whole time equivalent paediatric physiotherapist together with medical consultant time to adequately cover an increase in support for the shared care patients.

The principles of care are generally of a very high standard. Monitoring of home IV antibiotic courses needs more formal monitoring.

The network median BMI percentile is above average for paediatric services in the UK, but the median FEV1 is lower than the UK average and the number of children with chronic pseudomonas infection is above the UK average. These results need to be seen in the context of a socially and economically deprived population as a whole.

There has been a significant increase in funding under the 'payment by results' tariff. Staff estimate this will enable the centre to further drive up standards of care and attract the critical numbers of patients to grow the service.