

Cystic Fibrosis our focus

Great North Children's Hospital, Newcastle Paediatric Cystic Fibrosis service (Royal Victoria Infirmary paediatric)

The Newcastle-upon-Tyne paediatric cystic fibrosis service cares for around 190 children and has a shared care agreement with North Cumbria University Hospitals, as well as outreach services in Sunderland (although there has recently been a reduction in the number of hospitals with whom they share care). The multi-disciplinary team (MDT) is appropriately skilled and experienced but the absence of a psychologist remains a significant concern after not being addressed as a result of the previous peer review.

Service users have found the accessibility and cleanliness of the facilities and the caring communication of the MDT to be areas of excellence. A lack of additional snacks and processed food identified by the peer review team has been corrected. A lack of concessions on car parking and having to access out-of-hours care through A&E were identified as key areas for improvement.

The peer-review panel identified the experience, enthusiasm, dedication and communication skills of the MDT as areas of good practice, noting that all members attend local, national and international meetings to keep their knowledge up-to-date. The ethos of academic research and presentation/publications outputs is present across the MDT. All members of the MDT are highly valued by patients and families. The purpose-built facilities for children with cystic fibrosis are excellent, as are the school and parental accommodation facilities. Key outcome measures are consistently good.

Key recommendations include appointing a psychologist as part of the paediatric cystic fibrosis MDT, as other members of the team are providing this support in addition to their existing workloads, and as a response to a crisis rather than a preventative measure. Additionally, increasing from a 0.5 WTE pharmacist to a 1.0 WTE pharmacist would meet the Cystic Fibrosis Trust 'Standards of Care' (2011).