

Cystic Fibrosis our focus

John Radcliffe Hospital and network paediatric clinics

The Oxford Paediatric Cystic Fibrosis service delivers high-quality care to 185 children and young people. Of these, 56 have full care at the specialist centre, John Radcliffe Hospital. The rest share care with five network clinics: Northampton General, Reading Royal Berkshire, Milton Keynes, Heatherwood & Wexham Park, and Buckinghamshire (Stoke Mandeville & High Wycombe). Service Level Agreements are set up so each network clinic receives a standard amount of money per patient, irrespective of banding, all home intravenous antibiotics costs being claimed back from the specialist centre. Annual reviews take place at JRH, with network patients also seeing the Oxford multidisciplinary team (MDT) at one of the quarterly outreach clinics.

Service users identified the accessibility of the team, communication and outpatient cleanliness as areas of excellence, while outpatient waiting times, inpatient food and the carparking facilities were areas for improvement.

The panel have identified the strong central leadership and robust hub-and-spoke model, the excellent 'Mychox' guidelines provided online and the centrally funded home IV services as areas of excellence.

Key recommendations from the panel include a review of the existing multidisciplinary team manpower where there is shortfall, particularly in dietetics. The panel recommend that the psychology service should be rationalised, with increased resources at network clinics or outreach from the specialist centre, and that a CF social worker or family support worker should be appointed to free up nursing time and improve overall service to patients and families. They also recommend a more consistent transition to adult services, which there is opportunity to improve when the adult CF team move to the John Radcliffe Hospital. Further, the shortage of outpatient rooms and needs to be addressed and the central provision/funding of physio equipment considered.