

Cystic Fibrosis our focus

Birmingham Children's Hospital and shared care networks

The South and Central West Midlands Paediatric Cystic Fibrosis (CF) Network is a large specialist clinical network comprising around 300 children and teenagers. One third (108 patients) receive full care from the regional centre at Birmingham Children's Hospital (BCH) and the other two-thirds receive shared-care through six network clinics. Clinical outcomes, including UK CF Registry data, are generally excellent.

User feedback is also generally positive, particularly identifying the team's accessibility and communication, its approachable friendly and supportive staff and the weekday physiotherapy service, as areas of excellence. Areas users considered for improvement included the communication between shared care clinics and the centre, the lengthy out-of-hours waits in A&E, and the annual review arrangements.

The peer review panel identified the hard-working dedicated teams across the network, the increased investment at some sites to meet new CF service specifications, and the coordination of the network through the network board and annual clinical meeting, as good practice examples.

The panel identified a number of areas for improvement, which the centre director and network clinicians are aware of. These include a need for managers to prioritise agreeing and signing off the Service Level Agreements for network care, and the need to establish joint network multidisciplinary team clinics at each network site. Other areas include: a highly valued but under-resourced annual review process at BCH, variation in provision for transition to adult services and a need to review arrangements for newly diagnosed patients, with earlier involvement of the local centres in provision of shared care.

An urgent audit was recommended of chronic *Pseudomonas* infection rates at Coventry and the Heart of England Trust, which were substantially above the national average according to 2012 UK CF Registry data.